

**IBD and Mums-To-Be: Transition to Motherhood Within the Context
of Inflammatory Bowel Disease**

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The candidate confirms that the work submitted is her own, except where work which has formed part of jointly authored publications has been included. The contribution of the candidate and the other authors to this work has been explicitly indicated below. The candidate confirms that appropriate credit has been given within the thesis where reference has been made to the work of others.

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Abstract

There is a severe patient knowledge deficit about pregnancy and IBD resulting in women with IBD being more likely than healthy controls to remain voluntarily childless. It is surprising, therefore, that there is little research on the topic. Hence, this study addresses the research question: ‘What is the lived experience of women who transition to motherhood within the context of Inflammatory Bowel Disease?’. The study recruited 22 mothers with IBD (11CD, 10 UC, 1 IBDu) who had at least one biological child of a young age (roughly 2 to 7 years old). The sample was predominantly White (N=16) as well as educated and affluent. First, convenience and purposive sampling were used to maximize diversity of geographical location and experience (e.g., having an external pouch); and then theoretical sampling was used to close gaps in understanding of the experience of mothers with IBD. Face-to-face semi-structured interviews (N=20) and via Skype (N=2) were conducted, most of which were video-recorded (N=21). The data were analysed using Thematic Analysis. Three separate analyses were produced and represented in three separate chapters, each focusing on one central concept: *Blurred Lines*, *Transitional Challenges*, and *Reflecting on Others*. Six key findings span these three separate analyses. First, prior to the transition to motherhood, women experience difficulties establishing a relationship of trust with healthcare providers and some assume their IBD would be a barrier in forming romantic relationships. Second, managing IBD symptoms can help prepare women for their transition to motherhood. Third, there is a misconception that IBD medication can damage the foetus and the child during breastfeeding. Fourth, women can experience a diagnosis shadowing whereby their pregnancy and IBD symptoms can be conflated. Fifth, transition to motherhood with IBD is facilitated by having an extensive network of support. Sixth, having IBD and becoming a mother are both associated with loss of identity, of freedom, of friendships, and of intimacy for some women. These findings are of practical relevance to women with IBD, their partners, and healthcare providers and have been disseminated throughout the duration of the study including via ‘YouTube Medleys’ created with permission using video-recorded extracts from the interviews.

Table of Contents

Acknowledgements	iii
Abstract	iv
Table of Contents	v
List of Figures	xv
List of Tables	xvi
Chapter 1 Inflammatory Bowel Disease: Medical Perspective	1
1.1 Definition, Nomenclature, and Symptoms	1
1.2 Detection of Symptoms	3
1.2.1 None invasive procedures	3
1.2.2 Invasive procedures	4
1.3 Confounding and Concomitant Illnesses	5
1.4 Epidemiology	5
1.4.1 Mortality.....	5
1.4.2 Age of onset.....	6
1.4.3 Prevalence and incidence	6
1.5 Sex Differences	7
1.6 IBD and Ethnic Minorities	7
1.7 Protective and Risk Factors	9
1.7.1 Smoking	9
1.7.2 Appendectomy.....	9
1.7.3 Family history.....	10
1.7.4 Other risk factors	10
1.8 Aetiology	10
1.8.1 Infectious viral origins	11
1.8.2 Infectious bacterial origins	11
1.8.3 Psychosomatic origins.....	11
1.8.4 Dietary origins	12
1.8.5 Immune response and genetic factors	12
1.9 Available Treatments	13
1.9.1 Induction therapies.....	13
1.9.1.1 Anti-inflammatory drugs	14
1.9.1.2 Antibiotics.....	14
1.9.1.3 Symptomatic drugs.....	14
1.9.1.4 Step-up, top-down, or combination therapy	14
1.9.2 Surgical interventions	15

1.9.3	Alternative therapies.....	16
1.9.3.1	Faecal microbiota transplantation.....	16
1.9.3.2	Diet regulation.....	17
1.9.3.3	Psychological therapy.....	18
1.9.3.4	Complementary and alternative medicine.....	20
1.10	Summary.....	21
Chapter 2 Inflammatory Bowel Disease: Individuals' Perspective.....		22
2.1	Part I: Lifestyle Changes with IBD.....	22
2.1.1	Psychological and social impact.....	22
2.1.1.1	Quality of life.....	22
2.1.1.2	Stigmatisation and concealment.....	26
2.1.1.3	Body image.....	27
2.1.1.4	Dietary patterns.....	28
2.1.1.5	Knowledge needs.....	29
2.1.1.6	Social needs.....	31
2.1.2	Treatment impact.....	31
2.1.3	Summary part I.....	32
2.2	Part II: Family Planning and Motherhood.....	33
2.2.1	Definition.....	33
2.2.2	Transition to motherhood.....	34
2.2.3	Expectations and choices.....	35
2.2.4	The burden of medicalisation.....	36
2.2.5	Birth rate and timing.....	37
2.2.6	Sex-specific issues.....	38
2.2.7	Fertility and premature deliveries.....	38
2.2.8	Other complications.....	40
2.2.9	Pregnancy with an ostomy.....	40
2.2.10	Number of births.....	41
2.2.11	Voluntary childlessness.....	41
2.2.12	Summary part II.....	45
2.3	Summary.....	46
Chapter 3 Qualitative Meta-Synthesis on the Transition to Motherhood with IBD		47
.....		47
3.1	Systematic Research Review: Methodology.....	47
3.1.1	Key search terms protocol.....	47
3.1.2	Database selection.....	48
3.1.2.1	Tailoring of protocol to database.....	49
3.1.3	Screening selection and limitation.....	49

3.1.3.1	Screening by language and peer-review journals	49
3.1.3.2	Screening by article type and subject headings	50
3.1.3.3	Screening by content	51
3.1.3.4	Rigour assessment	53
3.1.3.5	Brief summary of articles included in the SRR	53
3.1.3.6	Combined characteristics of the articles.....	54
3.2	Analytical Approach.....	65
3.3	Results.....	65
3.3.1	Cluster 1: Burden on family	66
3.3.1.1	Theme 1: Inability to fulfil mother role	67
3.3.1.1.1	Caring, nurturing and feeding	67
3.3.1.1.2	Attending family events.....	68
3.3.1.2	Theme 2: Fears and concerns	69
3.3.1.2.1	Incontinence and drugs impact.....	69
3.3.1.2.2	Contaminating cycle of fear.....	70
3.3.1.3	Theme 3: Emotional load.....	71
3.3.1.3.1	Guilt and shame	71
3.3.1.3.2	Feeling vulnerable.....	72
3.3.1.3.3	Oscillating mood.....	72
3.3.2	Cluster 2: Coping.....	73
3.3.2.1	Theme 1: Negotiating control.....	74
3.3.2.1.1	Practical strategies.....	74
3.3.2.1.2	Toilet and housebound	75
3.3.2.1.3	Adjusting to new normality	75
3.3.2.2	Theme 2: Adjustments to family life	76
3.3.2.2.1	Close monitoring.....	76
3.3.2.2.2	Protecting family interests	76
3.3.2.2.3	Maturation	77
3.3.2.3	Theme 3: Support and communication.....	78
3.3.2.3.1	Need for support.....	78
3.3.2.3.2	Tighter bonds.....	79
3.3.2.3.3	Selective sharing	79
3.3.3	Cluster 3: Conceptualisation and integration.....	80
3.3.3.1	My IBD.....	81
3.3.3.1.1	Conceptualisation and integration	81
3.3.3.1.2	Triggers	82
3.3.3.1.3	Vivid awareness	82
3.3.3.2	Hidden illness.....	83
3.3.3.2.1	Advocacy for validation	83
3.3.3.2.2	Disparity of knowledge	83
3.3.3.2.3	Ambivalence towards healthcare professionals.....	84
3.3.3.3	Mums' needs.....	85

3.3.3.3.1	Centralisation of resources	85
3.3.3.3.2	Holistic approach.....	85
3.4	Summary and Discussion	86
3.4.1	Characteristics and content of articles	86
3.4.2	Synthesis saturation & cluster discussion	86
3.4.2.1	Burden on the family.....	86
3.4.2.2	Coping.....	87
3.4.2.3	Conceptualisation and integration.....	88
3.4.3	Reflection on the meta-analysis	89
3.4.3.1	Advantages.....	90
3.4.3.2	Limitations	90
3.4.3.3	Future directions	91
Chapter 4	Methodology.....	92
4.1	Ethics	92
4.1.1	Fieldwork and lone working	93
4.1.2	Consent	93
4.1.3	Risks for participants.....	95
4.1.4	Benefits for participants.....	96
4.1.5	Compensation.....	96
4.1.6	Confidentiality.....	96
4.1.7	Data protection	97
4.1.8	Declaration of conflict of interest.....	98
4.1.9	Ethical approval.....	98
4.2	The Researcher.....	98
4.3	Recruitment Aims	101
4.3.1	Target sample size	101
4.3.2	Inclusion criteria.....	101
4.3.3	Exclusion criteria.....	102
4.4	Recruitment Strategies.....	103
4.4.1	Press releases.....	103
4.4.2	Social media.....	103
4.4.3	Social events	103
4.4.4	Recruitment issues.....	104
4.4.5	Selection rate and online survey.....	104
4.5	Sampling Techniques	105
4.5.1	Convenience piloting (n=1)	105
4.5.2	Purposive sampling: maximum variation and intensity sampling (n=6)	106
4.5.3	Purposive sampling: maximum variation and criterion sampling (n=13).....	106

4.5.4	Theoretical sampling (n=2)	107
4.6	Sample Characteristics	107
4.6.1	Sample size	107
4.6.2	Description of included participants	108
4.7	Data Collection	112
4.8	Designing the Interview Schedule and Conducting the Interview	113
4.8.1	Aim of schedule	113
4.8.2	Question types	113
4.8.3	Construction and sequencing	114
4.8.4	Timeline	115
4.8.5	Practicalities and preparations	115
4.8.6	Pros and cons of face-to-face semi-structured interviews	117
4.9	Analytical Procedures - Thematic Analysis	118
4.9.1	Transcription level	119
4.9.2	Thematic Analysis defined	120
4.9.3	Dialectics	121
4.9.3.1	Theme delimitation	121
4.9.3.2	Latent versus semantic	122
4.9.3.3	Inductive vs. theoretical	123
4.9.3.4	Rich description vs. detailed account	124
4.9.3.5	Epistemology and ontology	125
4.9.4	Phases of TA	126
4.9.5	Pros and cons of Thematic Analysis	128
4.10	Summary	129
Chapter 5	Blurred Lines	130
5.1	Theme 1: Need for Readiness	131
5.1.1	Shocks and secrets	131
5.1.2	Need for maturity	134
5.1.3	Identifying blame	135
5.1.4	Fear of mortality	136
5.1.5	Seeking others' experience	138
5.2	Theme 2: Lifestyle Changes	140
5.2.1	Regime alterations	140
5.2.2	Libido loss	141
5.2.3	Dependence	142
5.2.4	Financial and career implications	144
5.2.5	Relationship and network changes	146
5.2.6	Sleeplessness and fatigue	147

5.2.7	Constant worry	148
5.2.8	Adapting to uncertainty	149
5.3	Theme 3: Monitoring Personal and Physical Development	150
5.3.1	Close scrutiny	151
5.3.2	Weight changes	152
5.3.3	Symptom confusion	153
5.3.4	Seeking respite	156
5.3.5	Identity change	158
5.4	Summary, Discussion, and Reflections	159
5.4.1	Implications of the analysis presented	165
5.4.2	Conclusion	166
Chapter 6	Transitional Challenges	167
Phase 1:	Nulliparous Life	169
6.1	Theme 1: Burden of Knowledge	169
6.1.1	Making sense of IBD	169
6.1.2	Overwhelming (lack of) information	170
6.2	Theme 2: Weighing Decision-Making.....	171
6.2.1	Acknowledging IBD	171
6.2.2	Trial and error	171
6.2.3	Restoring health.....	172
6.3	Theme 3: Blame and Guilt.....	173
6.3.1	Justifying IBD	173
6.3.2	Partner acceptance	174
6.4	Theme 4: Ambivalence towards Healthcare Professionals	175
6.4.1	Mixed feelings.....	175
6.5	Recommendations	176
Phase 2:	Planning for Pregnancy	177
6.6	Theme 1: Burden of Knowledge	177
6.6.1	Assumption of IBD interference	177
6.6.2	Lack of information.....	178
6.7	Theme 2: Weighing Decision-Making.....	179
6.7.1	Improving odds	179
6.7.2	Alternatives and acceptance.....	179
6.8	Theme 3: Blame and Guilt.....	181
6.8.1	Selfish desire.....	181
6.8.2	Social pressures	181
6.9	Theme 4: Ambivalence towards Healthcare Professionals	182
6.9.1	Mixed support	182

6.10	Recommendations.....	183
	Phase 3: Conception and Gestation.....	183
6.11	Theme 1: Burden of Knowledge.....	183
6.11.1	Haunting fears	183
6.11.2	Treatment conundrum.....	184
6.11.3	Lack of certainty.....	185
6.12	Theme 2: Weighing Decision-Making.....	185
6.12.1	Shift of priority.....	185
6.12.2	Tailoring support	187
6.13	Theme 3: Blame and Guilt	188
6.13.1	The good mum.....	188
6.14	Theme 4: Ambivalence towards Healthcare Professionals.....	188
6.14.1	Establishing trust	188
6.14.2	Power over birth plan.....	190
6.14.3	Liaising with specialists	191
6.15	Reflections and Recommendations	192
	Phase 4: Labour and Breastfeeding.....	192
6.16	Theme 1: Burden of Knowledge.....	193
6.16.1	Labour apprehensions	193
6.16.2	Mother earth	194
6.17	Theme 2: Weighing Decision-Making.....	195
6.17.1	Unplanned labour events.....	195
6.17.2	Feeding choices	196
6.18	Theme 3: Blame and Guilt	197
6.18.1	Easing guilt.....	197
6.18.2	Societal pressures.....	198
6.19	Theme 4: Ambivalence towards Healthcare Professionals.....	199
6.19.1	Speciality-focused.....	199
6.20	Recommendations.....	199
	Phase 5: Early Years of Motherhood with IBD	200
6.21	Theme 1: Burden of Knowledge.....	200
6.21.1	Performing mother role.....	200
6.22	Theme 2: Weighing Decision-Making.....	201
6.22.1	IBD management.....	201
6.22.2	Communicating need for help	202
6.23	Theme 3: Blame and Guilt	202
6.23.1	The good mum.....	202
6.23.2	Invisible illness.....	204

6.24	Theme 4: Ambivalence towards Healthcare Professionals	205
6.24.1	Lack of integration	205
6.25	Summary, Discussion, and Reflections	206
6.25.1	Conclusion	213
Chapter 7	Reflecting on Others	214
7.1	Theme 1: Shielding Child.....	215
7.1.1	Child as a shield	215
7.1.2	Shielding child from IBD.....	217
7.1.3	Reflecting IBD	219
7.2	Theme 2: Comparative Normality.....	221
7.2.1	People and me	221
7.2.2	Mothers and me.....	223
7.2.3	Myself and me.....	225
7.3	Theme 3: Two-Sided Mirror.....	228
7.3.1	Confiding platform	230
7.3.2	Wallow window	232
7.3.3	Staged performance	233
7.4	Discussion and Reflections.....	235
7.4.1	Conclusion	240
Chapter 8	Discussion	241
8.1	Summary of the Analyses.....	241
8.2	Key Findings Across this Research.....	242
8.3	Theoretical and Practical Application of the Findings.....	246
8.3.1	Altered self-concept.....	246
8.3.2	Avoidant, approach and attention-focussed coping styles	247
8.3.3	The Common-Sense Model: Illness representation as a dynamic process.....	248
8.4	Strengths and Limitations.....	250
8.5	Creation of YouTube Medleys and Research Impact	255
8.5.1	Clips content	255
8.5.2	Clips creation	256
8.5.2.1	Format.....	256
8.5.2.2	Feedback and checks.....	257
8.5.2.3	YouTube impact	260
8.5.3	Other types of research impact.....	260
8.5.3.1	Dissemination.....	261
8.5.3.2	Active engagement.....	263
8.6	Future Research	266
8.7	Conclusion	266

References.....	268
Appendices.....	282
Appendix A Database Selection across Fields of Psychology, Healthcare, and Medicine ..	282
Appendix B Search Hit Results per Database.....	288
Appendix C CASP Scoring and Evaluation Forms.....	291
Appendix D Risk Assessment for Fieldwork and Lone Working (Medium Risk Activities)	299
Appendix E Safety Protocol for Risk Assessment.....	302
Appendix F Flowchart of the Process of Consent for Participants Interviewed on Skype..	303
Appendix G Invitation Letter.....	304
Appendix H Information Sheet.....	305
Appendix I Background Information Sheet.....	309
Appendix J Consent Form.....	312
Appendix K IBD and Mums-To-Be: Confidentiality Agreement Form.....	314
Appendix L The Typing Works: Confidentiality Agreement Form.....	315
Appendix M CCUK News: Autumn 2014 Issue.....	316
Appendix N CCUK News: Winter Issue 2015	317
Appendix O Mumsnet Advertisement	318
Appendix P Recruitment Flyer	319
Appendix Q Conferences, Symposiums, and Oral Presentations.....	320
Appendix R Map of the Geographical Location of the Sample.....	321
Appendix S Recruitment Map	322
Appendix T Online Survey.....	323
Appendix U Description Table of Online Sample	329
Appendix V Guidelines for High-Quality Video-Recording	330
Appendix W Interview Schedule: First Draft	332
Appendix X Brainstorm Facebook Group: Questions and Excerpt Example from Friend..	333
Appendix Y Interview Schedule: Second Draft – Tested on Pilots.....	335
Appendix Z Interview Schedule: Third Draft.....	338
Appendix AA Interview Schedule: Fourth Draft	341
Appendix BB Timeline	344
Appendix CC Contribution Table of Blurred Line: Theme 1 Need for Readiness.....	345
Appendix DD Contribution Table of Blurred Line: Theme 2 Lifestyle Changes	346
Appendix EE Contribution Table of Blurred Line: Theme 3 Monitoring Personal and Physical Development.....	347
Appendix FF Contribution Table of Transitional Challenges: Nulliparous Life (Phase 1)	348
Appendix GG Contribution Table of Transitional Challenges: Planning for Pregnancy (Phase 2).....	349
Appendix HH Contribution Table of Transitional Challenges: Conception and Gestation (Phase 3).....	350
Appendix II Contribution Table Transitional Challenges: Labour and Breastfeeding (Phase 4).....	351

Appendix JJ Contribution Table Transitional Challenges: Early Years of Motherhood with IBD (Phase 5).....	352
Appendix KK Contribution Table Reflecting on Others: Theme 1 Shielding Child	353
Appendix LL Contribution Table Reflecting on Others: Theme 2 Comparative Normality	354
Appendix MM Contribution Table Reflecting on Others: Theme 3 Two-Sided Mirror	355
Appendix NN Number of Glances per Recording.....	356
Appendix OO Transcript Video 1: Planning for a Baby	357
Appendix PP Transcript Video 2: Pregnancy with IBD	358
Appendix QQ Transcript Video 3: Motherhood with IBD	359
Appendix RR Three Press Releases on Publication	361

List of Figures

<i>Figure 1.</i> Components of the digestive system (OpenStaxCollege , 2013)	2
<i>Figure 2.</i> Differences in inflammation in CD and UC (iStockPhoto , 2015).....	2
<i>Figure 3.</i> Flowchart of the process of consent for participants interviewed face-to-face	94
<i>Figure 4.</i> Visual mapping of the terminology used in Thematic Analysis.....	120
<i>Figure 5.</i> Looping navigation across the six phases of Thematic Analysis	126
<i>Figure 6.</i> Invisible illness toilet label.....	212
<i>Figure 7.</i> iPad recorder fixed on tripod.....	228
<i>Figure 8.</i> Interview triangulation.....	229
<i>Figure 9.</i> UCMumPi01C01 Glancing at the interviewer	229
<i>Figure 10.</i> UCMumPi01C01 Glancing at the camera.....	229

List of Tables

Table 1 <i>SRR Key Terms by Cluster</i>	47
Table 2 <i>SRR Screening Articles, Inclusion and Exclusion Selection (Round 1)</i>	50
Table 3 <i>SRR Final Inclusion and Exclusion Selection (Round 2)</i>	52
Table 4 <i>Summary of the Findings</i>	56
Table 5 <i>SRR Clusters, Themes, and Subthemes</i>	66
Table 6 <i>Contribution of the Cluster ‘Burden on the Family’</i>	67
Table 7 <i>Contribution of the Cluster ‘Coping’</i>	74
Table 8 <i>Contribution of the Cluster ‘Conceptualisation and Integration’</i>	81
Table 9 <i>Advertisement Success Rate</i>	105
Table 10 <i>Description of Participants Age (at Gestation and Pregnancy) and Their Children’s Age</i>	108
Table 11 <i>Description of Participants Age at Diagnosis, and Years living with IBD and Children</i>	109
Table 12 <i>Description of Sample Characteristics</i>	110
Table 13 <i>Example of Transcript Coding</i>	127
Table 14 <i>Overview of the Themes, and Subthemes of the Concept Blurred Lines</i>	131
Table 15 <i>Overview of the Themes, and Subthemes of the Concept Transitional Challenges, across the 5 Phases of the Transition to Motherhood</i>	167
Table 16 <i>Description of Participants who Contributed to each Phase</i>	168
Table 17 <i>Overview of Themes, Subthemes of Participants Diagnosed During Pregnancy</i>	192
Table 18 <i>Overview of Themes, Subthemes of Participants Diagnosed During the Early Years of Motherhood with IBD</i>	206
Table 19 <i>Themes and Subthemes of Reflecting on Others</i>	214
Table 20 <i>Video Glances Coding CDMum08C01</i>	230
Table 21 <i>Reviewers Comments on YouTube Medleys</i>	258

Chapter 1

Inflammatory Bowel Disease: Medical Perspective

The purpose of this chapter is to provide an overview of Inflammatory Bowel Disease (IBD) from a medical standpoint. A definition of IBD and its symptoms is provided along with some historical lineage to the first gastroenterologists and scientists who have described this illness. This chapter also covers techniques of IBD detection as well as ambiguity of concomitant and confounding illnesses. In addition, epidemiological information around mortality, age of onset, prevalence, incidence, sex, country as well as ethnic minorities are reported along with some of the suggested theories on the origin of the illness. The chapter further addresses the protective and risk factors to developing IBD and concludes by providing a few examples of current remedies and treatments used within the medical and paramedical fields in attempting to manage this chronic condition.

1.1 Definition, Nomenclature, and Symptoms

Inflammatory bowel disease is an umbrella term principally referring to two inflammation disorders affecting the digestive system: Ulcerative Colitis (UC) and Crohn's Disease (CD) (NHS, 2015). According to Bergen (1924) the term UC was initially mentioned by Wilks and Moxon in 1875 but was first described by White in 1888. Bergen (1924) also pointed out that according to Hawkins¹ the "pedigree of this disease can be traced back [to] nearly three hundred years in the 'bloody flux' of Sydenheim in 1669" (p. 332). As for the term Crohn's Disease, it was named after the American gastroenterologist Bernard Crohn who pinpointed the differences between CD and UC in 1932 (Crohn, Ginzburg, & Oppenheimer, 1932). Nevertheless, Korzenik (2005) believed that it was Dazliel who first reported in 1913 a new type of inflammation in the small intestine (ileitis), which was later recognised to be CD. The figure below illustrates the various parts of the digestive tract and assists in the visualisation of the various terminology used throughout the thesis.

¹ Date not specified.

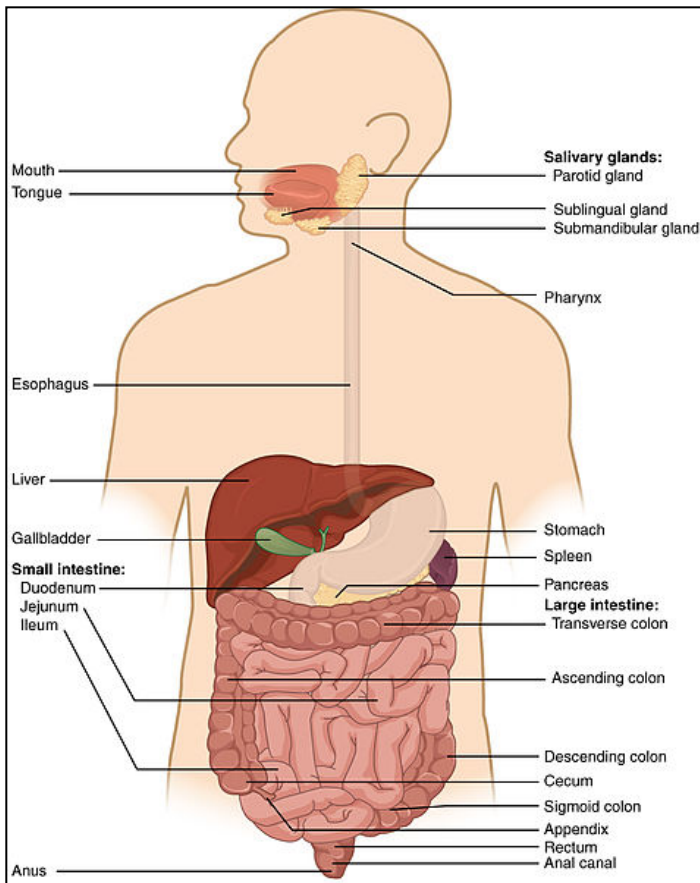


Figure 1. Components of the digestive system (OpenStaxCollege , 2013)

IBD is considered to be a chronic illness characterised by periods of active symptoms called flares or flare-ups, or fulminant phases, and periods of remission where symptoms are more or less dormant, also referred to as refractory phases (NHS, 2015). Crohn's Disease can affect any part of the digestive tract, informally referred to from 'gum to bum', and the inflammation is usually asymmetrical and discontinuous along the intestine and other affected areas. On the other hand, UC typically affects the large intestine (colon) and rectum area with usually continuous and symmetrical inflammation (see *Figure 2*).

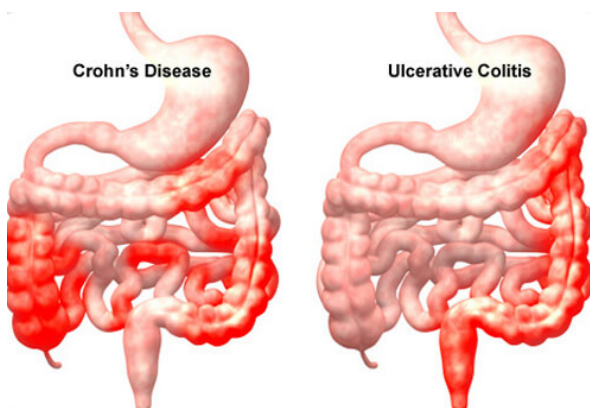


Figure 2. Differences in inflammation in CD and UC (iStockPhoto , 2015)

Although the two illnesses seem to affect substantially different areas of the digestive tract, the clinical presentation of the symptoms can be quite similar and sometimes difficult to tell apart based on patients' self-report (NHS, 2015). Typically, individuals with UC or CD describe stomach pains, fatigue, fever, rectal bleeding, recurring diarrhoea (often bloody with mucus or pus), and weight loss as common manifestations of their illness.

In some instances (9-20%) investigation of the affected digestive tract does not permit a clear distinction between UC and CD diagnosis, the term Indeterminate Colitis (IC) or IBD Unclassified type (IBDu) is used (Telakis & Tsironi, 2008). Guindi and Riddell (2004) suggested to revise the term IC (coined by Price in 1978) and use, instead, the term, 'IBD not yet classified,' as a more appropriate alternative. Moreover, Guindi and Riddell (2004) made the claim that with the progression of the illness there is often a shift of diagnosis to one of the two predominant types of IBD (notably UC or CD). This suggestion has been supported by Telakis and Tsironi (2008) who echoed the recommendation of the Working Party of the World Congress of Gastroenterology in Montreal and name 'Indeterminate colitis' diagnoses of undifferentiated UC and CD post-colectomy² and 'IBD-type unclassified or IBDu' diagnoses of undifferentiated UC and CD where no such surgical intervention was performed. For consistency and clarity, I used the term IBDu (unclassified) because it is the more conservative of the two options, except where I am reporting results of a study in which the authors used a different nomenclature.

1.2 Detection of Symptoms

Detecting IBD is not straightforward and doctors use a series of invasive and non-invasive procedures to identify the illness (NHS, 2015).

1.2.1 None invasive procedures

In the UK, General Practitioners (GPs) are usually the first person patients report to for their bowel disturbances and symptoms. In light of the clinical presentation of bowel symptoms, GPs typically ask for a serological test, which is a blood test also known as a CBC (Complete Blood Count) looking for the presence of anaemia or infection. Nonspecific inflammatory markers, such as an Erythrocyte Sedimentation Rate (ESR) and C - Reactive Protein (CRP) are easily obtained via blood tests and help establish the presence of an inflammation. These markers however, can be elevated in infectious diseases (unrelated to IBD). As such, an elevated white blood count, detected via a CBC, might indicate an inflammation but might also be a sign of an infection. A more careful look at the comparative proportion of the various white cells can

² Colectomy is a surgical intervention consisting of the excision of all (proctocolectomy) or part (hemicolectomy) of the colon (MayoClinic, 2015). Upon its removal, an analysis of a specimen of the colon can be done to determine the type of IBD.

further help differentiate between an infectious and inflammatory process. In the last decade, clinicians have used serological tests for specific antibodies (perinuclear antineutrophilic cytoplasmic antibody [p-ANCA] and anti-Saccharomyces cerevisiae antibody [ASCA]), which appear to be present either in CD or UC (Basu, Lopez, Kulkarni, & Sellin, 2005; Loftus, 2007). ANCA is more prevalent in individuals with UC, and ASCA is more prevalent in individuals with CD. However, as with the CRP, the ANCA and ASCA markers are not unique to IBD and can equally indicate an infection unrelated to IBD.

GPs can concurrently request a *Guaiaec* stool test, which is an easy method to detect the presence of faecal occult blood (blood not otherwise visible in the faeces) to help form their diagnosis. Another testing stool examination would be to test for faecal markers of inflammation such Lactoferrin and Calprotectin (Loftus, 2007). The presence of these two markers provides the potential to demark IBD from other illnesses such as Irritable Bowel Syndrome (IBS)³ and may also give an indication of the severity of the illness and its potential prognosis⁴.

Overall, clinicians will often rely on a clinical history, symptomatology and all of the tests mentioned above prior to referring the patient to a gastroenterologist specialist and request the more invasive but higher yield endoscopic investigative techniques described below (Loftus, 2007).

1.2.2 Invasive procedures

There are numerous endoscopic procedures, however, I only discuss the two main ones: endoscopy and colonoscopy.

Endoscopy and colonoscopy involve the insertion of a slender tube with an attached camera, either in the colon (colonoscopy) or the oesophagus (upper endoscopy), to look for signs of mucosal inflammation (NHS, 2015). The other types of endoscopic procedures target other areas of the bowel such as sigmoidoscopy, which looks at the end of the colon (sigmoid, refer to *Figure 1*), or double-balloon endoscopy which looks at the small bowel. Endoscopies in general can be accompanied by less invasive imaging procedures such as X-rays, Magnetic Resonance Imaging (MRI,) or Computerised Tomography (CT) scans, to further enhance the accuracy of the diagnosis.

As will be discussed in the treatment section, it is important to note and monitor the serological, endoscopic as well as Calprotectin markers of IBD as they often provide better insight into the ongoing activity of the illness compared to Patient Reported Outcomes (PROs) of activity (Lamb, 2016). Even though individuals with IBD may not be sensing the flare-up, mucosal inflammation can still cause extensive damage leading to irreversible changes.

³ IBS is more thoroughly described in section 1.3 below.

⁴ In order to demarcate IBD from IBS, GPs need to compare the test performance of faecal markers, blood leukocytes, CRP, and IBD antibodies.

1.3 Confounding and Concomitant Illnesses

It is important to distinguish, at this point, IBD from another potentially lifelong occurring gastrointestinal illness named Irritable Bowel Syndrome (IBS) (NHS, 2015). IBS presents similar symptoms to IBD such as diarrhoea and stomach pains; and like IBD it is more commonly reported in women versus men with an onset during the third and fourth decade of life⁵. The overlap is further reinforced by the fact that researchers often investigate the lived experience of IBS and IBD patients simultaneously (Fletcher, Jamieson, Schneider, & Harry, 2008; Fletcher, Schneider, Van Ravenswaay, & Leon, 2008; Schneider & Fletcher, 2008; Schneider, Jamieson, & Fletcher, 2009). Nevertheless, the illnesses are aetiologically different since IBS does not cause inflammation of the colon but involves a dysfunction of the digestive system. Furthermore, the two illnesses comprise different treatments. IBD patients receive immunosuppressant or corticoid therapy targeting the inflammation as well as a suggestion for a diet change; whereas IBS patients are mostly advised on an alternative food and lifestyle regimen and reducing stress, to target their symptoms. Furthermore, despite its name, IBD can present extra-intestinal manifestations (EIM) such as joint pain, dermatological illnesses (i.e., psoriasis), anaemia, eye conditions, and thromboembolism to name a few (Arvikar & Fisher, 2011). The most common EIMs are pains and joints-aches referred to as arthritis (if inflammation is found in the joints) or arthralgia (if no inflammation is found in the joints) (CCFA, 2015). The former type, arthritis, is most commonly found among IBD patients and can affect up to 30% of patients, whereas the latter, arthralgia, impacts 10-20% of IBD patients. Arthritis-IBD is painful and reduces flexibility which can severely impact the quality of life of individuals by impinging their autonomy to carry out daily tasks. Pizzi et al. (2006) found arthritis-IBD to be the second predictor of poor quality of life in IBD patients after disease severity.

1.4 Epidemiology

1.4.1 Mortality

Card, Hubbard, and Logan (2003) noted some inconsistencies in the literature on IBD mortality. Some authors reported an increased risk of mortality associated with IBD whilst others questioned evidence of a link between IBD and increased chance of mortality. Card et al. (2003) looked at the mortality rate of patients with IBD in a large cohort of IBD patients and healthy matched controls in the UK ($N_{\text{IBD}} = 16,550$, $N_{\text{Control}} = 82,917$). They accounted for confounding illnesses (such as heart diseases and diabetes), other chronic illnesses (such as lung cancer), sex, age, and smoking. The results showed that in the IBD cohort 17.1 per 1000 individuals/year

⁵ The epidemiology of IBD will be discussed in details in the following section.

died versus 12.3 per 1000 individuals/ year in the general population. This translated into a 0.5% greater risk of death due to IBD. The hazard risk was greater for the age groups 20-39 and 40 to 59 compared to older aged groups (59 >) or very young ones (below 20 <).

1.4.2 Age of onset

IBD can affect individuals at any age and is diagnosed in 1 in every 250 people in the UK (NHS, 2015). Typically children and adolescents' onset age occurs in the second decade of life (Day, Ledder, Leach, & Lemberg, 2012) whereas adult onset typically occurs between the third and fourth decade of life (Molodecky et al., 2012). Childhood and adolescent onset represents one quarter of all IBD cases while CD is more commonly diagnosed than UC in older children (school-aged), with a higher male to female ratio (Dubinsky, 2008). The manifestation of UC and CD in children appears to be different than in adults. In paediatrics, UC is commonly diagnosed as *pancolitis* which is a particularly severe form of UC, affecting the entire large intestine and symptoms tend to progress quickly within a short number of years (Day et al., 2012). On the other hand, CD in children, is typically located in the ileocolonic region (called *ileocolitis*, refer to *Figure 1*): from the connecting link of the small intestine – ileum – to the large intestine, as well as the large intestine. These differences are attributed to a greater influence of genetics in children versus adults and can have a profound and detrimental effect on growth spurts and psychological development of these young people (Day et al., 2012; Dubinsky, 2008). Van Limbergen et al. (2008) investigated the progression and aspects of IBD in 416 children (<17 years old) across three gastroenterology centres in Scotland and noted similar differences to Dubinsky (2008) which led the former authors to hypothesise that IBD's early onset is arguably aetiologically different than adult onset. That said, from here on I focus the discussion on adults with IBD, who constitute the population of interest of my thesis.

1.4.3 Prevalence and incidence

Molodecky et al. (2012) noted that the overall prevalence and incidence⁶ of IBD have increased in Westernised nations between 1930 and 2008. Similarly, incidence and prevalence of IBD in developing countries have risen, and have been attributed to the industrialization of these countries. Increasing numbers of people were diagnosed with IBD in North America and Europe as compared, in the review, to Asia and the Middle East. For example, the highest incidence of UC and CD in Asia and Middle East were respectively 6.3 per 100,000 person-annually for UC and 5.0 per 100,000 person-annually for CD. These rates were considerably lower compared to the highest incidence of UC and CD in North America of 19.2 and 12.7 per 100,000 person-annually and Europe 24.3 and 20.2 per 100,000 person-annually. Among the

⁶ The terms incidence and prevalence were respectively defined as the measure of new cases – of IBD – or onset at a given time, and the measure of the number of individuals expressing the disease per 100,000 individuals in that population

numerous results reported in Molodecky et al.'s (2012) systematic research review (SRR), pertinent to my topic are the 36 selected incidence studies in the UK. This reveals that the annual incidence rate of CD varies between 1.3 - 10.6 (10^5) and the annual incidence rate of UC varies between 2.0 - 15.1 (10^5). The authors also included in their review 14 prevalence studies pertaining to the UK that revealed a variance between 9 - 157 (10^5) for CD and 5.3 - 389 (10^5) for UC.

1.5 Sex Differences

Statistics showed no sex differences in prevalence and incidence in IBD across all countries investigated (Molodecky et al., 2012). However, looking closely at UK data (Appendix 4 p. 54 e 19), of the 11 studies that stratified UC incidence by sex, 9 indicated an equal or higher female to male ratio. Only 5 of these studies simultaneously computed CD incidence by sex, with 4 of them also indicating a higher female to male incidence ratio. These figures aligned with the NHS (2015) statistics indicating a slightly higher prevalence in women versus men in IBD. The authors found that the UK had the highest incident rates of CD compared to North America, Asia, the Middle East, and the rest of Europe with the most common onset of IBD occurring between the ages of 20 to 29 years. The NHS website also underlined, similarly to Molodecky et al. (2012), that IBD's onset occurred around the teenage years and early twenties thus directly hindering "their most formidable and productive years" (2012, p.52). Molodecky et al. (2012) argued that, since (1) IBD was often diagnosed in the third to fourth decade of a person's life, (2) prevalence and incidence have been increasing or unchanged in most countries investigated between 1930 until 2008, and (3) mortality rates with IBD were low (Card et al., 2003), it could only indicate that the global impact of IBD will continue to rise. The authors could only speculate as to the reason for this increase and suggested greater awareness of the illness and use of colonoscopy and medical advances.

In sum, Molodecky et al.'s (2012) comprehensive research gave an estimate of the burden of IBD worldwide and in the UK specifically; it pointed out that the prevalence and incidence were increasing, that CD was slightly more likely than UC in the UK, that female to male ratio was slightly higher for women with IBD, and that IBD was most commonly diagnosed during the reproductive years. These findings encourage further study to know more about the impact of IBD on individuals seemingly more at risk of developing IBD, including women in their childbearing years.

1.6 IBD and Ethnic Minorities

Basu et al. (2005) stated in their review that IBD was historically thought to be a disease that affected only Caucasian/White individuals. However, later evidence showed this to be untrue (Mangat, Evaschen, Lee, Yoshida, & Salh, 2011). The study of IBD's epidemiology in migrant

populations and ethnic minority groups, provided a unique way of looking at the effect of diverse genetic background in individuals sharing common lifestyles (Mangat et al., 2011). Mangat et al. (2011) examined retrospectively data from the Vancouver General Hospital database in Canada and found that, among the 185 IBD cases (103 CD, 80 UC, 2IC), the majority were Caucasians 86%; South Asians (East Indian, Pakistani or Sri Lankan) and Pacific Asians (Chinese, Japanese or Korean) represented respectively 8.6% and 4.3% of the cases, and other minorities (Black, Filipino, Southeast Asian, or South American) represented about 1%. All groups had a similar median time spent in hospitals (5 to 6 days), as well as median age of onset (mid 30s to early 40s); however, there was a small but significantly higher male to female ratio of IBD in the South and Pacific Asian groups compared to the Caucasian group.

Similarly, in the USA, a retrospective study on 148 IBD patients (82 CD, 61 UC, 5 IC) in Houston, Texas also revealed that Whites (40%) and African Americans (37%) composed the majority of the sample (Basu et al., 2005). Mexican Americans represented 20% of the sample and Asians 3%. Again, the two dominant groups had more diagnoses of CD than UC, and the Mexican and Asian groups had more UC than CD diagnoses.

In the UK, it has been established that Jewish communities of European lineage - Ashkenazi - were four times more likely to develop IBD than their non-Jewish counterparts (Levine & Schiff, 2016). Levine and Schiff (2016) explained that the Ashkenazi Jews' relatively high rate (5 in every 1000 individuals) could be understood as the interaction between the environment and a predisposing genetic component in this population. Furthermore, El-Tawil (2009) added that Jewish individuals were three to five times more likely to develop IBD in Western countries; however, in Israel Ashkenazi Jews still had higher incidence of IBD than Sephardi Jews. Similarly, Lynch, Brand, and Locker (2004) reported that Jews from European descent were more likely to have IBD than those from Russian descent.

Studies on minorities in the UK have also looked at South Asian immigrants, however most data are around 20 years old (Carr & Mayberry, 1999; Probert, Jayanthi, Pinder, Wicks, & Mayberry, 1992). A study by Alexakis et al. (2015) investigated the lived experience of minorities in the UK including Blacks and South Asians, however they were limited to a young population (adolescents and young adults aged between 16 and 24 years old). The study, however, added insight into the experience of young adults and their parents with the healthcare system and the experience of social restrictions due to intolerance to spices and other traditional foods. In terms of prevalence and incidence, there was a consensus that immigrants, particularly from South Asian countries, have increased reported incidence of IBD in the UK (Molodecky et al., 2012; Mukherjee, Beresford, Sebastian, & Atkin, 2015). That said, I could not pinpoint one study revealing the exact percentage of IBD cases in Black or South Asian minorities in the UK.

Understanding the manifestation of IBD amongst immigrants and ethnic groups could provide crucial information in the elucidation of IBD aetiology as well as barriers to treatments (Mangat et al., 2011; Mukherjee et al., 2015).

1.7 Protective and Risk Factors

1.7.1 Smoking

Parkes, Whelan, and Lindsay (2014) reviewed the impact of smoking on IBD's progression and attempted to shed light on the mechanism through which smoking affects the course of UC and CD. The authors noted the differential effect of smoking cigarettes on individuals with UC and CD. Individuals with UC who smoke had less severe disease course and smoking in and of itself seemed to protect against the development of UC. Furthermore, smoking cessation seemed to have a detrimental effect on UC patients as their uptake of immunosuppressant and corticosteroid medication increased, so did their disease activity. Conversely, Parkes et al. (2014) found smoking to have the opposite effect on patients with CD. Smokers with CD had longer reported-time of disease activity and longer periods of medication prescription. In addition, continuous smoking amongst CD was a predictor of disease progression and worsening as well as increased likelihood of surgery. As one would expect, smoking-cessation seemed to have a positive impact on the course of CD: ex-smokers with CD responded better to their medication treatments than current smokers. The authors further stipulated that although the link between smoking and IBD has been established it was likely that several factors were playing a role in this interaction, including the immunomodulatory property of cigarette components, the increase of gut microbiota⁷, and the potential impact of nicotine on the permeability of the intestinal barrier. Nevertheless, the precise mechanism through which smoking acts as both a protective factor in UC and a risk factor in CD remained unclear.

1.7.2 Appendectomy

Russel et al. (1997) wanted to see whether previous appendectomy (surgical removal of the appendix, refer to *Figure 1*) resulted in a risk to develop UC or CD. They recruited 490 IBD patients (232 UC and 209 CD) from the Netherland's South Limburg IBD Study Centre. They matched each patient by age and sex to a healthy control. Results showed that when combining the prevalent cases of UC and CD between 1984 and 1991 as well as the incident cases of UC and CD from 1991 to 1994, having an appendectomy appeared to be a significant protective factor against UC compared to healthy controls. However, no conclusion could be drawn for CD patients compared to healthy controls. As for CD, looking exclusively at prevalent cases, results revealed that appendectomy was a risk factor. These statistics remained unchanged even after controlling for smoking habits within the sample.

⁷ The human gut microbiota is composed of both viral and bacterial organisms which help protect, in conjunction with the immune system, against any pathogens (Carding et al., 2015). The microbiota also serves vital functions such as extracting nutrients from food, a key component for survival. Any alteration and imbalance in the microbiota, from toxins in the environment, is referred to as *dysbiosis* and could cause inflammatory reactions in the gut.

1.7.3 Family history

The greatest risk of IBD is familial inheritance; having first-degree relatives (FDRs) with IBD, particularly a sibling, posed the highest risk for developing the illness (Russell & Satsangi, 2004). Russell and Satsangi (2004) reported, from the studies reviewed, that when a FDR was affected with CD there was a relative 5 to 21-fold increase in risk of developing CD compared to a 3 to 6-fold increase to develop UC. However, when a FDR was affected with UC, there was a 2 to 15-fold increase risk for an individual to develop UC and 2 to 3 folds risk for him/her to develop CD. These relative risks seemed to be higher amongst the Jewish community (as discussed in section 1.6 *IBD and Ethnic Minorities*).

The risks of having a child developing IBD were substantially higher when both parents were affected with CD or UC (or even a mix of IBD types, one parent has UC and the other CD) compared to a single sick parent (Russell & Satsangi, 2004). These risks extended to second-degree relative even if they substantially dropped in numbers. The more relatives were affected by IBD the more likely it was that another member of the family might get IBD.

1.7.4 Other risk factors

It has been noted that the intake of contraceptive pills, breastfeeding, urban environment, sanitisation of the environment, house dust mites as well as number of family members and number of toilets in a household could play a role in triggering IBD (Fiocchi, 2015; Ko et al., 2015; Korzenik, 2005; Tulic et al., 2016). The heterogeneity and diversity of risk factors only pushed the understanding of the aetiology even further, and researchers are still attempting to elucidate the mechanism by which IBD is activated.

1.8 Aetiology

The one consensus investigators have reached by exploring the origins of IBD is that, to this day, no single explanation provided can account for all the cases of Ulcerative Colitis, Crohn's Disease, and IBD unclassified (Korzenik, 2005). Grossly, IBD is accepted to be the product of a combined interaction of genetic and environmental factors (Korzenik, 2005) resulting in over activation of T-cells (white blood cells) which are responsible for the protection against antigens (Lymphoma, 2012).

In his review of past and current, accurate and inaccurate, theories of IBD, Korzenik (2005) divided the gathered literature into five categories to shed light on possible instigators of the overly active immune system. Korzenik (2005) mentioned infectious origins, psychosomatic origins, diet and allergy, immune deficit, and alteration in the gut mucosa. I used Korzenik's structure to relate the findings that are contemporarily contemplated to be at the root of IBD and added at times other theories not covered in his original review. However, no attempt was made

to be all inclusive in the enumeration of the many theories posited, and I recognise that other theories have been suggested that were not covered in this section.

1.8.1 Infectious viral origins

Amongst the many viruses that were suggested to cause IBD, Diplostreptococci, Influenza B, Chlamydia, Herpes, and Poliovirus were at the heart of investigations in the early part of the 20th century (Korzenik, 2005). Some vaccines were developed to eliminate these viruses with little success in curing IBD. The two main agents that have received support are the Measles and the Mycobacteria Paratuberculosis (MAP). MAP is the agent responsible for a type of *ileitis* in cattle called *Johne's Disease* and it causes similar gastric symptoms to IBD in ruminants. Dr Crohn, himself, had entertained the idea that this same agent could be responsible for CD in humans. Nevertheless, identifying MAP in individuals with CD has proven to be difficult and therapeutic trials were inconsistent. As for Measles virus, Korzenik (2005) also reported that findings were inconsistent but some research suggested that exposure to measles vaccines increased chances of developing CD in individuals. Moreover, earlier research found that exposure to measles during gestation increased the chance of developing CD in offspring (Wakefield, Ekblom, Dhillon, Pittilo, & Pounder, 1995).

1.8.2 Infectious bacterial origins

Hendrickson, Gokhale, and Cho (2002) mentioned as a potential pathogenesis the increased number of adherent bacteria (i.e., Clostridium and E. coli) in the epithelial layers of the gut mucosa. This close proximity of bacteria to the digestive mucosa was thought to be at the basis of the immune system attacking the gut lining and the cycles of inflammation. As explained in Footnote 5, a *dysbiosis* in the gut microbiota could trigger an immune reaction and subsequently an illness. Furthermore, some bacterial imbalance were detected in the mucosal layers of newly diagnosed children with CD but not in their faecal samples, suggesting the gut mucosal layer was the origin starting point (Carding et al., 2015). Nevertheless, the findings were still inconsistent and no one bacteria have been detected as the sole culprit of IBD, nor has it been established if the dysbiosis was a result or a cause of IBD onset.

1.8.3 Psychosomatic origins

Gerson (2002) elaborated on the psychoanalytical perspective on IBD saying that “individuals with characterological difficulty in expressing rage, when threatened by separation from an important object, implode the rage inward and thereby inflame and damage their intestinal lining” (p. 381). Gerson acknowledged that psychoanalytical aetiology tended to draw linear causal effect between affect and behaviour, which has seldom been systematically established. Nevertheless, despite the lack of evidence, there seemed to be a belief in the medical field that there is such a thing as a “typical IBD personality” (Doughty, 1994, p.25). Among the personality traits that were commonly reported to influence the course of IBD were neuroticism,

introversion, perfectionism, and alexithymia (Kurina, Goldacre, Yeates, & Gill, 2001; Robertson, Ray, Diamond, & Edwards, 1989; Sajadinejad, Asgari, Molavi, Kalantari, & Adibi, 2012). Murray (1984) and later Gerson (2002), recognised and underscored the problematic that personality or characteristic traits could arise prior, during, or as a result of, the illness with no clear directionality established to this day.

1.8.4 Dietary origins

The Epidemiology Group of the Research Committee of IBD in Japan investigated— amongst other things – the link between the consumption of westernised foods such as margarine, bread, butter, cheese, meats, ham, and sausages and IBD (Kurata, 1994). The sample, recruited from 20 different hospitals sites, consisted of 101 UC patients and 143 controls who suffered from a chronic illness other than UC (diabetes, liver, respiratory and other diseases). Consumption of westernised foods was significantly associated with increased risk of developing UC, and eating vegetables and fruit seemed to be a protective factor but was not significantly associated with a reduced risk of developing UC. Amongst all the food items investigated, margarine seemed to be the only one significantly linked to a higher risk of developing UC. Kurata (1994) also collected childhood medical history such as occurrence of measles, appendectomy, bronchial asthma, and feeding method (breast- or bottle feeding) and found no significant relation between any of these factors and the development of UC in the Japanese sample.

In their review of environmental factors affecting Japanese individuals, Asakura, Suzuki, Kitahora, and Morizane (2008) found that individuals consuming meat and confectionary/sugars were at higher odds for having either CD or UC. Individuals consuming fish/shellfish and fats/oils also commonly reported having CD; UC on the other hand, was more common in those individuals eating fast foods. Soft drinks were not significantly linked to the increase in IBD incidence.

1.8.5 Immune response and genetic factors

IBD related genes have been implicated in the pathology of the disease (Fiocchi, 2015). Fiocchi (2015) traced back initial findings of a genetic component to Kirsner and Spencer's (1963) observation of IBD familial aggregation. Since then, 50 years elapsed until Jostins et al. (2012) identified, in their meta-analysis of over 75,000 cases and controls, a total of 163 loci susceptible to be implicated with UC and CD occurrence. Around 60% of these loci were implicated in the development of both UC and/or CD. The rest could be strictly linked to either UC or CD onset. According to Fiocchi (2015), having the risk alleles for IBD did increase the probability of developing the illness, but only accounted for 25% of IBD cases. Thus, a genetic-environment interaction could be at play to explain the remaining variance of IBD cases. . However, the identification of alleles implicated in the onset of IBD raises the question of the role of genetic testing in detecting who is at risk of developing IBD. According to Cummings and Rubin (2006), the most researched allele is NOD2/CARD15 as a third of CD patients carry

a variant of this allele compared to less than 10-15% of the population. Cummings and Rubin (2006) emphasized that genetic testing will play a role in informing future parents about the risk of their child developing IBD. Nevertheless, to this day, genetic testing does not guarantee diagnostic confirmation of UC and CD, nor can it predict the individual risk of having IBD when one or both parents have IBD.

Even though all the listed theories have shed some light on the understanding of IBD, and pushed forward the advances in medication therapy in the hope of finding a cure, the precise aetiology of IBD remains elusive and all the suggested theories may be refuted as medical advances progress (Korzenik, 2005). That said, the retained theory today is that IBD is manifested by a deficient immune system, particularly (CD4⁺) T-cells, caused by an interaction of alteration in the gut mucosa, environmental changes as well as genetic influences (Fiocchi, 2015).

1.9 Available Treatments

To this day, no cure has been found for IBD. Classifying a patient under a specific category and grasping the aetiology are crucial to determine treatment, prognosis, and the potential need for surgical intervention (Guindi & Riddell, 2004). Doctors, however, will typically prescribe as a first line of treatment drugs - also known as induction therapy - to attain remission (CCFA, 2012; CCUK, 2014). If remission is attained then maintenance drugs are prescribed to ensure IBD is kept at bay. Where drug therapies prove ineffective at controlling symptoms, surgery may be required. I enumerate in the following paragraphs the three main lines of treatments currently available for both UC and CD, notably induction therapies, surgical interventions, and alternative therapies; and when relevant their mode of administration and efficacy.

1.9.1 Induction therapies

Drug therapy, also referred to as induction therapy, for IBD can be administered in several forms: orally through tablets or granules, topically via the rectum using ointments, enemas (liquid or foam) and/or suppositories, or intravenously using needle-injections (CCFA, 2012). The administration of the drug will depend on the area targeted and the time required to release the active ingredients (CCUK, 2014). For immediate and generalised effect intravenous injections are used, and for more localised and punctual effect suppositories or ointments are used. Drugs can usually be classified into one of three broad categories: (1) Anti-inflammatories (Immunosuppressants, Corticosteroids, Aminosalicylates (5-ASAs) and Anti-TNF Biologics); (2) Antibiotics; and (3) Symptomatics. Each of these categories will be detailed below with their respective subcomponents:

1.9.1.1 Anti-inflammatory drugs

This drug category comprises four other classes of drugs. First, there are *Immunosuppressants*, also referred to as Immunomodulators, which reduce or modulate the immune response that can be overly stimulated in IBD (CCFA, 2012). Second, there are *Corticosteroids*, or simply *Steroids*, which act to reduce in a fast and effective way the inflammation and to block the immune system from over-reacting. They take their name from their close chemical similarity to cortisol, which is a stress hormone released by the body. IBD patients typically notice improvements within days of starting steroids, however, due to the toxic effect of prolonged therapy, patients cannot remain indefinitely on them and need to be weaned off gradually (CCFA, 2012). The third class is *Aminosalicylates (5-ASAs)*, commonly prescribed for UC patients, which can help reduce the immune response allowing the digestive tract to heal. Depending on type of 5-ASAs, these drugs can act either on the entire digestive tract or help dissolve the inflammation and heal specific areas of the ileum or colon (CCFA, 2012). Lastly, the fourth class is called *Anti-TNFs (Tumor Necrosis Factor-alpha)*, or *Biologics*, which target for the most part a naturally-produced protein in the body called Tumor Necrosis Factor-alpha (Probert, 2016). The protein is involved in the regulation of immune cells. These anti-TNFs reduce the impact of the protein which can be overly secreted in IBD. They were initially used in severe or advanced cases of UC and CD that have not responded to other induction therapies. However, nowadays, biologics are sometimes prescribed earlier in the treatment of IBD to avoid the progression and complications of the illness (Probert, 2016).

1.9.1.2 Antibiotics

As the name implies, this class of medication fights microbial or bacterial infections and is more commonly prescribed to individuals suffering from Crohn's Disease (CCUK, 2014).

1.9.1.3 Symptomatic drugs

The components of these drugs vary, but they all maintain a similar purpose which is to reduce the by-product symptoms of inflammations such as pain, diarrhoea, and constipation (CCUK, 2014). Under this category one can find laxatives, antispasmodics, analgesics, and antidiarrheal pills. They are often purchased over the counter and do not require a prescription.

1.9.1.4 Step-up, top-down, or combination therapy

The commonly used approach of administering drugs dosage upon need is referred to as the *step-up approach* and is supported by the National Institute of Care Excellence (NICE) guidelines⁸. Hence, consultants typically prescribe conventional drugs (such as immunosuppressant and corticosteroids) and then anti-TNFs in instances of non-responsiveness

⁸ NICE is a national (England-only) health authority providing guidelines to care treatment to maximize homogeneity and uniformity in NHS quality services (2016).

(Probert, 2016). However, Probert argued that the guidelines are outdated and for some patients, who clearly showed poor prognosis and lack of receptivity to standard treatments, these guidelines would be detrimental. Probert predicted that the NICE guidelines will soon incorporate a *top-down approach* in order to change the course of the disease as more evidence and research is showing the benefit of such an approach. A *top-down approach* would entail starting with anti-TNFs or ‘heavy’ drugs and slowly weaning off the patients from the anti-TNFs to a more standard medications. It is important to ensure that treatments are tailored to the individual’s needs and that they factor in the severity, location, and spread of the illness. Accumulating data from endoscopic, serologic, microbial, and genetic parameters allow physicians to better predict the course of the illness and inform the patients of the timing of treatment, best course of action, as well as necessary withdrawal time (Raine, 2016).

To reduce the chance of developing antibodies to the anti-TNFs, physicians have used a combination of immunosuppressive drugs and Anti-TNFs (Parkes, 2016). Two studies, the Sonic study in CD and UC-Success study, have shown the efficacy and advocated the use of a combination approach conveying no additional risks to patients (Lees, 2016). However, Parkes (2016) insisted that the use of such combinations seem to place the patient at greater risk to catch random infections and increased chance to develop cancer (i.e., skin cancer or lymphoma) . Kennedy responded by recommending consideration of the timing to withdraw patients from the outset, to mitigate susceptibility to develop serious complications (Kennedy, 2016).

1.9.2 Surgical interventions

Surgical intervention used to treat IBD have progressed a long way since the days when prefrontal lobotomies were performed on UC patients (Korzenik, 2005). Initially lobotomies were performed on individuals who had failed to remit through medical or psychiatric treatments. Levy, Wilkins, Herrmann, Lisle, and Rix (1956) provided five case studies of UC patients who have been described as having some of the following characteristics: hostility towards their mothers or partners, periods of depression and suicide attempts, obsessive-compulsive behaviours and chronic anxiety, as well as frequent stools passing (8 to 25 times a day). The psychiatric symptoms and stool frequency seemed to have diminished postoperative interventions in three cases, however the last two individuals died postoperatively due to an intestinal stricture and septicaemia. This surgical procedure is no longer in use.

Nowadays, one of these five surgeries is commonly performed: (a) *Colectomy* with an external pouch, it involves the excision of the large intestine and rectum creating an opening called a *stoma* from the ileum to eliminate the waste (CCFA, 2016); (b) *Restorative Proctocolectomy*, or *Ileoanal-Pouch Anal Anastomosis* (IPAA) also involves the excision of the colon and rectum but a pouch or sac is formed internally near the rectum using the ileum so that patients can pass stools through the anus (CCFA, 2016); (c) *Resection*, as the name implies it involves cutting out unhealthy or necrotic parts of the intestine and joining the outer ends

together (CCFA, 2016); (d) *Strictureplasty*, sometimes parts of the bowel become narrow due to inflammation and need surgery to widen the walls and allow nutrients to flow through the gut (CCFA, 2016); and (e) *Removal of abscesses or fistulas*, some *abscess* (mass filled with pus) or *fistula* (abnormal tract formation) can require surgical excision or sealing through sutures (CCFA, 2016).

Consultants and IBD Nurses are faced with the difficulty of choosing which course of action will achieve remission and relief as fast and as effectively as possible, but also as long as possible. To help healthcare professionals in their tasks, Lamb (2016) suggested using the Crohn's Disease Activity Index (Best, Bechtel, Singleton, & Kern, 1976) to assess the severity of the illness. The CDAI is a tool that quantifies patients' reports of IBD symptoms along eight clinical and laboratory variables (pain, stool passing and shape, subjective wellbeing, weight, red blood cells count, and use of (anti-) laxatives). Lamb however stressed that patients' reports of symptoms as well as phenotypical markers of the disease (passing stools several times a day or bloody diarrhoea) are not sufficient indications of inflammation and progression of the disease. Inflammation and scar tissues could occur without any apparent outcome to patients. Lamb (2016) hence added to use CDAI and test for endoscopic and serological markers to determine the best course of action.

1.9.3 Alternative therapies

Langmead et al. (2006) reported that the absence of a cure and uncertain aetiology pushed individuals (and healers) to look for alternative therapies to the mainstream induction and surgical treatments such as complementary alternative medicine (CAM). The word 'alternative' refers to those therapies used instead of conventional methods of healing and the word 'complimentary' refers to concomitant use of those non-recognised treatments along with other standardised methods of care (NCCIH, 2015). The National Care Centre for Complementary and Integrative Health (NCCIH) opted to use the term *Integrative Medicine* to refer to the concomitant use of complimentary and conventional therapies. In the following paragraph, I address the relevant alternative treatments to IBD: faecal transplantation, diet regulation, and psychotherapies as well as CAM.

1.9.3.1 Faecal microbiota transplantation

Faecal Microbiota Transplantation⁹ is a technique involving the insertion of faeces from a healthy donor (usually a first degree relative) into the gut of the ill patient to populate his or her digestive flora with a healthy balance of bacteria (CCFA, 2016). Initially FMT was used by Eiseman on individuals infected with a bacterium called "Clostridium Difficile" (Eiseman,

⁹ Also known as: Faecal bacteriotherapy (FB), "human probiotic infusion", "stool transplant", "faecal transfer", or "faecal microbiota transplantation" (FMT).

Silen, Bascom, & Kauvar, 1958). However, interest grew into microbiome-based therapies for IBD (Kahn, Gorawara-Bhat, & Rubin, 2012). A comprehensive systematic research and meta-analysis of 18 studies (8 Case studies, 9 Cohort studies, 1 RCT¹⁰) indicated that FMT was well tolerated by patients and a relatively safe procedure (Colman & Rubin, 2014). Complications tended to arise from the method of administration, such as irritation due to colonoscopy tube-insertion, and not because of FMT itself. Clinical remission was higher for individuals with CD versus those with UC (66% vs. 22%) and studies focussing on younger patients (7 to 20 years) tended to report higher clinical remission rates (64.1%) compared to older individuals. In total out of 119 patients, included from the 18 studies, 54 achieved clinical remission (45%). The authors concluded that FMT was still in its infancy and more research was needed, notably on number of administrations necessary to reach remission, applicability to various severity levels, location and spread of IBD, and recruitment of larger samples of individuals to determine its ‘true’ efficacy.

Looking at patients’ perspective on FMT, Kahn et al. (2012) interviewed (in six focus groups) 15 adults with UC and 7 parents of children with UC about their views on FMT compared to other therapies as well as their willingness towards adopting such treatment. Most participants elaborated on the “yuck factor” that would easily be overcome by the benefits of the treatment. They also expressed concerns and reservation about sharing the use of such treatment with some of their friends, families, and (for the parents) even discussing the details of the treatment with their affected child. FMT was seen as a safe and “natural” treatment comparable to probiotics (live bacteria and yeasts found in food supplements). FMT’s mechanism was thought to replace the “bad bacteria” with “good bacteria”. A great deal of attention was given to the donor selection, length of treatment, and delivery method (enemas and colonoscopy insertion were preferred over nasogastric tube injection). Many subjects believed that FMT would be beneficial and wished it was made available to them. Nevertheless, their choice of starting the treatment would still be greatly influenced by their consultant’s recommendation.

1.9.3.2 Diet regulation

Diet has been recognised as part of the environmental factors influencing IBD (Korzenik, 2005). However, that is not to say nutrients or diet is at the root of IBD, but rather that diet is one of the ingredients in the complex chain of interacting factors leading to the onset of IBD.

Some diets have been reported anecdotally, and through research, to be useful in inducing remission of IBD, particularly in children (Kahn et al., 2012). Individuals across countries and cultures – USA, China and India – self-reported having changed their diet within one year of receiving a diagnosis of IBD (Al Kazzi et al., 2016). A change in diet was more often detected amongst American patients with Crohn’s Disease compared to their Chinese and Indian counterparts. The change of diet was also more commonly self-prescribed rather than

¹⁰ RCT: Randomised Control Trial.

medically prescribed across the three countries. A change in diet was not significantly different amongst individuals affected with UC across countries; however, there was an increase in the number of individuals who changed their diet. The two notable nutrients that were significantly altered were milk and alcohol consumption. In the US, CD patients significantly reduced the consumption of milk and alcohol whereas their Chinese counterparts significantly increased their consumption of these same elements. A change in nutrition seemed to be intuitively appealing to individuals receiving a diagnosis of IBD; however, individuals who self-prescribed a new diet or were medically prescribed a diet did not have significantly fewer surgeries than those who did not change their nutrition.

Diets based on the exclusion of certain foods such as the *Exclusive Enteral Nutrition* (EEN), *Specific Carbohydrate Diet* (SCD) and the *Crohn's Disease Exclusion Diet* (CDED) have received some attention and proven to induce remission; however they lack tailored individualisation (Lee & Suskind, 2016). Exclusion diets typically involve a period of one to two months of exclusive elemental and polymeric liquids (Kansal, Wagner, Kirkwood, & Catto-Smith, 2013). An elemental liquid is made of protein broken down into its specific amino acids, whereas a polymeric liquid contains the whole protein chain. Although the efficacy of exclusion or partly exclusive diets was shown, the exact mechanism by which these diets work is yet to be determined.

In a randomised control trial, IgG4 indicators were used to guide the inclusion and exclusion of dietary elements to reduce CD activity (Gunasekeera, Mendall, Chan, & Kumar, 2016). IgG4 is a class of antibodies that circulates in the blood and helps regulate the presence of antigens in the body. IgG4 is secreted in response to chronic reactions to antigens and thus excluding foods that produce high IgG4 reactivity could lead to remission. Seventy-six patients with validated CD were randomly and double-blindly assigned to either a diet excluding four food types high in IgG4 concentration (such as beef, pork, egg, and milk; this was referred to as the 'true diet', N=37) or a diet excluding four food types with low IgG4 titres (notably rice, chicken, tomato, and potato; referred to as the 'sham diet', N=39). The authors hypothesised that individuals in the true diet would reach remission more often than the ones in the sham diet. The results confirmed the hypothesis, and individuals eating beef, pork, eggs, and milk showed fewer improvement on their symptoms on the Crohn's Disease Activity Index (CDAI)¹¹ than individuals who had excluded those four elements. Dietary changes and regulation by exclusion of IgG4 reactive food showed promising clinical applicability through patient report, but more research is needed to verify changes at the mucosal and serological level.

1.9.3.3 Psychological therapy

It was found that stress exacerbates symptoms of IBD (Goodhand, Wahed, & Rampton, 2009), and McCombie, Mulder, and Geary (2013) mentioned that stress-management and

11 An indicator of CD severity, as explained in 1.9.2 Surgical interventions.

psychotherapy counselling were promising tools to reduce IBD patients' distress. However, psychotherapy has yet to be recognised as an effective treatment for IBD (McCombie et al., 2013; Timmer et al., 2011).

McCombie et al. (2013) conducted a systematic review to determine whether psychological interventions had an effect on IBD. They included 18 studies and a total sample size of 924 IBD participants. Results indicated limited to mixed results on the effectiveness of therapeutic interventions to reduce anxiety and depression, as well as to improve quality of life. Among the therapies used in the various articles were: Cognitive Behavioural Therapy (CBT), Psychodynamic Therapy, Solution Focused Therapy, and Problem Solving Therapy. Some modest but encouraging results indicated that therapy might benefit medication adherence and symptoms reduction, however the authors recommend targeting patients who might be more receptive to psychotherapy by using screening tools such as the Assessment of the Demand for Additional Psychological Treatment (ADAPT) (Miehsler et al., 2004).

Similar results were shown by Timmer et al. (2011) and Kennedy et al. (2003) where psychotherapy interventions did not seem to benefit quality of life measures, but patients did self-report improvements in their symptoms and fewer hospital visits. Adding to these findings, Gracie et al. (2017) conducted a systematic review and meta-analysis of 12 contemporary RCTs studies on the effectiveness of psychological therapies vs control therapy and found that amongst hypnotherapy, relaxation techniques, and psychodynamic therapies, CBT significantly improved the quality of life of patients in the short-term but not on follow-up. Although CBT was shown to be significant in improving the quality of life of IBD patients it did not alter their depression or anxiety scores nor did it alter their perceived stress scores or reduce clinical activity of the disease.

In a pilot RCT study Mindfulness Based Cognitive Therapy (MBCT) was found to decrease anxiety and depression symptoms amongst IBD patients (Schoultz, Atherton, & Watson, 2015). The intervention group had 16 hours of MBCT over eight weeks and the control group received a leaflet on wellbeing with IBD. Improvements were noted in depression and anxiety scores in the control intervention vs the control group. In a parallel and nested study to the RCT, Schoultz, Macaden, and Hubbard (2016) held two focus groups to identify the views of those participants who attended the MBCT therapy sessions. Among the benefits stated were the therapeutic and healing aspect of MBCT and its educational and informative aspect. In terms of barriers, participants named traveling to and from the session as well as fixed timing of the session as a barrier to attendance and participation. Furthermore, Terry (2016) commented on the usefulness of MBCT tools at the yearly IBD Summit in Birmingham and the need to develop self-administered management tools in the future to promote patient-led practices. Psychotherapy has the potential benefit to induce psychological relief to patients, and could be a cost-effective tool to reduce financial burden on hospitals and healthcare services (Richardson et

al., 2006) if one could target which type of therapy is most effective for this specific illness and for individual patients (Timmer et al., 2011).

1.9.3.4 Complementary and alternative medicine

Complementary and Alternative Medicine (CAM) represents any group of medical and health practices and/or products outside conventional or Western standardised medical care (CCFA, 2012; NCCIH, 2015). CAM can belong to any of the following categories: (1) *Mind-body interventions*, such as meditation and hypnotherapy; (2) *Manipulative and body-based therapies*, such as reflexology and chiropractic medicine; (3) *Energy medicine*, such as Reiki and Electromagnetically field; (4) *Biological medicine*, such as herbalism and dietary supplements; or (5) *Others* based on holistic systems such as Homeopathy, Naturopathy, or Traditional Chinese medicine (including Acupuncture)¹².

The premise for (1) the *mind-body intervention* is that altering the mind state will have a ripple effect on the body's health. As for (2) the *manipulative body and mind therapy*, the premise is that through movements and changes in the body and mind one can bring about remission and healing. Closely related is (3) the *energy medicine* that holds as a premise that any ailment is a result of disruption of the energy flow with one's body and mind. Lastly, (4) *biological medicine* will use natural elements such as foods, and non-comestible components to achieve healing.

Langmead and Rampton's (2006) review of CAM usage and users placed herbal remedies as the most commonly used CAM and individuals with IBD amongst the most common users of CAM treatments, with as much as half of IBD patients trying CAM at one point in their life. Practitioners, can no longer ignore the potential dangers of interactions of CAM with standard care and conventional therapies. Langmead and Rampton (2006) reported that, although some research did support CAM's benefits in IBD, they were seldom available in English, methods lacked standardisation of protocol, and funding was scarce to determine ultimate efficacy of such treatments.

Scott, Verhoef, and Hilsden (2003) found that patients with IBD often use more than one complementary method to treat their IBD. They interviewed 14 patients (9 women) on their reasons for choosing CAM. The patients mentioned the uniqueness of their personal context for resorting to CAM, the particular impact of their symptoms and perceived benefit of using CAM. Those individuals who suffered most from IBD symptoms were more likely to try out several forms of complementary therapies; particularly when IBD came in the way of their role as parents or their work. Also, all 14 participants believed that complementary medicine treatments were safer than corticosteroids, hence a desire to avoid surgery or to constantly medicate was a

¹² The first four CAM treatments mentioned are discussed as they can be summarised by their premises, underlying philosophy and current reviews; however, the fifth category is heterogeneous and is left out as it stands outside the point of this chapter.

reason for using CAM. Some said that taking CAM was like assuming responsibility and taking action to manage their lifestyle as part of actively dealing with IBD, particularly when conventional therapy failed. Lastly, participants felt supported in their usage from their social network and discussing CAM methods with them was useful; however, some participants were worried about mentioning it to their doctors for fear of being dissuaded.

Hypnosis and hypnotherapy benefits have been reported in the literature however, no consistent randomised controlled trial has been performed solely on IBD patients; reviews and research tended to lump findings of hypnotherapy on IBD patients and other gut disorders such as IBS or Functional Gastrointestinal Disorders (FGIDs) (Szigethy, 2015). Szigethy (2015) also pointed out that most studies focused on gut-guided hypnotherapy (FGH) developed by Whorwell, Prior, and Faragher (1984). Nevertheless, the review drew conclusions that hypnotherapy might impact some inflammation markers in IBD patients and could be the result of brain-mediated activity that activated a naturally anti-inflammatory system in the body called *vagal parasympathetic system*. The author insisted on the importance of using hypnotherapy as part of an integrative holistic care of IBD patients, thus in conjunction with conventional medical treatment.

1.10 Summary

IBD is a cluster of two main inflammation diseases called Ulcerative Colitis and Crohn's Disease. The prevalence of IBD has increased in the Western and non-Western parts of the world. In the UK, IBD occurs in 1 in every 250 individuals with women more commonly affected than men. The common age of onset is within the childbearing years thus affecting individuals' most productive and reproductive years.

Several risk factors and protective factors have been linked to the exacerbation and attenuation of IBD; however, the exact mechanism through which these factors come to play remains unknown. Similarly, several theories have been reported to explain the aetiology of IBD with no clear and definite answer to this day. The most widely accepted theory is that IBD is a result of genetic predisposition, and environmental factors affecting the gut mucosa leading to an overactive immune reaction. No causality or directionality of these influences have been established. Thus, it is of no surprise that the number of available medical treatments and screening tools have flourished in the last few decades, with IBD patients being one of the highest consumers of non-conventional medicinal therapies. Unfortunately, despite the multitude of surgeries, drugs, and diets proposed, no cure has been found to date.

In sum, Chapter 1 focussed predominantly on the medical aspect of IBD and Chapter 2 will introduce an overview on individuals' experiences with IBD in everyday life.

Chapter 2

Inflammatory Bowel Disease: Individuals' Perspective

The aim of the chapter, which will be considered in two parts, is to explore the impact of IBD on individuals' lifestyle changes as well as IBD's role on family planning and the transition to motherhood. Part I starts by looking at the psychological and social impact of IBD, notably on individuals' quality of life, body image, and stigmatisation, as well as dietary, knowledge availability, and social needs. Part I follows by detailing the treatment impact of having a temporary or permanent external pouch. In Part II, Family Planning and Motherhood, the chapter tackles the joint experience of motherhood with IBD, mainly looking at mothers' expectations, burdens, birth trends, fertility and pregnancy complications, as well as voluntary childlessness.

2.1 Part I: Lifestyle Changes with IBD

Devlen et al. (2014) looked at IBD's impact on individuals' lifestyle and found the illness to affect the psychological, social and treatment level. Devlen et al. (2014) drew their conclusion, from an extensive search of the literature for qualitative articles, looking at reported outcomes of patients with IBD. From the 454 abstracts found, they selected only 21 full-text qualitative articles looking at the impact of IBD to form their findings. In light of their results, I decided to partition the section 'Lifestyle Changes with IBD' using the three levels reported in their review (psychological, social and treatment) as subheadings to cover as much as possible the topic at hand. I also tried whenever feasible to discuss findings from other qualitative studies to provide a rich insight into the currently available literature. Devlen et al.'s (2014) findings only served as a template to ensure the most relevant topics of lifestyle changes were addressed. This is in no way to say that the chapter is all-inclusive on the subject. Furthermore, I tried to section the chapter by topic, but seldom did one study address a unique set of themes (or variables). Hence, some cross-overs are to be expected, for example, the topics addressed in the Psychological and Social Impact section would also sometimes be discussed in the Treatment Impact section, and vice-versa.

2.1.1 Psychological and social impact

2.1.1.1 Quality of life

Pihl-Lesnovska, Hjortswang, Ek, and Frisman (2010) looked at how individuals with CD made sense of their quality of life using grounded theory (symbolic interactionism). Eleven individuals with an established diagnosis of CD were selected from an outpatient clinic in

Sweden (6 males, 7 females, aged 29 to 83 years old). They had lived on average 11.4 years with IBD. One core category named *limitations* emerged from the data with 5 categories relating to it (*self-image, confirmatory relations, powerlessness, attitude toward life* and *sense of wellbeing*). The meaning of quality of life for participants seemed to evolve around managing and coping with IBD, within the restrictions and limitations imposed by the illness. *Self-image* was limited by IBD, which restricted their desire to be intimate. Participants also hid their weight loss with baggy clothing. They often felt useless when experiencing symptoms of IBD. There was a need for *confirmatory relations* noticeable as participants experienced unconditional love from their family, friends, colleagues, or sometimes pets. Unfortunately, the *sense of wellbeing* brought upon the support of others was spoiled by the informants' feelings of being a burden and dependent on others. *Powerlessness* emerged from the lack of control over the illness's trajectory or ability to bring about remission despite treatments. Some informants expressed fear of death and fear of passing on the disease to their next of kin. Those who had a positive *attitude toward life* reported feeling less powerless. A positive attitude meant to trust that events could be managed, and to have faith that by engaging in various activities and accepting the illness one can cope with it. Lastly, the *sense of wellbeing* was greatly influenced by their ability to socialise, for example by having a meal with others. Achieving some control over the illness through diet and being able to relax was conducive to a better quality of life. The findings emphasised the importance of individuals' sense of wellbeing with parameters that go beyond the bodily functions and disease activity. These parameters form a good basis for a holistic view and healing approach to IBD.

Sammut, Scerri, and Xuereb (2015) looked at the subjective experience of 10 adults with UC (6 men and 4 women, all married, with a mean age of 45.3 years). The authors attempted to rectify a gap in the literature by capturing the needs and concerns that are unique to UC. The interviews were analysed through Interpretative Phenomenological Analysis (IPA). The authors report three themes labelled *living with physical discomfort, emotional turmoil*, and *social interactions*. Among the physical discomforts patients mentioned include enduring tremendous pain, necessitating hospitalisation, and being bound to look for a toilet at all times. As for the *emotional turmoil*, both altered body image, due to steroids (i.e., weight gain) and feeling embarrassed, due to incontinences, were notable. However, participants also mentioned dismissal of medical staff, self-blame and guilt for having UC, fear of cancer, and fear of not having children as other sources of turmoil. As for *social interactions*, having UC led to social restriction from holidays, isolation and impact on sexual intimacy. Sammut et al. (2015) concluded that there is a pressing need to raise awareness about the causes and symptoms of UC within the population, as well as a need to improve patient-doctor relationships and communication.

Purc-Stephenson, Bowlby, and Qaqish (2015) looked at the *change* in quality of life of 378 individuals diagnosed with IBD (251 CD, 127 UC) via an online survey. The sample

comprised 312 women, the average age was 31 years old ($SD = 9.9$) and were for the most part Caucasian, from Canada or the USA. The participants were mainly in full-time work, married, and had at least a college or higher degree. The authors used thematic analysis (TA) to look at the *positives* and *negatives* of IBD on participants' lives. Most commonly the sample endorsed positive changes with regards to their interpersonal relations. They mentioned forming stronger bonds and sifting through friendships that stood the test of the illness. Positives also included seeking information and reaching out to others with IBD, as well as personal growth, valuing life, discovering new life paths, and spiritual growth. Participants described developing empathy, strength, and resiliencies, in the face of the illness, as a positive outcome. As for the *negatives*, the most commonly reported was freedom restrictions, particularly the inability to enjoy or perform the things they did prior to the diagnosis (e.g., food types, sexual activities, and leisure activities). Participants also mentioned being plagued by the fear of passing IBD to their children which impacted their family planning. Other negatives included being more reclusive and insular as a result of IBD as well as a loss of sense of self due to the extensive and invasive surgical treatments. The authors concluded that participants integrated both positives and negatives, as part of their self-views, enabling them to better cope with the illness and its cyclical recurrences.

It is worth mentioning that both Purc-Stephenson et al. (2015) and Sammut et al. (2015) pointed to social restrictions and isolation as well as impact on family planning as detrimental consequences to IBD. However, Purc-Stephenson et al. (2015) also underlined positive aspects to living with a chronic illness but Sammut et al. (2015) did not. A possible speculation for this difference, could be that the main research question of the former study sought to elicit the positives, whereas the latter study focused instead on the needs and challenges of the informants. Unfortunately, Sammut et al. (2015) did not clearly state their research question in their article, which leaves no clear answer as to why there were no stated positive outcomes, if any, for living with IBD.

Hall, Rubin, Dougall, Hungin, and Neely (2005) looked at people with IBD in the community who self-reported having a low quality of life. A questionnaire was sent to 283 individuals with IBD and those with the lowest scores were invited to take part in the study. A total of 31 interviews were conducted (12 men, 19 women, 14 had CD and 17 UC, adults, ages unspecified). The interviews varied between one-to-one and focus groups. The authors used grounded theory to analyse the results and conveyed their theoretical framework developed from one of the core categories: *health related normality*. The framework explored three inherent categories to *health related normality*, it looked at how individuals with IBD elaborated on their *continued reassessment of normality*, their *fight to maintain normality*, as well as *maintaining appearance of normality*. First, Individuals often compared themselves to previous states of health prior to IBD or even to states of intense flares to assess their health. Interestingly they did not rate themselves as doing poorly although they were selected for their

lowest scores on a health-related quality of life questionnaire. The down comparison to individuals with more severe IBD allowed them to have a positive view of their situation. Hall et al. (2005) mentioned the possibility of a *response shift* where standards of health and criteria change over time (becoming less stringent), which allowed maintenance of a positive sense of health and self. Another explanation given was that the state of health and normality was closely linked to self-definition and, by preserving their impression on their health; participants were preserving their sense of identity.

Second, the *fight to maintain normality* was achieved through various psychological, behavioural, social, and biomedical (i.e., medications) means (Hall et al., 2005). Participants varied in their journey and amongst themselves on how they adapted and accepted their illness as well as in their will and determination to gain control over it. The two main “weapons” mentioned to fight IBD were diet and medication, however, they preferred to self-manage their medication intake using their consultant only for guidance. According to the authors, restoring control was pivotal in coming to terms with the unpredictability of IBD and at the essence of the fight for normality.

Third, *maintaining appearance of normality* and avoiding the stigma of being labelled as sick, pushed some to fake a smile and contain sharing their pain to appear “normal”. During the focus groups, they felt comfortable to disclose sensitive issues such as intimacy, body image, and the use of marijuana to relieve pain in front of others sharing a similar illness. These topics were not spontaneously brought up in one-to-one interviews. Hall et al., interpreted these findings as the importance of context and ease to disclose to others who share the illness compared to a researcher who could be considered an outsider to their experiences. The authors also raised the possibility that self-help groups might share some of the added benefits perceived in the focus groups.

Furthermore, similarly to Purc-Stephenson et al. (2015) and Sammut et al. (2015), Hall et al. (2005) also found that IBD prevented individuals from fulfilling caring roles within their family, meeting job expectations and attending social events. The symptoms of the illness imposed a constant assessment of bathroom availability and adjustment of outings according to bowel movements. Individuals expressed the wish to be normal and able to do whatever they fancied without the burden of planning and compromising.

As demonstrated by the three mentioned studies, there are various aspects to the quality of life of individuals with IBD. One can note the positives and negatives of living with a chronic illness, or investigate the health beliefs at the source of a low quality of life, or even breakdown the experience in terms of biopsychosocial impact. These different ways or themes are part of the richness of qualitative data and give a new angle and perspective with every study enriching further the understanding of how IBD impacts people’s lives.

2.1.1.2 Stigmatisation and concealment

The UK Government defines disability as a condition that hinders substantially, and for a prolonged period of time the emotions, intellect, mind-set, senses, development, and/or behaviours of an individual (Gov.UK, 2015). IBD is disability that is both chronic due to its cycles of flares and invisible due to the localisation of the inflammation to internal organs (mainly the bowels). Nicole Defenbaugh (2013) provided an essay on *revealing and concealing ill identity* as illustrated with the following quote indicative of the hidden factors of her illness¹:

At the event I will be recognised and “honored” for my achievements – who knew you could win an award for being sick! I slip into my pale-blue t-shirt and prepare to step out of the water closet. As I look in the mirror I reflect on the simultaneous feelings of fear and freedom from wearing a t-shirt displaying my hidden ill identity [...] In this shirt I am a visibly ill person, at least for one day (Defenbaugh, 2013, p. 159).

Through a personal narrative, Defenbaugh (Defenbaugh, 2013) showed the reader the cathartic effects of revealing one's ill identity to loved ones or others sharing the same fate. She recalled telling others, at times, bluntly “I have an autoimmune disease” and at others less so; It took her over a year to reveal having IBD to her partner out of fear he would walk away. She used inopportune timing whilst watching a movie, where the protagonist had a chronic illness, as a pretence to indirectly tackle the subject. Through her biographical account, she increased the general understanding of the hidden and chronic aspect of IBD, particularly through the vivid description of the *water closet* or bathroom. The water closet served as a metaphor binding individuals to concealment. A place of comfort and shelter from the eyes and ears of others (IBD can cause severe flatulence and explosive diarrhoea) as well as a place of war, where her body battled itself unleashing a cascade of pain and fluids. She washed it all away in the water closet, applied her make-up and was ready to face the world again. IBD was invisible once more. Her ritual of cleansing and hiding away from others was one of the many ways she felt stigmatised and forced to shy away from the eyes of others.

Moreover, Frohlich (2014) looked at a sample of 14 individuals with IBD (7 UC, 7 CD, 7 women), and noted that stigmatisation² could occur along several areas of a person's life, including in a medical setting where one would assume tolerance and professional mannerism on behalf of the staff. Participants reported feeling perceived as different through the eyes of others but also inflicted a self-stigmatisation where they pushed loved ones away and kept them in the dark out of fear of their reaction. The authors related some unfortunate incidents where two participants had to drop their semesters at university, and one got laid off work due to their repetitive sick leave. One woman was also reprimanded for being “overly dramatic” and told to

1 Defenbaugh won a national contest for producing a video on living with IBD. She described attending the award ceremony in the excerpt.

2 Stigmatisation as defined Goffman (1963) occurs when a person is (perceived as) devalued and rejected due to a certain attribute by his or her society.

“buck up and get on with life” (Frohlich, 2014, p. 133). However, in most cases when participants revealed IBD the support outweighed the stigmatisation both at work or school.

2.1.1.3 Body image

Body image (BI) is defined as a person’s perception of their physical representation and sexual attractiveness established by personal observation and reactions from the environment (NEDC, 2015). Muller, Prosser, Bampton, Mountifield, and Andrews (2010) looked at the impact of IBD on body image (BI) in an Australian sample of 217 individuals (aged 18 to 50 years old, 143 women). Around 67% of the respondents declared having dissatisfaction with their body image, more prominently amongst women and those respondents who had surgery. Male participants did not reveal the same difference with regards to surgery and no differences were found in body image dissatisfaction between UC and CD groups.

Another study by McDermott et al. (2015) also investigated BI dissatisfaction in relation to IBD disease activity, treatment choices, psychosocial factors (i.e., anxiety and depression), sexual satisfaction, self-esteem, and quality of life. A total of 330 patients with IBD were recruited from ambulatory clinics in Dublin. Their ages ranged from 18 to 83 and the sample comprised 169 men. The investigation comprised both self-assessed questionnaires and qualitative open-ended questions on BI dissatisfaction. The authors used grounded theory to analyse the responses and found dissatisfaction on three axes: physical, social, and psychological. The demographic factors associated with high body image dissatisfaction were young age (below 35 years old), being a woman, having a flare, having high body mass index³, having steroid treatment, and having surgery (with or without a stoma). The duration of the disease or educational level had no impact on their BI dissatisfaction.

As for psychological factors, lower scores of BI were associated with anxiety and depression as well as low quality of life, self-esteem, and sexual satisfaction. Sexual activity however, was not impacted. On the open-ended questions, the authors quantified the number of times participants mentioned being dissatisfied with their BI, and found that 80% of patients mentioned, at least once, being unhappy with their BI. Among the physical factors that troubled participants were stomach pains, diarrhoea, scars, having a stoma bag, and weight gain. The open-ended questions also revealed issues around having to take a part-time job, constant toilet needs, and other interferences with daily activities.

This research did suffer from being a correlational study, which prevented drawing any causality inferences; also, the mixed method was poorly described with regards to the qualitative method, methodology, and findings. The authors mentioned using grounded theory but the results are presented in a table using frequency percentage. Nevertheless, studies on BI

³ The cut off point for high BMI was not specified in the study.

and IBD are limited and none, to my knowledge, explored the comparison between IBD and general population.

2.1.1.4 Dietary patterns

Living with IBD imposes a constant battle on a daily basis with food offending agents (Fletcher, Jamieson, et al., 2008). Fletcher, Jamieson, et al. (2008) gathered food diaries and conducted semi-structured interviews with eight young women diagnosed with a Gastrointestinal (GI) disorder in Ontario Canada (5 IBS, 1 UC, 1 CD, 1 Both UC and CD⁴, aged 18 to 23 years old). The phenomenological analysis indicated that women engaged in negative adverse behaviours with regards to their medications and food habits. Participants expressed being constantly reminded and restricted by the impact of food on their health and wishing they could eat without care or concern. Restriction in diet of certain trigger foods was often, but not always, encouraged and assisted by nutritionists and medical professionals. One participant mentioned her doctor saying diet was irrelevant to her colitis inflammation and left her unarmed with regards to food management. Some participants mentioned restricting food eating altogether before a long car ride, a day out, or an exam. Managing their diets also meant not eating to avoid being sick around specific social events. Furthermore, finding time for cooking was not always easy and eating varied nutritious foods was deemed expensive or potentially conducive to diarrhoea due to their fibrous content. With regards to medication compliance, the authors found participants failing to partially (or completely) adhere to the recommended dosage. Women seemed to rationalise their inconsistency as either involuntary (forgetting to take the pills), or deliberate; injecting drugs in their system was not something they could sustain for long periods of time, especially when they were not perceiving the added benefits to their health.

Dietary changes do not have the potential to cure or resolve the GI disorders but are part of the known management tools to help keep the symptoms at bay. Understanding the rationalisation process of young women who opted to engage in restrictive and selective food diets could prove useful to address treatment barriers. Fletcher, Jamieson, et al. (2008) recommended to recognise the uniqueness of each GI disorder and tailor (diet) treatment plans to patients rather than to GI disorders in general.

A nested study looking at this same sample of eight college women (5 IBS, 1 UC, 1 CD, 1 Both UC and CD) reported their decision-making process when they indulged in foods known to trigger negative consequences (Schneider et al., 2009). The study followed a heuristic inquiry and phenomenological approach to data analysis. All participants reported succumbing to foods and beverages known to trigger negative symptoms; however, they only did so within controllable settings. For example, they would *physically and psychologically rely on a*

⁴ I believe this would fall into IBDu.

medication intake to either proactively or retroactively rectify their indulgence. Having the medication at hand or at sight would also play a reassuring role even though it was not always consumed. Also, being in the comfort of their own home vs. being out in unfamiliar places influenced whether or not women would indulge in their ‘forbidden’ foods. The *awareness and timing of the surrounding* thus played a crucial role in the thought process of choosing what (not) to eat. Moreover, the data revealed that women formed a hierarchy of thoughts in assessing the cost-benefits of their negative behaviours ranging from sheer *denial*, that the food would cause harm, to a *blatant disregard* for the consequence, or to a *desire for normalcy*. Some women expressed wanting to feel like everyone else, and not marginalised from others in terms of illness and food choice. Interestingly, some participants reported using the trigger foods to cleanse their body from excessive medication intake and feeling as if they had hit the reset button after passing their stools several times. The authors argued that elucidating the mind-set of women’s decision-process may give clinicians a set of tools to understand why sudden flares and resurgence of symptoms occurred and target these thought processes to better advise on alternative treatments.

It is interesting to note that looking at the last few subheadings of Part I, notably, quality of life, stigmatisation, body image and dietary patterns one can see the recurrent need to ‘strive for normalcy’. Whether it was to appear, eat, or feel normal, participants reminisced of a time prior to the illness or a quiescent period where they could act and look as themselves (or anyone else) without restrictions.

2.1.1.5 Knowledge needs

Welfare, Colligan, Molyneux, Pearson, and Barton (2006) looked at the self-identified important topics for individuals with UC using focus groups and interviews (40 IBD patients, aged 19-71 years old, 20 females, from Northeast England). The authors noted the answers clustered in nine main categories including: 1) finding the origins and cause of the illness, 2) finding a cure, 3) prevention measures, 4) daily tips for living with colitis, 5) conventional and non-conventional side-effects of treatments, 6) management of specific symptoms, 7) have more research available on colitis, 8) establishing better communication with healthcare professionals and 9) improvements on service delivery. These categories came in no order of frequency or priority however the results did indicate that individuals with UC had a wide and broad range of concerns and need for information.

Moreover, Lesnovska, Borjeson, Hjortswang, and Frisman (2014) interviewed 30 IBD outpatients from a Swedish clinic (16 females, aged between 29 and 83 years old) about their knowledge needs related to living with IBD. Using inductive content analysis, the interviews revealed that participants wanted to know more about the course of the disease, managing their daily life with IBD, and facing difficulties in comprehending and taking in information. Patients mentioned a need to have a better understanding of the trajectory of their illness, if surgery would be required, or if they ought to expect many relapses and flares. However, knowing about

potential illness complications was not always sought after, patients were mitigated in their opinions, some wanted to know about eventual complications and believed it was a necessary warning; others preferred not to be unduly concerned. In terms of daily management of IBD, some patients expressed a desire to know more about behaviours and possible dietary patterns that could hinder remission or trigger a flare. There was a shift of need of information at the time of diagnosis and during relapses, with more information sought then compared to other quiescent phases of the illness. And, the means of acquiring knowledge oscillated between verbal information given by healthcare professionals, internet readings, or hearing from others who share IBD. However, teasing out between valid and invalid Internet information was challenging. Understanding medical jargon and interpreting test results also proved to be difficult for most of them.

A sense of control and active engagement seemed to comfort participants who sought more knowledge whereas others stayed away from burdensome information out of fear of irreversible facts. This study was innovative in gathering in depth information about the needs of patients with IBD and the use of qualitative methods allowed to depict the complexity and intricate feelings amongst individuals.

Although Lesnovska et al. (2014) underlined a shift in need for information from remission phases to flare phases, that was not to say that during a remission individuals were concern-free (Keeton, Mikočka-Walus, & Andrews, 2015). Keeton et al. (2015) reviewed a large number of individuals (N=294) and asked them about their main concerns with IBD. The authors found that 96% of the sample were significantly concerned about their diminished quality of life, the unpredictability of the illness, and the distressing symptoms and treatments. These findings were collected from a sample that was predominantly (74%) in remission. These results also echoed those of McDermott et al. (2015) where younger patients, and women expressed lower quality of life and more concerns than the older, and male counterparts.

In order to identify knowledge availability, amount, and quality of information accessible to IBD patients, Promislow, Walker, Taheri, and Bernstein (2010) looked at questions marked as important for newly diagnosed individuals with IBD and those with longer disease duration. After entering key words into a main search engine (Google), they identified 21 websites readily accessible that provided IBD-related information. The authors rated the websites using a 5-point Likert-type scale ranging from no information available to comprehensive information available. Regarding IBD symptoms, causes, and treatments, most websites had adequate information. However, the results were scarce regarding the side effects and long-term prognosis, and impact on fertility. There was no systematic information on how to access care and manage symptoms or dietary guidelines. None of the 21 websites addressed leave of absence from work or medical insurance management. Individuals with IBD

researching on the Internet answers to their common questions⁵ were hence left with little information to cope with their social, physical, and health situation.

Hence one can see the plethora of needs for tailored information addressing the specific needs and queries of individuals living with IBD. These needs also change depending upon the phases of the illness and possibly creating or promoting available resources that would address the different demands could prove useful to people with IBD.

2.1.1.6 Social needs

A good way to draw conclusions from several qualitative studies is to look at meta-syntheses which allow to integrate and interpret thematic outcomes (Kemp, Griffiths, & Lovell, 2012). Kemp et al. (2012) conducted a systematic search on qualitative studies addressing quality of life with IBD from patients' perspectives. The authors ran a search across 5 databases collecting 1395 potentially relevant papers. After screening for relevance, duplicates, full-text availability, and quality appraisal, only seven publications: six papers and one dissertation remained. The authors who analysed the research concluded that individuals with IBD live in a permanent tension referred to as a "*push*" and "*pull*". On one hand, participants pushed to maintain their illness under control, hence attaining control was perceived positively and losing control was perceived negatively. On the other hand, IBD pulled and detained the individuals from social gatherings, isolating them through fear of incontinence. The messiness and constant conflict to keep the illness at bay were noted amongst individuals with IBD, even though they equally attempted to accept the illness and its outcomes. The meta-synthesis allowed to interpret how individuals with IBD permanently *pushed* for a normal life and how their illness cyclically *pulled* them back.

2.1.2 Treatment impact

Having surgery involving the removal of a part of the gut and formation of an external pouch to void is a life-changing event for individuals suffering from IBD. Notter and Burnard (2006) provided insight into the experience of women preparing for, and post of, a restorative proctocolectomy⁶. They reviewed the literature and noted that most studies focused on the functional aspect of individuals after surgery, and little attention was given to how individuals restore normal activity and adapt to the practical management of the pouch. The authors interviewed 50 women who had a restorative proctocolectomy and used descriptive phenomenology to analyse the transcripts. No indication was given regarding the illness composition of the sample, only that for the most part women suffered from UC. The findings showed that, despite receiving adequate pre-surgical information, patients' perceptions of the

⁵ Important questions to IBD patients were identified in a previous study, refer to Bernstein et al. (2011).

⁶ A restorative proctocolectomy involves in the initial stage, the incision of the ill parts of the intestine, the formation (for a prolonged period of time) of an ileostomy - thus the need for a bag - followed by a later stage of restoring normal voiding function to the individual.

outcomes of surgery were far worse than their expectations. The surgery was described as traumatic and painful and shocking. The pain was disconcertingly debilitating and rated worse than acute flares or even giving birth. The disfigurement and scars (made worse with the swelling) brought about by the intervention left women in a great deal of distress, a distress further exacerbated upon the initial reaction of some partners post-surgery. Most women however, expressed having supportive and reassuring partners who showed affection and desire to remain intimate. Unfortunately, a small number did report their partners being repulsed, forcing them to hide all stoma-related equipment away from sight. The ileostomy was termed as the separation from being human to the degrading animal-like state. Participants felt like animals, subjected to involuntary control of their bowel, smelly and unable to remain clean. Women in the study preferred to remain homebound rather than facing embarrassing leaking accidents or kneeling in public toilets to empty the bag.

There was an overall description of loss of womanhood, a loss of self, and loss of perceived desirability. The key issues to be addressed for women undergoing a restorative proctocolectomy were pain relief, body image, and intimacy. These issues have implication for practice and urge the need to have better pain relief protocols, psychological counselling for the women and their partners, as well as a more thorough pre and post-surgical education of what to expect and how to cope practically with an ileostomy.

Living with an ostomy has its own challenges and adaptation to the pouch often involves changes in the social participation and reliance on others to change the appliances (Cetolin, Beltrame, Cetolin, & Presta, 2013). One participant in the Notter and Burnard (2006) study recounted never having looked at her formed ileostomy and entirely relied on nurses to change the appliances whilst in hospital. Once at home, she called upon her mother routinely to empty her bags. Although the burden imposed on the family, relatives and spouse, through the experience of surgery and living permanently (or temporarily with an ostomy), is beyond the scope of my thesis, I deemed it necessary to touch upon it, to contextualise the living experience of women with IBD and their dependence upon others to adjust to their new life.

2.1.3 Summary part I

In conclusion, Part I showed that on the psychological and social level, individuals with IBD suffered from reduced self- and body image and experienced freedom restriction due to their symptoms. Individuals reported feeling lonely and stigmatised for having IBD. A general sense of powerlessness and feeling of being a burden on others reduced their quality of life. Diets and medication adherence were often tools used to restore control over the illness but also at times channels to rebel against the illness and a window to act carelessly. Individuals with IBD aspired for 'normalcy' and reminisced of a former freer life before IBD. Furthermore, several gaps in knowledge regarding the trajectory of the illness and how to manage IBD, which were further obscured by the medical jargon, left individuals with IBD unarmed and ill-prepared.

Individuals wanted to interact more with others and found solace when they met others who shared their illness but the symptoms often pulled them back into isolation due to the pain and incontinence. Lastly, with regards to treatment impact, having a permanent or temporary pouch left women in particular with a sense of loss of womanhood and desire for intimacy. Family, partners and healthcare providers played a pivotal role in the post bowel surgery adjustment, and women who had supportive social networks recovered better compared to those who did not.

The second part of this chapter presents a review of the literature on the transition to motherhood followed by a review on motherhood within the context of an illness. The chapter then focuses on birth timing and trends, covering IBD sex-specific issues, fertility, premature deliveries and other complications. A quick overview at pregnancy with an ostomy is provided along with the statistics on the number of births in IBD mothers. The chapter ends by tackling some of the reasons for voluntary childlessness and listing the updated European Crohn's and Colitis Organisation (ECCO) guidelines for a successful transition to motherhood.

2.2 Part II: Family Planning and Motherhood

The second part of this chapter presents a review of the literature on the transition to motherhood followed by a review on motherhood within the context of an illness. The chapter then focusses on birth timing and trends, covering IBD sex-specific issues, fertility, premature deliveries and other complications. A quick overview at pregnancy with an ostomy is provided along with the statistics on the number of births in IBD mothers. The chapter ends by tackling some of the reasons for voluntary childlessness and listing the updated European Crohn's and Colitis Organisation (ECCO) guidelines for a successful transition to motherhood.

2.2.1 Definition

The definition of the noun mother comes in many forms. In its simplest explanation one finds “a female animal in relation to its offspring” (Oxforddictionaries, 2018), implying the link to giving birth as essential to the definition as well as the sex as mandatory (male seahorses are known to carry their young ones and give birth to them). The more urban understanding of the term mother, also found in the web, is a vivid and heavily construct-laden definition:

The woman who loves you unconditionally from birth, the one who puts her kids before herself and the one who you can always count on above everyone else. Just telling her your problems makes you feel better because mums always know how to make it all go away. Even if you fight, know that she's just looking out for your best interests (Urbandictionary, 2016)

Moreover, looking at the spelling and pronunciation of the word *mother* across languages and countries we find that out of the 116 reported languages the word mother starts or contains the letter “m” in more than 82% of the tongues (most start with “m” and contain the letter “m” in

the middle or end of the word, i.e., French *Maman* or Arabic *Oum*) which is not without acoustic resonance with the French and Latin root for the word “love”.

Hence reflecting on these various definitions of the term imposed elucidating the claims, or lack of, made in my thesis. I made no claim about the level of care and affection portrayed by mothers who were interviewed. I limited the definition of being a mother to its simplistic form – a woman who has given birth to (at least) a (living) child. I also made no assumption regarding planning for pregnancy, or the sexual orientation of the mother.

2.2.2 Transition to motherhood

Nelson (2003) conducted a meta-synthesis of nine qualitative reviews on the transition to motherhood and argued that there is little consensus on which variables contribute to a healthy transition to motherhood. The continuous focus on the physical health in gestation and labour as well as the sole focus on the baby in the postpartum phase left mothers ill-prepared to face the transition with little support and attention given to their emotional welfare. Moreover, complications such as neonatal intensive care admission or postpartum depression could alter the wellbeing of the mother and family in general. Nelson’s (2003) meta-synthesis resulted in a proposed model of two processes: *engagement* and *growth and transformation* enabling transition to motherhood. Nelson found five categories and potential areas of disruption during the transition: a) commitments, b) daily life, c) relationships, d) self, and e) work.

According to Nelson (2003) women who become mothers got involved in their new role through *commitment* and *engagement*. As for their *growth and transformation*, it accompanied and was dependent upon women’s investment in motherhood. This latter process implied facing challenges and adapting to changes and demands of the new life stage. The maternal-infant bond started for some in the antepartum phase and was strengthened during the postnatal phase, particularly once they breastfed their child. The responsibility towards their unborn child also grew during the gestation and was accentuated by seeing and discovering their child.

In *daily life*, women learned to become mothers particularly postpartum once they began to feel drained and realised the endless potential for resource they could have for their child. They adapted to the individual needs of their unique child and learned to care for him or her, using – at times – role models to assess their competences.

As for *relationships* and *work*, the transition shifted the couple dynamic into a family dynamic centred on the newborn baby. Intimacy suffered and different sets of values regarding upbringing of a child surfaced causing tension in the dyad. A shift of closeness to one’s own family as well as preference for friends who have children was commonly reported. On the other hand, their attitudes towards work was conflicted; to return to work or remain at home imposed sacrifices. A change of priorities and hours was noted, but these conflicts depended on financial circumstances and if women’s identity was linked to their work.

Lastly, regarding the *self*, participants across the studies reported a myriad of changes sometimes positive such as increased patience or empathy towards other parents and sometimes negative such as loss of sense of self. This category is partitioned in three experiences, the first being facing the past and how one was mothered and beliefs about what type of parent one can be. The second is facing one's self, in terms of personal evaluation of weakness resilience and personal tolerance to pain (through childbirth for example) and lastly coming to feel like a mother which is time sensitive: some feel it in the postpartum phase, others well before or much later. In conclusion, understanding the phenomenon of the transition, even though not generalisable through this synthesis of qualitative studies, is of use in grasping what changes, feelings and emotions can come into play whilst undergoing the transformative experience.

Similarly to Nelson, Smith (1999) also looked at the transition of 4 mothers in the UK, during the first, second, and third trimester as well as after birth. The qualitative longitudinal and multi-method approach involved a collection of diaries, repertory grid analysis, and face-to-face interviews. Smith analysed the data using a phenomenological approach focusing on the idiographic experience and similarities across participants.

The early phase of the pregnancy is tainted with adjustment processes where participants prepare mentally for the new life ahead, some feel a lack of readiness while others are expecting physical changes to mark the beginning of the process. The lack of any physical growth or transformation was problematic in relating to the "newness" of the situation.

In the second trimester, Smith notes a penchant to remove oneself from social and work environments. Women withdraw and focus more on their personal family network. Questions about eventual return to work are thought through. The closeness to the family was not seen in all four women, however the absence of it was not necessarily perceived as a bad experience. The repertory grid analysis demonstrated that most women converged from beginning to end of the pregnancy towards important figures in their lives. A shift of priorities is palpable with less desire to delve into the public world. These findings coincide with Nelson's disruptions in work, relationships, and commitments. In the last phase of the pregnancy mothers hold mixed feelings of excitement and fear of the upcoming labour and early days of motherhood. After the birth, the earlier shift away from work is accentuated by a focus on the family world and accompanied by a transformation of life goals.

In summary, the advantages of this study are the follow up and sense of continuity provided through the accounts at each trimester and postpartum. Pregnancy time was seen to prepare the women psychologically to the changes; this identity development is closely followed by social and cognitive changes in the mother-to-be's life.

2.2.3 Expectations and choices

Sjogren (2000) revisited the trends and expectation change of mothers particularly in Sweden and noted three areas where choices have varied. First with regards to still birth, in the 1960's

women were more readily induced within the initial 24 hours of diagnosis of still birth and were often not encouraged to hold their baby after birth. Midwives and other medical staff would prefer to leave the mother to rest after the traumatic loss rather than discuss the matter. The second area of change pertains to prenatal testing for anomalies and choices of voluntary termination of the gestation in cases of malformation and sometimes sex biases. Mothers stated having freedom of choice over prenatal tests however the reality according to Sjogren (2000) is often different as mothers feel obliged to have them. Lastly, the choice of labour increased its trend with regards to C-section whether due to medical reasons or personal fear of pain and mortality. Mothers-to-be still face a lot of stressors even if the conditions of labour and medical advances in most modern societies have made the gestation and delivery safe. Sjogren (2000) concludes that careful attention to the needs ought to be tailored to the changing times and choices made by mothers to reduce long-term stress, depression and anxiety.

In line with Sjogren (2000) Garrod (2015) wrote an essay on women's identity and the impact of birthing on mothers. She interviewed 10 women aged 21 to 42 years on their birth experiences and analysed the discourse through grounded theory. The results indicated a mismatch between what women envisioned during childbirth and the reality, which was filled with anxiety, fear and a sense of lack of control over the process. The experiences varied but a level of trauma and distress was depicted along with a lack of control over the decision of use of medical equipment, inducement and even a strong sense of being let down by the medical community. One mother felt unprepared to care for and breastfeed her twins and was later found to suffer from severe infection from a gauze forgotten inside her by the midwives. The negligence and unapologetic medical care left that mother in a state of shock and led to a diminished bonding with her children. The author argued that mutual recognition from the maternity staff and care providers towards mothers giving birth is crucial to abolish the top down patriarchal medical approach often perceived in labour care.

The plethora of hormonal and physical changes that occur during pregnancy are nature's way of ensuring not only developmental growth of the child but of the mother as well (Lothian, 2008). The current cautionary approach and instigated fear over nutrition, activities, blood testing, and foetal abnormality testing leaves women unable to negotiate the tasks and transition to motherhood; they wilfully follow whatever healthcare professionals recommend and fail to experience the powerful transformations of natural birth, breastfeeding and motherhood.

2.2.4 The burden of medicalisation

The changes in pregnancy are described as evolutionary and bear the task to heighten the sensitivity and emotionality of the mother rendering her more fearful for her own safety and that of the baby. Lothian (2008) reports that traditionally pregnant women were considered experts in their gestation only guided by their relatives and close friends who had undergone a

pregnancy or were familiar with the process. The family support network held an adjacent role of alleviating the gestating women from heavy tasks and provided her with comfort and good food throughout her journey. Contemporary care, on the other hand, benefits from fewer birth and pregnancy risks due to the advances in technology and medicine, however, the motherhood transition is a conceptualised medical process rather than a natural one. From the testing stick to the first visit to the obstetrician, women place their faith and reliance on the expertise of technology and medical healthcare providers. The routine checks strip women from self-reliance and places them in a state of fear for their child from one visit to the next. Furthermore, the escalation of food restrictions and nutritional supplements have not been systematically supported by research however, women abide by them out of fear of regret or to err on the side of caution. Women no longer believe they are the experts in their pregnancy and devalue their own instincts over external medical-led advice.

In conclusion, these intensive medical interventions during the prenatal phase as well as during birth have the ability to disrupt the natural transition and maturation of responsibility and risks that comes with motherhood. Lothian (2008) writes that no experience in life comes with certainties and guaranties however the excessive monitoring and close follow up on mothers transitioning only accentuates and brings to light the uncertainties. The role of midwives and other professionals is thus to nurture these feelings of self-confidence and promote self-reliance and trustworthiness whilst navigating pregnancy decisions as well as birthing ones.

2.2.5 Birth rate and timing

In developed countries, such as the USA, France and New Zealand birth rates varied between 12 and 13 births per 1000 individuals in the population (IndexMundi, 2015). In contrast, developing countries such as Chad, Ethiopia, Iraq and Cambodia had birthing rates varying from 37 to 24 births per 1000 individuals. As for the UK, the birth rate was as the other developed countries around 12 births per 1000 persons. There has been a gradual increase in conception in England and Wales from 2001 to 2010; the number of live births increased from 594,634 to 723,165 (ONS, 2016). The rate dropped a little since but overall conception rate remained stable from 2013 to 2014 (around 696,000).

On average women in 2014 have their maternity at 30.2 years of age, however, the number of women having their children between 25 and 34 and those having children at the ages of 35 and above has dramatically risen (over 50% increase) from 1938 to 2014. Statistics in Scotland are somewhat similar, with a relatively stable rate of birth in the past 2 years (about 57,000) and the highest number of births occurring in the 30-34 age group closely followed by the 25-29 age group (ISD, 2015). Mothers under 30 years of age were in the majority (65%) from households employed in intermediate and routine occupations, whereas those aged 30 and over were from households employed in higher managerial, administrative and professional occupations.

I was not able to pinpoint statistics of birth rate per age group for women with IBD in the UK. However, the average age of giving birth coincides with the average age of diagnosis (Molodecky et al., 2012). Indeed IBD patients are often diagnosed in their third and fourth decade of life, which is coincidentally (and in general) the time around which individuals are considering forming a family (CCUK, 2015).

2.2.6 Sex-specific issues

According to the Rosenblatt and Kane (2015) review, women face sex-specific issues when diagnosed with IBD such as higher risk for cervical cancer and cervical dysplasia as well as irregular menstrual cycles compared to women who do not have the diagnosis. There is a reciprocal effect of IBD on hormones regulating menses and these hormones affect in turn the GI tract (Rosenblatt & Kane, 2015). Women experience cyclical alterations of their GI symptoms during their menses. Another complication mentioned is endometriosis, when tissues of the uterus are found and implanted outside the uterus. It is important to recognise that these biological and physiological phenomena can impact the course of family planning as well as sexuality. Moreover, on the psychological level, women with IBD suffer from altered body image due to fistulae, scars, ostomy placement as well as recurrent faecal incontinence and stomach pains which can affect their libido and desire for intimacy. Another common inhibitor to sexual activity was depressed mood, which was found commonly amongst individuals with IBD.

As for surgery, particularly IPAA, there are reports of loss of some fertility post-surgery however sexual satisfaction seemed to be unaltered or improved. Women undergoing IPAA are advised to opt for a C-section when pregnant to avoid damage to the pouch. Unfortunately, these issues are rarely addressed when talking about family planning and maternity, the most common aspects targeted by gastroenterologist and obstetricians are fertility and gestation progress.

Similarly, Muller et al. (2010) found that sexual satisfaction was reduced in women and that half of the sample believed that IBD had a negative impact on their relationships; amongst the specified answers participants stated that their impaired BI affected most their relationships along with the need for an understanding partner. They suffered from mood changes and restrained activities both socially and sexually due to IBD. These results resonate with the narratives of Defenbaugh (2013) and Frohlich (2014) who report both relationship failures as a result of IBD and relationship strengthening in face of the illness.

2.2.7 Fertility and premature deliveries

Infertility is defined as the reduced ability or incapability to reproduce, after a year of unprotected and regular intercourse (Mahadevan, 2006). Mayberry and Weterman (1986) compared 275 women with CD to controls from various centres in Europe (Wales, Netherland, Czechoslovakia, Sweden, and Switzerland) on a number of children before and after diagnosis,

premature delivery (more than 3 weeks prior to due date), contraception, infertility, mode of delivery, and miscarriages. The two groups were subsequently matched for age and marital status as well as obstetric history. The results showed that women with CD had a reduction in fertility however the study did not factor in the desire (or lack of) to have children and considered as infertile any married women not using contraceptive and failing to have children after 6 months. The study also did not take into account the disease activity only disease spread and location. Patients with CD were often advised against pregnancy and some were advised to terminate their pregnancy; these numbers were higher than in the control group but did not reach significance. Furthermore, post CD diagnosis women were more likely than controls to have premature deliveries (16% of births) but no difference existed between the two groups in modes of delivery (Vaginal delivery vs. C-sections delivery) or number of miscarriages. Similarly Baird, Narendranathan, and Sandler (1990) argue that the risk of miscarriage was no different in the IBD group vs. the control group however as with Mayberry and Weterman (1986) the percentage of premature delivery was higher for women with CD and UC compared to control.⁷

Today it is recognised that IBD does not seem to impact fertility and physically there seems to be nothing preventing women from having a healthy pregnancy (CCUK, 2013 (CCUK, 2013)). That said, experts nevertheless recommend to achieve and maintain remission from the moment of conception all throughout gestation (Kwan & Mahadevan, 2010). Having IBD controlled and in remission at the time of conception, for CD can affect the chances of conception (Kwan & Mahadevan, 2010). In addition, the guidelines highlight that, with the exception of some X-rated drugs⁸ (i.e., Methotrexate and Thalidomide), the benefit of maintaining induction therapy throughout the pregnancy far outweighs the risks of using drugs and potential of flare recurrence (AmericanPregnancyAssociation, 2017; Kwan & Mahadevan, 2010). As for surgery, the by-product of an Ileal-Pouch Anal Anastomosis (IPAA) can cause damage to the reproductive organs and impede the chances of conception and fertility for women with CD, however, this is due to the technique of surgical intervention rather than the illness (Selinger, Leong, & Lal, 2012). Similarly, women with UC undergoing surgery in the pelvic area can have a reduced fertility. Overall, any course of action during or prior to pregnancy must be carefully thought through and discussed in length with the gastroenterologist and obstetrician (Kwan & Mahadevan, 2010).

Bortoli et al. (2007) evaluated the impact of IBD on pregnancy (before and after receiving the diagnosis) as well as the impact of pregnancy on disease outcome. The study

⁷ The UK population estimated risk for miscarriage during the first trimester is around 1 in 5 pregnancies will result in a miscarriage before 20 weeks (Maconochie et al., 2007).

⁸ X-rated drugs are classified as extremely dangerous for women who are pregnant or attempting pregnancy. Animals and, or human studies have demonstrated foetal malformation and risks whilst using these drugs. A full list of the drug categories can be found on the American Pregnancy Association website.

looked at the reproductive history of women with UC (N= 121) and CD (N= 78) vs. controls in the general population (N=996). The data were taken from patients recruited from 17 different hospitals in Northern Italy. Information was collected from patients' records and face-to-face interview with a physician. Participants were later divided in two groups for analysis of the date; those having their pregnancy(ies) before the diagnosis and those who had their pregnancy(ies) post diagnosis. Results in the pre-diagnosis group show significantly higher rates of preterm deliveries, less than 37 weeks of gestation, in CD patients compared to UC and controls respectively. Birth weight was statistically lower in CD compared to those of UC mothers; however, this difference did not reach significance when comparing the entire IBD sample to controls. There was no difference in terms of preterm deliveries between UC and controls. In addition, UC patients were more likely than controls to have a C-section. No differences were reported in terms of number of live births, congenital abnormalities or spontaneous and therapeutic abortions.

Results in the post-diagnosis group indicate only the birth weight of babies of CD mothers was significantly lower than those of UC and those of controls respectively. No statistical difference was found on other measures such as number of live birth, mode of delivery, preterm delivery or congenital abnormality. When comparing the two groups, pre-diagnosis and post-diagnosis of IBD, women from the post-diagnosis group had significantly higher rates of therapeutic and spontaneous abortion and consequently the pre-diagnosis group had significantly higher numbers of live births. Lastly, for women who were in remission or having a flare at the time of conception, there was not a statistical significance.

In conclusion, close monitoring a cautionary approach must be adopted to follow women who have IBD during gestation. Kwan and Mahadevan (2010) state that in the future all women with IBD ought to be followed as high-risk pregnancy and monitored closely. Moreover, risks to the child both during gestation and in the early days of childhood must be closely followed to assess any delays or developmental deformities due to interactions with drugs.

2.2.8 Other complications

Selinger et al. (2012) conducted a thorough review on papers published between 1980 and 2010 in PubMed mentioning the latest evidence on birthing complications as well as patients' perspective on IBD and pregnancy. The authors report mixed evidence on congenital abnormalities within women with IBD with some research showing no more congenital malformations than in healthy counterparts and others showing an increased risk of urinary track, limb or other multiple malformations.

2.2.9 Pregnancy with an ostomy

Pregnant women with an ostomy can adjust as any other pregnant women to the changes induced by the pregnancy, however certain extra considerations ought to be managed

collaboratively with healthcare professionals to ensure a smooth process from prenatal care to postpartum period (Aukamp & Sredl, 2004). The authors review the literature and assure that there is no evidence to suggest women with ostomy should have a C-section or a preterm birth or even a miscarriage. Women with an ileostomy however are more susceptible to dehydration if they are subject to nausea and vomiting as the ostomate forces the women to lose three to fivefold more daily fluids than a non-ostomate woman. Other considerations involve the change and sealing of the bag as the belly expands. Also, women with an ostomy are susceptible to obstructions infections or hernia due to the strains of the body changes in the second and third trimester. Aukamp and Sredl (2004) discuss the possibility of using alternative therapies rather than drugs to reduce nausea and hypnobirth to manage the anxiety surrounding giving birth naturally.

2.2.10 Number of births

Nevertheless, in their review of research on pregnancy and fertility Kwan and Mahadevan (2010) note that there is an indication that women with IBD tended to have smaller families or fewer births than the general population; the study referenced was conducted in Illinois and the sample of women were compared to data taken from the US Census Bureau (Baird et al., 1990; Kwan & Mahadevan, 2010; Marri, Ahn, & Buchman, 2006) stated that the reduction in number of births could be attributed to a personal choice rather than a biological impairment to have children (the reasons for personal choices are detailed in the voluntary childlessness section below). There are a number of considerations and a chain of decision-making processes regarding treatment and medication for women with IBD who wish to have a child (Selinger et al., 2012). There is thus a pressing need to understand more the factors and reasoning behind the decision to have a family whilst having a diagnosis of IBD.

2.2.11 Voluntary childlessness

Toomey and Waldron (2013) looked at the current practices in a hospital in Ireland and found that among the 31 women investigated (9 CD, 22 UC) 58% reported not factoring IBD into their decision of family planning. However, half of these responders had already had at least one child, which could have biased their answers, in a sense that they had already gone through pregnancy and do not need to factor in IBD in their family planning anymore. The majority of the responders believed that GPs ought to discuss medication and lifestyle changes prior and during gestation, however, only 32% had such a discussion with their GP. The authors also assessed patients' knowledge with regards to IBD and pregnancy and found that a third of the sample believed that all drugs ought to be ceased during pregnancy and 35% thought that medications are more harmful than a flare for the baby. Furthermore, 19% reported they would interrupt medication intake even against medical advice should they fall pregnant. Not surprisingly 67% of women were concerned and anxious about the effect of their drugs on gestation. There is a significant lack of knowledge amongst IBD patients causing unnecessary

fears around taking medications during pregnancy. The authors suggest non-acute guidelines delivered and followed by GPs to promote discussion and talks around family planning from an early stage.

Selinger et al. (2012) were also of the same view that patients' knowledge-deficit places women at risk of making possibly regrettable choices of remaining childless or choices that could harm the pregnancy, such as interrupting their drug intake. The authors thus developed and tested a tool for assessing IBD patients' attitude and knowledge around pregnancy (Crohn's and Colitis Pregnancy Knowledge Score, CCPKnow). CCPKnow was validated as reliable and accurate on content, discriminatory, readability, internal consistency and construct validity. The questionnaire comprises 17 items assessing knowledge regarding conception, fertility, delivery, breastfeeding treatment as well as other pregnancy issues on a 5 item Likert-type scale. Scores varied between 0 and 17, with 0-7 indicating *poor* knowledge of pregnancy-related topics, 7-10 *adequate*, 11-13 *good* and ≥ 14 *very good* knowledge. The questionnaire was tested on 145 women with IBD (65 CD, 65 UC and 15 IBDu) from various hospitals and gastroenterologists' offices in Australia. Results indicated that although married women had significantly better knowledge than single women, on average their level of knowledge was adequate (Mean=8.65, median not reported). Similarly, Caucasians Women were more knowledgeable than women from ethnic backgrounds (Asian, Aboriginal, African and Others) (Mean=8.62). Looking across diagnosis time, number of children, and members of the support group for Crohn's and Colitis, the results showed at best adequate knowledge for the most expert patients (highest mean was of 10.18) and 65 women (44.8%) had poor knowledge. There is thus a pressing need to educate patients to make better informed decisions about family planning and remove unwarranted fears possibly hindering the safe course of conception.

Marri et al. (2006) wanted to further explore the concerns and the decisions of women with IBD around childbearing. They gathered survey data from 169 women with IBD (110 CD, 59 UC) aged between 15 and 44 years old from a Crohn's and Colitis group in Illinois. The sample was predominantly Caucasian and a third had a graduate degree. About 38% of women in the sample were voluntarily childless (VC), which was defined as any woman who could have children but decides otherwise. The rates of UC and CD's voluntarily childlessness were compared to population-based controls data extracted from the US Census Bureau; the results indicated that the rates of CD and UC for VC were higher than the population but only significantly higher for women with CD. There were no differences in the rates of non-voluntary childlessness in the sample compared to the general population. Among the women who decided to remain voluntarily childless the concerns and reasons for their choice involved for the most part the outcome of pregnancy on their illness; they feared IBD would flare or worsen as a result of getting pregnant. Other concerns expressed were the potential heritability factor of IBD and stress as well as the ability to care for a young one. Furthermore, the sample had significantly lower birth rates than the US population average. In terms of sources of

information sought to discuss pregnancy and IBD women with IBD reported seeking by order of frequency their gastroenterologist, the internet and lastly their primary physician and medical journals. The authors explain the lower rate of children in the sample could be due to the fact that the women were predominantly Caucasian and Caucasian women tend to have fewer births compared to other ethnic groups; similarly, education level can play a role in the number of birth in the sample with more educated women having fewer children; however more often than not women in the sample tended to decide to have children despite having IBD.

Nevertheless, the high rate of voluntary childlessness warrants further explanation, one attempt at unveiling patients with IBD's views on childlessness was a study conducted by Selinger et al. (2013) in tertiary outpatient units in Sydney, Australia. The authors attempted to understand the interaction between poor-knowledge of pregnancy and IBD-related issues and negative views that medication could affect the outcome of pregnancy. To assess attitudes towards pregnancy and IBD related issues both general and personal statements were generated by a team of experts. The topics explored were fertility, breastfeeding, delivery mode, delivery outcome, and medication during pregnancy. Patients' knowledge was assessed using the CCPKnow questionnaire. The sample included 145 women with IBD (65 UC, 65 CD, and 15 IC), 49 of whom had at least one successful pregnancy post IBD diagnosis and 23 prior to their diagnosis. The sample's median age was 32 years of age; they were for the most part Caucasian and in a long-term/married relationship. More than a third of the sample (34%) assumed that IBD impacted the rates of fertility. One quarter of the women stated that even if a flare started during pregnancy it would be more important to tolerate the symptoms than to resume induction therapy; a third believed that medication in general is not good for gestation and the baby; and almost 70% assumed that if taking medication breastfeeding ought to be avoided. There was also a reported fear that pregnancy with IBD would involve difficulties and complications. As for the women who never had children (nulliparous) the assessment tests revealed that almost all of them were concerned about the effect of IBD and medication interactions on their pregnancy. The most commonly reported concerns were worries about having a flare whilst pregnant, transmitting the illness and being infertile. A little less than 30% were considering voluntary childlessness due to IBD.

As for the association between knowledge and attitude, Selinger et al. (2013) found that women who had lower scores on CCPKnow tend to have less positive views about maintaining medication during conception and pregnancy as well as whether flares should be tolerated vs. resuming treatment during gestation. Women with IBD, who were members of a support group for Crohn's and Colitis, had higher scores and more positive views towards treatment, breastfeeding and pregnancy. The authors conclude that poor knowledge could provide a piece of the puzzle in understanding non-adherence and compliance to medication during pregnancy as well as fears leading to voluntary childlessness. However, fears of inheritability and infertility were not associated with poor patient knowledge but were still a concern among

patients. The authors speculate that personal experiences and emotions may be at play in leading women to have unnecessary fears.

A further study by Selinger, Ghorayeb, and Madill (2016) explored the rate of VC among a sample of British women and attempted to estimate the impact of poor patient-knowledge on pregnancy issues on the rate of VC for women who wish to remain VC vs. those who wish to have children in the future. Individuals were recruited from the Crohn's and Colitis UK charity and demographic factors, disease activity and disease treatment information were tested against their child-status and patient-knowledge scores (CCPknow score). A total of 1324 women with BD (776 CD, 496 UC, 52 IBDu) answered the survey. The results indicated as predicted that women who remained VC had poorer CCPknow scores overall and significantly lower CCPknow scores than women who wish to have children in the future. Women who chose to be VC tended to seek less medical advice, be older, single and unemployed. They also tended to have more often a diagnosis of CD and more hospitalisation compared to women who wished to have children later on. Similar concerns to those reported in Selinger et al.'s (2013) study were found in this cohort; women feared passing the disease as well as not being able to muster the energy to care for a young one.

In conclusion, patient education seems to be at the heart of improving and providing holistic care for women with IBD. It can positively influence women's decision towards child upbringing and grant them a more informed decision leading towards a patient-centred therapy. Using medical staff and the Internet to target patient-knowledge deficits seems to be a good focal point, as women tend to refer to the two sources to gather information.

Mountifield, Andrews, and Bampton (2014) looked at the effect of a single group intervention session on patients' education for pregnancy related issues in IBD. The authors targeted members and non-members attending the Crohn's and Colitis Australia support group, the CCPknow questionnaire was handed before and after a short 24-slide presentation targeting current practices on medication and IBD, pregnancy, breastfeeding, fertility and inheritance. A total of 155 individuals participated (107 women) and score average significantly improved from pre- to post-testing irrespective of sex. Overall 90.6% of individuals who responded had low knowledge pre-information session and post-intervention 95% demonstrated 'good' to 'very good' knowledge. Participants improved their knowledge more acutely in some areas than others such as the impact of disease activity on fertility; similarly, more participants had accurate perceptions about the safety of taking certain drugs during pregnancy. The dramatic and positive learning curve demonstrated in this study shows promising results to be replicated and used to increase reproductive knowledge of patients with IBD.

In sum the European Crohn's and Colitis Organisation (ECCO) reached consensus on seven statements comprised of subsections regarding reproduction with IBD (Van der Woude et al., 2015). The ones pertinent to the topic at hand are conveyed in no specific order:

1. Most IBD drugs are classified from safe to relatively safe with the exception of Methotrexate and Thalidomide.
2. Ulcerative Colitis and inactive Crohn's Disease do not impact fertility
3. Induction therapies do not impact fertility in women
4. Surgeries in women can increase the risk of infertility
5. A C-section is recommended when a pouch is present or if the patient suffers from or has a history of perianal disease.
6. Pregnancy influences positively the course of IBD, and conception during remission increases the chance of flare-free pregnancy
7. Medication continuation in the postpartum period reduces risk of flare
8. Children with two parents with IBD are at greater risk to develop the illness
9. Adverse pregnancy outcomes are more frequent amongst mothers with CD
10. Maintaining medications during pregnancy outweighs in most women the risk of discontinuation and flare during gestation.

The guidelines recommend that in order to optimise a successful conception pregnancy and delivery all women with IBD ought to be referred to counselling prior to family planning.

2.2.12 Summary part II

In Part II of the chapter, I point to some of the theories of transition to motherhood indicating a transformative experience in terms of engagement and commitments. Mothers experience changes in their daily life, work, intimate and social relationships as well as within themselves. This transition is accompanied by a myriad of expectations and confrontation of choices to make regarding nutrition, lifestyle changes and preference of natural or C-section labour. Research points to a medicalisation of the process progressively increasing the reliance on experts and disempowerment of women to trust their bodies and themselves. With relation to IBD, birthing timing and trends in the general population seem to coincide with the timing at which women receive their diagnosis. Having IBD engenders a plethora of complications notably, a higher risk for cervical cancer, disrupted menstrual cycles, low body image and sometimes low libidinal desire. Moreover, complications of surgery can result in infertility, and pregnancy with IBD may result in low birth weight babies and in rare cases congenital malformation. Extra consideration must be taken and particular attention and monitoring are key elements of a successful pregnancy with IBD and is highly emphasised by the ECCO guidelines. Lastly, in terms of number of births, research shows that women with IBD tend to have fewer children and are more likely to remain voluntarily childless; some of the potential reasons for it are the remarkably low level of pregnancy related knowledge amongst IBD patients and the amount of unwarranted anxieties and fears around transmission of the illness.

2.3 Summary

In this chapter, I have given a succinct overview of what it means to live with IBD as well as a quick overview of the process of transition to motherhood with some key specific issues pertaining to becoming a mother with IBD. In Chapter 3, I will systematically review the literature and provide a meta-synthesis on studies looking at the transition to motherhood with IBD using qualitative research to account for mothers' lived experience of the illness.

Chapter 3

Qualitative Meta-Synthesis on the Transition to Motherhood with IBD

The aim of this chapter is to build a much-needed systematic overview of the qualitative research conducted on the topic of motherhood and Inflammatory Bowel Disease (IBD). The chapter will describe the elaborated protocol for searching the literature and provide extensive details on the selection and exclusion criteria of articles. Furthermore, I used an exploratory thematic analysis to synthesise and integrate the findings of the seven articles found to address the transition to motherhood with IBD. The analysis is detailed with relevant codes and extracts from each article.

3.1 Systematic Research Review: Methodology

3.1.1 Key search terms protocol

The key research question of the systematic research review (SRR) is identical to the one posed in my PhD thesis: ‘What is the lived experience of women who transition to motherhood within the context of Inflammatory Bowel Disease?’ The key terms of the SRR were generated in four clusters to capture all aspects of the research question (see Table 1 below). The first two clusters comprised key terms relevant to IBD and mothers; whereas the last two clusters tapped into the transition to motherhood and terminology related to qualitative methods.

Table 1 *SRR Key Terms by Cluster*

Inflammatory Bowel Disease: Cluster 1	
1. Bowel* Surger* (W/6) ¹	9. IBD OR IBDs
2. Colitis*	10. (Ileo-Anal*) W/6 Pouch*
3. Colon* Disease* (W/6)	11. Inflammatory Bowel Disease*
4. Crohn*	12. Pouch*
5. Digest* Disease* (W/6)	13. Stoma OR Stomas
6. Digest* Surger* (W/6)	14. Ulcerat*
7. Gastrointestinal* Disease* (W/6)	15. 1-14 (Or)
8. Gastrointestinal* Surger* (W/6)	
Mothers: Cluster 2	
16. Adult* Female*	20. Mum OR Mom(s)
17. Human Female*	21. Wom?n
18. Matern*	22. 16-21 (Or)
19. Mother*	

¹ For an explanation of Booleans and proximity operators used refer to section 3.1.2.1 below: tailoring of protocol to database.

Transition to Motherhood: Cluster 3	
23. *Trimester*	39. Educat*
24. Abort*	40. Experience*
25. Baby OR Babies	41. Famil*
26. Birth OR Born	42. Health Visitor* (W/6)
27. Breastfed* OR Breast-fed*	43. Infan*
28. F?Etal OR F?Etus*	44. Kid OR Kids
29. Mother* Experience* (W/6)	45. Midwi*
30. Mother* Phase* (W/6)	46. Postnatal* OR Post-Natal*
31. Mother* Role* (W/6)	47. Prenatal* OR Pre-Natal*
32. Mother* Transition* (W/6)	48. Raising
33. Neonatal*	49. Toddler OR Toddlers
34. Newborn*	50. Doula OR Doulas
35. Pregnan*	51. Deliver*
36. Child*	52. Labor OR Labour
37. Cope OR Coping OR Coped	53. 23-52 (Or)
38. Development*	40. Experience*
Qualitative Methods: Cluster 4	
54. Content Analys* (W/6)	64. Phenomenolog*
55. Discourse OR Discourses	65. Psychoanaly*
56. (Focus W/6 Group(s))	66. Qualit* Approach* (W/6)
57. Framework Analys* (W/6)	67. Qualit* Research* (W/6)
58. Grounded Theor* (W/6)	68. Qualit* Stud* (W/6)
59. Interpretat*	69. Quali* Method* (W/6)
60. Interpretative Phenomenological Analys*	70. Subjective Experience* (W/6)
61. Interview*	71. Thematic Analys* (W/6)
62. Diaries OR Diary	72. 54-71 (Or)
63. Lived Experience* (W/6)	
73. 1-14 And 16-21 And 23-52 And 54-71	

3.1.2 Database selection

In order to ensure broad and systematic database selection and capture relevant literature, I listed all the accessible and known databases of academic research found on the University of Leeds Library website which explicitly covered areas of psychology, healthcare, and medicine. I then proceeded to the inclusion or exclusion of each database based on the relevance of its content. The list of all 80 databases available on the University of Leeds Library's website, along with a description of each one of them, can be found in 8.7 Appendix A. Each database was reviewed and included if it contained relevant information to the research question and areas of interest. The databases were excluded if it pertained to unrelated areas such as History, Law, etc. The justification of the inclusion and exclusion criteria can also be found in Appendix A. In addition, some databases, such as PsycInfo and PsycArticles were aggregated in a broader search engine, that I will call the aggregator. In those instances, the original databases were individually dropped from scoping but still searched through the aggregator.

As a result, the key terms listed in the table above was searched across a selection of eight different databases: (1) Cochrane Library (including [WHO reproductive health library](#)

[online](#)), (2) Ovid (including Medline, Medline in process, OldMedline, PsycInfo, PsycArticles, AMED, EMBASE, EMBASE Classic, Maternity and Infant Care, and CAB Abstracts Online), (3) Proquest: Health and Medicine (including ERIC, International Bibliography of the Social Sciences, PAIS International, Social Services Abstracts, Sociological Abstracts, ASSIA, Physical Education Index, and PILOTS Database), (4) Web of Science (including Biosis previews online, [Science Citation Index](#), and [Social Sciences Citation Index](#)), (5) CINAHL ([Social work abstracts](#)), (6) PubMed, (7) Popline, and (8) Scopus. Science Direct, Social Care Online and WHO Regional Databases were relevant in terms of content to my search, however they were not included in the scoping because their interface did not support a systematic search of all 73 key terms listed in the protocol. These databases were thus excluded to maintain consistency of protocol search entry across all databases.

3.1.2.1 Tailoring of protocol to database

As can be seen in

Table 1, Booleans, truncations, wild cards, and proximity operators were used to capture the key terms in any phrase or sentence of the article and/or abstract. Scopus recommended to use proximity operator between 1 and 5 words of each other (“W/5” within 5 words) to capture key terms in any order within a same sentence and up to W/15 to find key terms within a same phrase (Scopus, 2016). I selected W/6 as a proximity operator across all databases. The hit search for each key term and grouped key terms per database is listed in Appendix B. Note, the proximity operators had different names in different search engines, notably, in Scopus they were termed *W* for within, in Cochrane they were termed *N* for near, and in Ovid they were termed *ADJ* for adjacent.

3.1.3 Screening selection and limitation

3.1.3.1 Screening by language and peer-review journals

Most of the databases allowed for selection of English language only and the selection of peer-reviewed articles. Table 2 below provides the detail of each screening tool available per database. In the instances where limiting tools were not available, I excluded manually from the final counts any article not meeting the two previously mentioned criteria. The decision to include English only articles was motivated by the need to work within the time and resource limits of the PhD. As for the peer-reviewed articles, their inclusion met the requirement to collect good quality articles.

Table 2 *SRR Screening Articles, Inclusion and Exclusion Selection (Round 1)*

Databases	Cochrane Library	Ovid	ProQuest Health & Medicine	CIN-AHL	Web of Science	Pub Med	Pop Line	Scopus ²
Total Hits Reviewed	19,728	1,316	187	106	8,735	271	0	28,256
English Only	N/A ³	1,203	169	92	7,454	248	-	18,964
Peer-reviewed Only	N/A	1,191	163	84	N/A	N/A	-	N/A
Topic Limits ⁴	1,348 ⁵	N/A	149	77 ⁶	934 ⁷	235 ⁸	-	14,226 ⁹
Removed Intra-Database Duplicates	N/A	984	143	N/A	N/A	N/A	-	N/A
Content Selection (Eyeballing)	0	111	11	21	66	38	-	-
Selected Papers for Depth Reading	0	45	11	20	27	19	0	-

3.1.3.2 Screening by article type and subject headings

The Cochrane Library revealed a total of 19,728 relevant articles; the search was then limited to Cochrane reviews, and excluded other reviews, trials, methods studies, technology assessments, economic evaluations and Cochrane groups as they could not yield methodologically relevant SRR (e.g. qualitative). The search conducted on the first week of August 2015 revealed 1,348 SRR none of which were relevant to the topic of interest. The interface did not allow screening for Systematic Research Reviews published in peer-reviewed journals or in English language only.

The Ovid database was also searched on the first week of August 2015 and the search yielded 1,316 relevant articles, of which only 984 were retained after accounting for language limits, peer-reviewed journals and intra-database duplicates.

The ProQuest Health and Medicine database search was conducted on the second week of August 2015 and yielded 187 relevant articles. From this count only 143 articles were kept after accounting for language limits, topic exclusion (cancer and diabetes), peer-reviewed journals and intra-database duplicates.

The CINAHL database was searched on the second week of August and 95 hits resulted from the list of combined key terms. Only 77 were retained after exerting the relevant language,

² This database was not searched after seeing the extensive number of hits that is why no numbers are found in the bottom rows.

³ N/A: Not Available.

⁴ Excluded reviews, cancer and diabetes topics.

⁵ Included Cochrane Reviews, Excluded Other Reviews, Trials, Methods Studies, Technology Assessments, Economic Evaluations and Cochrane Groups.

⁶ Excluded diabetic patients, diabetic foot and Irritable Bowel Syndrome (IBS).

⁷ Included Articles only from Social Sciences and Arts Humanities and excluded those from Science Technology.

⁸ Filtered by only journal articles and human participants.

⁹ Filtered by field Medicine, Nursing, Psychology, Social Sciences, Health Professions and Arts & Humanities - only journal articles.

type, and content limitations. Articles about diabetic patients, diabetic foot, and Irritable Bowel Syndrome (IBS) headings were excluded.

Web of Science database was scoped on the third week of August 2015 and yielded 8,735 relevant articles. The count was narrowed to 934 after language selection and limitations to “Journal Articles” in “Social Science and Humanities”; the “Science and Technology” heading was excluded.

The PubMed Database was scoped on the second week of September 2015 and the hit count was 271. The total count retained after filtering for language, and articles with human subjects only was 235.

The last two databases, PopLine and Scopus were searched on the last week of August and September 2015 respectively. PopLine yielded zero hits and Scopus had to be excluded from the search as the returned hit search was of 14,226 relevant articles. The hit search number was not realistically manageable to scope within the limited timeframe set to conduct the SRR.

3.1.3.3 Screening by content

All five databases with hit results were scoped by content to determine which articles addressed topics relevant to mothers with IBD. The screening occurred in two rounds and took about two months to be completed.

The first round consisted of eyeballing both titles and abstracts to exclude as many irrelevant articles as possible (see last two rows of Table 2). Abstracts including IBD in conjunction with other disorders such as IBS, cancers, diabetes, arthritis or other bleeding disorders were excluded. Having multiple diseases assessed simultaneously draws the attention away from the uniqueness of each disease. Although some diseases may overlap in symptoms or in the ability to debilitate individuals from their autonomy, one cannot assume that cancer and IBD have similar consequences on women and thus the subjective experience of each illness ought to be addressed separately. Moreover, abstracts discussing children or adolescents with IBD and those relevant to chronic illness in general were excluded. Lastly, abstracts indicating the sole use of quantitative methods were excluded. When I could not clearly pinpoint the sample used, the relevance of the findings, and/or the method of analysis, a conservative approach was carried and the articles were retained for more in-depth reading. The last row of Table 2 indicated the number of remaining articles that were explored in more depth in each database.

The second round of scoping is detailed in Table 3 and it consisted of careful reading of the articles to determine their relevance by content. The full text version of some articles was not found through the Leeds University Library access. In these instances, I systematically attempted to retrieve the article through the following steps: First, by contacting my supervisors (Professor Anna Madill and Dr Peter Branney) to see whether they would have privileged access to other institutional journals' subscriptions. Second, by emailing the authors of the article to see whether they would agree to send the full text. Third, when steps 1 and 2 were

unsuccessful after a week of emailing the authors, I ordered the article through interlibrary loans.

Table 3 *SRR Final Inclusion and Exclusion Selection (Round 2)*

Databases	Ovid	ProQuest Health & Medicine	CIN AHL	Web of Science	PubMed
Selected Papers Reading	45	11	20	27	19
Full-Articles Unavailable at Leeds	-4	0	-2	-5	-4
Found via Other Institutional Access	0	0	+1	+3	+3
Found by Emailing Authors	0	0	0	+2	+1
Interlibrary loans	+4	0	+1	0	0
Remaining Articles	45	11	20	27	19
Excluded Papers					
IBD but Not Pertinent to Motherhood Experience ¹⁰	-8	-4	-4	-12	-8
Not Selective or Specific to IBD Sample	-12	-3	-7	-3	-4
Relevant to Children with IBD	-3	0	-1	-1	0
Quantitative Methodology	-7	-4	-2	-1	-1
Reviews, Policies, Guidelines, or Conference Abstracts	-7	0	-2	-3	-1
Full Text is not in English	-2	0	0	0	-1
Retained Papers	8	0	4	7	5
Added Articles from Reference List and 'Cited In' Scoping	+7	0	+1	+1	+1
Removed Duplicates Across Databases	-1	0	-2	-3	-4
Removed Numerical Content Analysis	-8	0	-1	0	-2
Removed for Not Specifying Illness (e.g. ostmates only)	-3	0	0	-1	0
Not Specific to Mothers but Family in General	-1	0	-1	0	0
Total Included	2	0	1	4	0

The details of the exclusion and retention of the remaining articles are provided in Table 3 and will not be described in text. A thorough reading of reference lists of the selected articles, and all articles citing them, led to the addition of ten articles. However, upon further in-depth reading only two pertinent to my topic were retained (Kimura & Ohmori, 2015; Sammut et al., 2015). In Sammut et al. (2015), the results could not be separated by sex and only three quotes in the findings were indicative of the experience of mothers with IBD thus the article was not retained. Kimura and Ohmori's (2015) study was deemed pertinent to this SRR and was

¹⁰ The articles addressed topics pertaining to fathers with IBD, or surgical and other treatment focus.

included in the final count. No grey literature search was conducted as it is deemed to be irrelevant to the nature of the research question and only published research would have gone through a peer-review process. Seven articles were retained, however the inclusion of some of them warrants some explanations as described below in section 3.1.3.5 (Brief summary of articles included in the SRR).

3.1.3.4 Rigour assessment

All seven articles were assessed for rigour as a last measure of screening. The Critical Appraisal Skill Programme (CASP, 2013) is a checklist tool aimed at evaluating the research quality and rigour. It identifies a score from 0 to 10 with higher scores indicative of better quality articles. I used the CASP checklist and found that all seven articles varied between a score of 7 and 10 out of 10 (See Table 4 All the articles had appropriate methodologies and rigorous findings which contributed to the understanding of IBD and motherhood. Hence, the checklist showed that all articles were of good to excellent quality, which warranted their inclusion. All six articles which failed to receive a perfect score did not tackle the relationship between the researcher and the participants. One article (Liss & Sharma, 1970) had no mention of ethical approval. Two articles (Liss & Sharma, 1970; Dudley-Brown, 1996) did not state the particular strategy of data recruitment. Lastly, Cooper et al., (2011) failed to clearly state the aim of their study. These limitations are linked to the transparency of the authors in reporting the details of the procedure. The strict wording count in journal articles could be a reason for these omissions. Only I undertook the scoring, but with continual discussion with my supervisor, so am confident that it is of strong consistency over the seven papers (See Appendix C for a detailed breakdown of CASP scoring of all seven articles).

3.1.3.5 Brief summary of articles included in the SRR

In the Ovid Database two articles were retained; the first was by Mukherjee, Sloper, and Turnbull (2002a) who detailed the lived experience of mothers (N= 19), and some fathers (N= 4) who have IBD. The article was retained as it provided sufficient insight into the lived experience of mothers and the authors even stated that “a small number of fathers participated in the study (...) it would be unwise to draw conclusions at this stage (regarding fathers)” (p. 361). The second article was a case study by Liss and Sharma (1970) recounting the lived experience of a 36-year-old woman suffering from UC. The account reflected interviews with her mother, maternal grandparents, and husband. Only results pertinent to the research question were used.

In the CINAHL Database a case report tapped into the experience of a 35-year-old mother experiencing bowel symptoms and later receiving diagnosis of UC during her pregnancy (Cooper, Collier, James, & Hawkey, 2011).

In the Web of Science Database four articles were retained. The first by Dudley-Brown (1996) described the lived experience of three patients with IBD, two men and one woman. The results were segregated by participant and those involving female participants were retained in

the analysis. The second article by Lewis, Konda, and Rubin (2009) detailed the results from focus groups amongst men and women with IBD as well as separate focus groups including their first degree relatives regarding their opinions about genetic testing for IBD. Although the results are not segregated by sex, the article was retained because IBD transmission is not particular to the sex of the parent so that the input of any parent would warrant inclusion and provide insights about family decision planning and lived experience. The third article by Mukherjee, Sloper, and Lewin (2002b) conveyed the meaning of parental illness in their children. This article was retained as it was deemed to shed light on the lived experience of mothers with IBD who often wonder about the impact of their illness and disability on their children. In this article 20 out of 23 children interviewed reported having an ill mother with IBD. The ratio of mothers to fathers was considered large enough to warrant inclusion and relevance to the research question. The fourth article by Kimura and Ohmori (2015) explores the challenges and coping strategies used amongst eight mums with IBD. The authors used semi-structured interviews to depict the experience of child rearing and pregnancy amongst women in Tokyo.

3.1.3.6 Combined characteristics of the articles

A summary¹¹ of the selected articles can be found in Table 4. Articles are listed chronologically from oldest to most recent publication date. This table also lists the aim of each article, research question, research design and analysis used, theoretical framework (when applicable), sampling method, sample characteristics, CASP scores as well as the country where the research was conducted.

In sum, participants sample size varied from 1 (Cooper et al., 2011) to 48 (Lewis et al., 2009). Time lived with the illness varied from 13 months to 36 years; women included had more often a diagnosis of CD than UC although the exact number cannot be determined since some studies combined parents' description of IBD type. The treatments received were also seldom mentioned in detail and their specific impact on the lived experience was not explored. The interviews varied between one-to-one to focus groups with one study using a combination of the two techniques (Mukherjee et al., 2002a). Only one study had a theoretical framework of personal control theory (Cooper et al., 2011) and one other hinting at a psychoanalytical perspective although it was not explicitly stated as such (Liss & Sharma, 1970). For the most part the aims of the studies were to look at the lived experiences, needs, challenges and coping mechanisms of mothers with IBD. One study informed on the challenges of mothers with IBD from the perspective of their children (Mukherjee et al., 2002b). The CASP scores varied between 7 and 10 with an average of $M= 8.57$; and three studies were conducted in the UK, two

¹¹ A detailed elaboration of the synthesis procedure and analysis method used can be found in section 3.3. The summary presented in section 3.1.3.5 is merely a content summary of the data, methods, and theoretical frameworks used; it does not represent the synthesised findings of this SRR.

in East Asian (Hong Kong and Japan) and one in the USA. Lastly, it is worth noting that four out of seven of the selected articles were published in nursing peer-reviewed journals.

Table 4 *Summary of the Findings*

Author(s) , Year	Aim	Findings relevant to RQ ¹	Research Design and Analysis	Theoretical Framework	Samplin g Techniq ue	Sample				CA SP	Country
						N	Sex, Disease and Age	Years lived with IBD diagnosis age	Treatment Received		
Liss and Sharma (1970)	The paper portrayed the precipitating factors and repetitive patterns of UC within and across several generations of the family of a woman with UC. It attempts to add to the understanding of the causes and consequences of UC.	Only results relevant to the experience of motherhood were recorded for the purposes of this SRR. Symptoms of UC seem to be precipitated by emotional tension between the couple and distancing from the participant's mother. The exacerbation and progressive deterioration of the illness promotes a close relationship and dependency with the participant's mother. The couple's dynamic is centred on the illness, the husband is portrayed as "wonderful" during times of flares but the relationships is soon contrasted	Case Study, face-to-face interviews, tape-recorded, data analysis not specified, nor was the type of interview schedule specified. No mention of where the interview was conducted.	None (Mention improving on past theories and examining as a psychosomatic illness by looking at mother-child relationship and multi-generational determinants – Implied psychoanalytical perspective)	Not specified	1 woman with UC (the study included 4 individuals: 3 Non-ill Related Family)	The participant had UC, age 36, white, married, mother of two sons (ages unspecified) Husband, 42 years old, Not affected by IBD Parents of woman: Mother 59 years old and Father 62 years old both unaffected by IBD	Symptoms started 12 years ago (age 24) and diagnosed was received 10 years ago (age 26)	Hospitalisation once a year for weeks or months at a time, and cortisone medication	7	UK

¹ RQ: Research Question

and described as
submissive,
“alcoholic”, and
abusive in times of
remission. There is a
reversal of the role of
the carer and sick
person. By becoming
a mother, the
participant felt a
profound shift of
attention from her
husband to her
children. This
prioritising was not
well-received and
made the husband
jealous of his
children. This pattern
seems to be
transferred across
generations; the
eldest child being
jealous of the
youngest one.
Similarly, another
transgenerational
pattern in the
dependence and
overreliance of
children on their
mother and the
subsequent rejection
of the mother who
wishes to see them
“grow-up”. Bowel
symptoms are
reported across the

Dudley-Brown (1996)	Described the lived experience of having UC in three adults	three depicted generations as a means to receive attention and promote dependency on the mother. Only results pertinent to the female participant were recorded for the purposes of this SRR. Distress was caused due to the unpredictable facets of IBD with regards to onset and duration of each episode. There is a constant fear of incontinence in public spaces, pushing the subject to always locate and stay in close vicinity of toilets, or restrict leaving home. The subject longed for a cure and return to a pre-illness state. She stated how IBD symptoms interfered with her family, social and professional life. UC's restriction on	Pilot Study using semi structured face-to-face audio-taped interviews. Transcriptions were analysed through a phenomenological and holistic approach. The authors did not specify which one but detailed that they used a coding memo system to form themes, looking at similarities and differences across accounts.	None	Not specified	1 woman with UC used (the study included 3 individuals, two others were men)	Woman with UC, 35 years old, married, mother of two daughters (6 and 10 years old) (The two other participants were men, had UC, were also married with children and were aged 30 and 58 years old)	8 to 10 years, for two participants including the 35-year-old woman. 1 year for the 58-year-old man. Female participant was thus diagnosed at about 26 years	Medication, type unspecified	8	Hong Kong * ²
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² In some instances, the place of recruitment was not mentioned (or multiple indistinct sites were used); only the country and town of the lead researcher was added and marked with an asterisk (*).

mobility and work agility. She found being home-bound to be the easy way out to control her symptoms. The overwhelming fear of incontinence forced her to wear adult diapers and resents leaving the house even in phases of remission. She feels guilty and ashamed to be missing out on activities and staying home all the time. This constant battle and struggle to regain control is exacerbated by the lack of understanding from friends and family as well as the dismissive attitude of her consultant for alternative complimentary treatment for UC. However, she was overall satisfied with the level of medical care received from her consultant. Any impact on the children was not mentioned.

60 Mukherjee et al. (2002a)	Identified the positive and negative impact of IBD on parents and their children.	As there were predominantly more mothers affected than fathers the results were retained. Parents experienced both difficulties to care for young ones when they were in the hospital as well as positive effects of being more attuned to children's needs than previous to the illness. Similarly, they perceived their children to be embarrassed by them. Several coping strategies were used to maintain parenting role, one of them being postponing having another child to better care for the current one. Lastly, support from services was pivotal in helping parents cope with their illness, particularly schools, social services and medical staff. Parents had very clear suggestions on how	Semi-structured interviews were tape-recorded or notes taken (focus groups – location not mentioned and one-to-one interviews at their homes). Use of Framework approach (Ritchie & Spencer 1994)	None	Purposive sampling	24 (19 women), cannot tell how many have UC or CD	19 mothers, 5 fathers, 14 parents CD; 8 UC; 1 IC ³ ; 1 proctitis. Aged between 26 and 54 with an average of 40 years. Their children aged between 1 and 22 years old	Lived with illness from 2 to 36 years - average of 15 years	14 had surgery with 7 having ileostomy. Some were on steroids (number not specified)	10	UK*
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³ IC: Indetermined Colitis, aka IBDu

Mukherjee et al. (2002b)	Provided insight into the experience of children with an ill parent (understanding, daily life and coping strategies)	<p>to improve services, which led to a list of recommendations to improve quality of life of parents with IBD.</p> <p>Only the qualitative analysis was selected from this mixed method study</p> <p>The sample was predominantly consisting of mothers with IBD; the results were thus retained as they shed light into the experience of ill mothers from their children's point of view. The children in this study were recruited from the previous study detailed here above (Mukherjee et al., 2002a)</p> <p>Children's perception and fear for parents varied according to expression and verbalisation of symptoms in parents. Not all children discussed the disease and some expressed negative effect of IBD regarding</p>	One to one basis interviews, semi-structured conducted at participants' home. Siblings interviewed together. Use of a tape-recorder and transcription of the interviews. The analysis was carried out using Framework Analysis (Ritchie & Spencer 1994)	None	Convenience Sampling	23 children, non-ill, 15 families, 3 of which were mono-parental	Unaffected relatives, 14 girls and 9 boys (6 to 20 years old), mean age 11.6 years; 20 of them had an ill mother 3 an ill father (age of parents can be estimated from the study above in Mukherjee et al. 2002) For 14 children the ill parent had CD, for 8 children the ill parent had UC, and for 1 child the parent had IC	Lived with illness from 1 to 36 years - average of 14 years	They mention hospitalisation, medication intake and homeopathic treatment. No specifics are given	9	UK*
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activity level. However, most expressed sadness for parents. Children adopted various strategies to help themselves and the ill parent including carrying out more house chores. Help from other adults close to the family was much needed.

Lewis et al. (2009)	Depicted the needs, challenges and preferences of individuals and their relatives around genetic testing for IBD.	Only the qualitative analysis was selected from this mixed method study Most patients and relatives agreed on performing genetic testing if it helped identify a better treatment or if it foresaw whether their children would develop IBD (prognostic, diagnostic and therapeutic purposes). Results of the tests would facilitate life choices for some, but all participants asserted it would not change	Independent focus groups for IBD and relatives. Open-ended questions, video and audio-recorded sessions. Transcripts were uploaded to Atlas.ti. Interviews were conducted in an outpatient clinic of a local university medical centre. Analysis was done through identifying similarities and differences	None	Convenience sampling	30 parents (18 unaffected FDR or spouses ⁴)	18 CD, 11 UC, 1 IC, 14 unaffected FDR, 4 spouses. IBD group: 16 women, 14 men (average age 39 years); Non-patients: 12 women and 6 men (average age 47 years)	Mean age at diagnosis 27.7 (SD=14.6), mean age of onset 26 years (SD= 14.9)	Not specified	9	USA
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⁴ FDR: First Degree Relative

		planning to have children; they would still become parents regardless of the outcome.	across the accounts of the different participants								
Cooper et al. (2011)	Described the uniqueness of having an onset and receiving a diagnosis of IBD during pregnancy	The challenges faced in getting diagnosed with IBD during pregnancy affected initial attachment to the baby. Participant expressed embarrassment in sharing IBD bowel symptoms with her husband as well as the burden of being dismissed and left untreated for her symptoms by medical staff.	Case Study, qualitative, one to one semi-structured interview. Analytical technique not specified in this study.	The previous study was interpreted in light of theories of personal control (Rotter, 1966; Bandura, 1977; Wallston et al, 1978) and addressed the impact of IBD on physical, psychological, social and environmental factors. There was no reference to a theoretical model used in this case study	Identified through a previous study by Cooper, Collier, James, and Hawkey (2010)–convenient sampling	1, UC	Woman, 35 years old, UC, 2 children (4 years and 8 months), married	Diagnosed for 13 months, had symptoms for a few months before diagnosis	Not mentioned	8	UK*
Kimura and Ohmori (2015)	Explored the challenges and coping experiences of women with IBD during pregnancy and child raising	Participants reported facing several challenges mainly in relation to their interaction with the medical staff. First, they were bothered to be under a high-risk management care closely monitored by their consultant and obstetrician. Second, participants were	Face-to-face semi-structured interviews at participants' homes. The interviews were tape-recorded. Inductive content analysis (Graneheim & Lundman, 2004) was used to explore the	None – Exploratory analysis	Purposive sampling	8 women	5 CD, 3 UC. Ages between 27 and 41, mean age of 34 years. All married 4 women had 1 child, 3 women had 2 and 1 had 3 children	Age at diagnosis varied from 18 to 35, the time lived with IBD between 4 and 6 years	3 women with CD used Biological preparation or mesalazine during the transition 2 women with CD resumed their	9	Japan

challenged by their bowel symptoms which was burdensome physically, mentally as well as socially. Lastly, they faced the hurdle of absence of information around pregnancy and IBD, some reported being unable to choose whether to breastfeed or bottle feed. The results also indicated that the participants made use of several coping mechanisms such as receiving help from social support systems and maintaining self-care to better deal with the transition.

similarities and differences in the accounts

Children's ages varied between 7 months and 7 years. There is no mention of marital status although some excerpts indicate some women had a husband

treatment due to flare postpartum (1 of them has enterectomy)
3 women with UC used mesalazine and predonine during the transition.

3.2 Analytical Approach

Before tackling the result section, it is worth noting that some of the synthesised themes in the analysis depicted below resonate with some content found in the seven articles. However, the conceptual organisation and explanation of each theme and how it came to be represented is elaborated on in the next paragraph.

In order to synthesise the results I used a meta-synthesis approach as described by Thomas and Harden (2008). In order to ensure transparency of the technique, since the word meta-synthesis could describe different approaches (Paterson et al., 2009), I recorded in a research diary the steps taken to synthesise the findings. I can cluster them in a four-step approach; the first step involved reading and extracting from the findings of the seven articles experiences and results relevant to the research question ‘What is the lived experience of women who transition to motherhood within the context of IBD?’ and later entering these extracts in an Excel sheet. Each article was represented in a separate row. In the second step, I clustered together those excerpts relating to a similar idea and labelled these subthemes with preliminary headings. The subheadings helped in generating broader analytical themes giving insight into the experiences of mothers across the selected articles. In the third and fourth steps, themes depicting a unifying cluster were meshed together and a title was given to that cluster to better capture the overarching meaning. In order to ensure a good match between the names of the clusters, themes, and subthemes, I read and reread the content of each of these categories and refined the labels and headings provided to ensure a faithful inductive analysis. Having the sub-themes, themes, and clusters with their content laid out in an Excel sheet allowed comparative analysis across the articles and ensured cohesiveness of the synthesis. Furthermore, the epistemological and ontological stance adopted in this systematic review, is one of “critical realism” as explained by Madill and Gough (2008), where I accept that the account of motherhood and IBD represents reality for the participants in each of the articles; however, I also accept that this reality is influenced by context, culture, and other socio-political factors (Madill & Gough, 2008).

3.3 Results

As a result of this inductive thematic synthesis, three levels of analytical themes were formed. At the highest level, three clusters were formed labelled *burden on the family*, *coping* and *perception and integration*. Each of these clusters depicted several themes and subthemes relating to the experiences of mothers with IBD (See Table 5 *SRR Clusters, Themes, and*

Subthemes). The subsequent paragraph will define each cluster, theme and subtheme with illustrative quotes¹ from the articles.

Table 5 *SRR Clusters, Themes, and Subthemes*

Cluster 1. Burden on the Family	
Theme 1. Inability to Fulfil Mother Role	Subthemes Caring nurturing & feeding Attending family events
Theme 2. Fears and Concerns	Subthemes Incontinence and drugs impact Contaminating cycle of fear
Theme 3. Emotional Load	Subthemes Guilt and shame Feeling vulnerable Oscillating mood
Cluster 2. Coping	
Theme 1. Negotiating Control	Subthemes Practical strategies Toilet and housebound Adjusting to new normality
Theme 2. Adjustments to family life	Subthemes Close monitoring Protecting family interests Maturation
Theme 3. Support and Communication	Subthemes Need for Support Tighter bonds Selective Sharing
Cluster 3. Perception and Integration	
Theme 1. My IBD	Subthemes Conceptualisation Triggers Vivid awareness
Theme 2. Hidden Illness	Subthemes Advocacy for validation Disparity of knowledge Ambivalence towards healthcare professionals
Theme 3. Mums' Needs	Subthemes Holistic approach Centralisation of resources

3.3.1 Cluster 1: Burden on family

IBD placed a significant weight and burden on mothers and their family. The illness disabled them from caring, nurturing and feeding their babies. Participants reported that IBD made them miss out on family time and attending family events. Mothers also expressed their fears and concerns, notably that foetal development could be affected by medication intake or that IBD might be transmitted to their young ones. This cycle of fear is contagious and impacts the entire

¹ For the purpose of clarity and conciseness irrelevant and long passages were shortened using (...). When the pronoun or description was not clear [] were used for precision. If a quote already contained any of the two punctuation marks it was adapted to match the stated legend.

nuclear family, from partners to children who tend to project their frustration and anger in their own way. In addition, the emotional load of their lived experience is depicted in various ways from feelings of guilt and shame as well as vulnerability to oscillating moods due to treatment and illness course.

I have placed a contribution table for each cluster to better visualise which articles contributed to which themes and subthemes within each cluster. As an example, in Table 6 *Contribution of the Cluster 'Burden on the Family'*, one can see that most studies are well represented within most themes and subthemes. These tables (Table 6, Table 7, Table 8) reflect how the analysis developed circles around the content of all seven articles and portrayed the experience of mothers with IBD across all contexts (rather than around the specific aim and results of each individual study).

Table 6 *Contribution of the Cluster 'Burden on the Family'*

<u>Cluster 1</u> <u>Themes</u>	Burden on the Family						
	Inability to Fulfil Mother Role		Fears and Concerns		Emotional Load		
<u>Subthemes</u>	Caring nurturing & feeding	Attending family events	Incontinence and drugs impact	Contaminating cycle of fear	Guilt & shame	Feeling vulnerable	Oscillating mood
Author(s), (Year)							
Liss & Sharma (1970)	✓			✓		✓	✓
Dudley-Brown (1996)	✓	✓	✓		✓	✓	✓
Mukherjee et al. (2002a)	✓	✓	✓	✓	✓	✓	✓
Mukherjee et al. (2002b)	✓	✓		✓	✓	✓	✓
Lewis et al. (2009)				✓	✓	✓	
Cooper et al. (2011)	✓		✓	✓	✓	✓	
Kimura & Ohmori (2015)	✓	✓	✓	✓	✓	✓	✓

3.3.1.1 Theme 1: Inability to fulfil mother role

3.3.1.1.1 Caring, nurturing and feeding

IBD symptoms interfered with mothers' ability to care for their children such as performing daily household tasks like cooking and cleaning as noticed by their children. One mum expressed her sadness at how IBD and its treatment were preventing her from caring for her newborn and another stated that her initial attachment to her newborn was impeded by the delay in receiving diagnosis during pregnancy.

In some families, tasks [household tasks] were simply left for the ill parent to do when recovered (...) and in a few families, young people were looked after by other people while their parent was ill (Mukherjee et al., 2002a, p. 482)²

IBD not only impeded mothers' ability to care for their young ones but also interfered with the ability to feed and soothe their baby. At times they were forced to leave them in the company of strangers when rushing to the toilet in a mall.

Incontinence and diarrhoea 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 (Mukherjee et al., 2002a, p. 358)

Furthermore, flaring in the early days postpartum often imposed interruption of breastfeeding and early weaning if the child refused bottle feeding whilst the mother was hospitalised. One woman said breastfeeding makes her "feel like a mother" (Participant quoted in Kimura & Ohmori, 2015, p. 41), and shared her wish to be like all her other mum-friends who have breastfed their babies. One would assume that the inability to do so would have hindered her experience of motherhood.

Contrastingly, the inability to demonstrate affection, care and love towards one's child(ren) was perceived by Liss and Sharma (1970) to be a generationally transcended³ pattern which could be at the root of IBD, rather than a consequence of the illness as seen in the other articles. Flare and onset of UC were brought upon and exacerbated when the UC patient was separated emotionally or geographically (physically) from her mother.

Mrs Muller [patient's mother] could not accept her daughter's [UC participant] cries for love (...) one could see this pattern repeated by the patient when she stated with a smile that her seven-month hospitalisation and separation from home is helping her sons mature and get over being "spoiled" by her (Liss & Sharma, 1970, p.473-4)

Once UC flares the patient returned to a dependent state which made her unable to attend to her children and pushed her own mother to help her care for them. The mother-child symbiotic relationship was thus restored and maintained through UC.

3.3.1.1.2 Attending family events

The need to rush to the toilet kept mothers from walking children to and from school and sometimes from supporting them by attending to their school events and activities.

It makes a difference to everything. If there are toilets it's not too bad, but she can't eat out, she can't go out, she can't go on holidays, she runs to the toilet all day and she's just really tired. I can't remember going out for a meal with my Mum or Dad. I'd like to take her to the cinema, we never go to the cinema . . . she

2 To distinguish between quotes from participants cited in the study, and the authors voice, I will specify "participant quoted" at the end of the annotation.

3 Mrs Muller [the patient's mother] was depicted as not demonstrating much affection towards her daughter, and similarly, the patient in this study, is reporting not being affectionate with her two boys.

did go to school sports day when I was younger, she could do that (Child of IBD parent quoted in Mukherjee et al., 2002b, p. 482)

Both parents, as well as their children, expressed the burden of these restrictions. Not being able to muster the energy to attend or promote family activities severely handicapped mothers' with IBD in their parental role.

Some days you're in that much pain, and you're going to the toilet that frequently, you can't get out the bathroom door let alone to the front door and you hear 'I want to go to the park, I want to go swimming, why can't we go here, I want to go there' (Participant quoted in Mukherjee et al., 2002a, p. 359)

The pains and chronic diarrhoea that accompanied IBD severely hindered, in times of flare, the ability of a mother to interact with her children and put a damp on family holidays.

We went to Williamsburg at Christmas (...) and all of a sudden I get a cramp, and go running off to the bathroom (...) I couldn't go far from it (...) I just sort of walked around the bathroom while my husband took the kids (...) I feel that I miss things because ... and that's the part I hate about it [the disease] (Participant quoted in Dudley-Brown, 1996, p. 62)

Lastly, being in hospital during pregnancy made one mother with IBD miss out on maternity classes, which made her feel on a lower par relative to healthy mothers; arguably during gestation IBD also placed a damp on mother-child time.

3.3.1.2 Theme 2: Fears and concerns

3.3.1.2.1 Incontinence and drugs impact

Although some women mentioned maintaining regular medication intake to limit any adverse effect of IBD on the foetal growth, ingestion of pills in and of itself was a source of concern as were the emergency admissions to hospitals due to IBD flares during gestation.

I searched for the effects of Infliximab and painkillers on the internet. But I couldn't find accurate information on the fetus and breastfeeding, so I was afraid of the effects (Participant quoted in Kimura & Ohmori, 2015, p. 41)

Even before knowing the diagnosis, the excessive bleeding and symptoms caused fear to a participant's husband as well as medical staff regarding the foetus' life.

'It got to the point where I knew I wasn't putting weight on because I was going to the toilet that much (...) Then I started bleeding almost constantly. I rang my husband who said, 'is it the baby?' (...) [Participant went to the hospital, and] the doctor said, 'we're going to do a scan first to make sure the baby's alive', so they did that and the result came back as fine (Participant quoted in Cooper et al., 2011, p. 30; 32)

Another concern was the worry that a flare might start unexpectedly. The unpredictable aspect of the illness caused fear and incapacitates mothers from carrying on in their daily lives: going to work, attending to events, or going shopping. One participant shared her worry about visiting

her clients at their home particularly due to the long car rides. Even on days of remission, the worry of a potential recurrence of the symptoms made them anxious.

I am not comfortable being out in public. It (the symptoms) tends to be pretty constant when I am not in remission. I don't like going out shopping, now even though I'm in remission. It still makes me nervous (Participant quoted in Dudley-Brown, 1996, p. 62)

3.3.1.2.2 Contaminating cycle of fear

The fear of flares spread throughout the family unit. Mothers notice the anxiety and frustration caused by the illness on their children. The fear of not seeing the parent (or partner) return from the hospital and recover, as well as the anger and attention-seeking behaviour demonstrated by children and sometimes the spouse when their mother became ill made dealing with the illness's symptoms even harder.

If I'm not well then he [spouse] gets particularly anxious and it just goes out into the family and she [daughter] is a very sensitive girl and she just picks it up on me being ill. If you made a graph of it she would be directly proportionally anxious and stroppy and attention-seeking and just generally difficult, which makes the whole thing so much more difficult. (Participant quoted in Mukherjee et al., 2002a, p. 359)

It seemed as if mothers with IBD and their family dealt with questions and fears of mortality vividly. Also, prior to receiving a diagnosis there was an automatic assumption of the worst-case scenario that they were going to die.

I was thinking I've probably got bowel cancer and everybody's just telling me I'm an overly hormonal, neurotic mum. I just thought cancer, because they're the symptoms and I had all of them (Participant quoted in Cooper et al. 2011, p. 32)

Furthermore, the awareness that IBD could be hereditary appeared to weigh heavy on mothers' shoulders and never really left them worry-free; particularly when children experienced bowel disruptions or got diagnosed with a different autoimmune disease. The fear that they might pass on the illness hovered above their heads similarly to Damocles' sword⁴.

It's not going to prevent me from having children one day, it's just a thought [but] I don't think anybody wants to give their child anything (Participant quoted in Lewis et al., 2009, p. 498)

Some participants reported refraining recommending a genetic test to determine IBD, if one were to be made available, to their family due to the terror that would follow a positive test result.

⁴In Greek mythology, Damocles was forced to sit beneath a sword suspended by a single hair to emphasize the instability of a king's fortunes (Cambridgedictionary, 2018). The idiom refers here to an imminent and constant threat hovering over an individual.

Many expressed concern that the results of genetic testing for IBD would create stress among patients and family members, especially if the result is positive in an otherwise asymptomatic individual (Lewis et al., 2009, p. 498)

Lastly, the fear of inheritance was transmitted and older children cogitated on the eventuality that they might develop IBD.

One young person, who had a parent and a grandparent with IBD, spoke about concerns that she and her children might also develop the condition (Mukherjee et al. 2002b, p. 482)

3.3.1.3 Theme 3: Emotional load

3.3.1.3.1 Guilt and shame

Embarrassment and shame of (potentially) having an accident in public led mothers to confine themselves at home and hence sometimes force the rest of the family to housebound activities. Mothers reported that children could solely invite friends over, as it was easier than to take the children out to socialise. Also, suffering from incontinence meant that IBD mothers had to delegate their child whilst rushing to the loo, sometimes to strangers, which caused them great distress.

I did walk into town knowing there's a disabled loo. I'd get to them and then I had to give the baby to a complete stranger whilst I made it to the toilet, all the while thinking, 'Will I come back to find the baby there?' And they're just looking at me, you know, 'mad woman'. And I had nowhere to go to talk about this...I just couldn't deal with it (Participant quoted in Mukherjee et al., 2002a, p. 359)

In return children expressed similar feelings of guilt partly when mothers' symptoms returned for taking part in activities with them. Furthermore, some children blamed their ill-parent for not managing to do more with them and some were embarrassed to talk to their parents about IBD. One mother even got blamed by her gastroenterologist for wanting to get pregnant.

I don't want to mention, but the doctor said to me "Don't you care about your husband and children and the problems they'll have because of your IBD? (Participant quoted in Kimura & Ohmori, 2015, p. 41)

Furthermore, one woman expressed feeling ashamed and embarrassed from passing blood rectally and hesitating to show the symptoms to her partner until it was too uncontrollable and he had to call an ambulance. Another person related how she had to use a potty, in a parking lot, in front of work colleagues that she did not know very well. Also, some mothers mentioned using their children to pretext the presence of displeasing smells resulting from IBD.

Access to toilets was easier with a young child, and parents were able to blame embarrassing smells on babies (Participant quoted in Mukherjee et al. 2002a, p. 360)

Lastly mothers who had passed on the illness to their offspring reported vividly their self-blame feelings as seen in the following quote:

I feel a little bit guilty. My son was diagnosed [with IBD] and my daughter was just diagnosed with autoimmune. So part of me feels kind of guilty for passing this on. I'm feeling responsible basically (Participant quoted in Lewis et al., 2009, p. 498)

3.3.1.3.2 Feeling vulnerable

IBD made mothers feel vulnerable and dependent upon other people's support. In times of flare and hospitalisation some women left their children in the care of their partners or mothers (-in-law); when family was not available social services were called which caused a great deal of distress to the ill parent. In addition, IBD in and of itself left women feeling embarrassed by their condition (i.e., carrying a potty around or wearing adult diapers).

I had never used Depends, but ... we're at the windmill and all of a sudden I get a cramp, I go running off to the bathroom, and I couldn't make it (Participant quoted in Dudley-Brown, 1996, p. 62)

Moreover, some participants mentioned that if a genetic test were to identify who would get IBD it would place them in a weak position relatively to insurance companies and employers; and emphasised that these tests should be kept confidential. They also stated it would single them out and stigmatise them even though they may be asymptomatic.

Overall, the illness left mothers defenceless in the hands of others, particularly medical experts, leaving some to feel completely powerless and subdued to test results. The feelings of dependence and vulnerability went further as some participants described they were unable to maintain a job and were thus physically, financially, and psychologically dependent on others.

These patients were all at the peak of their careers and social and family life. They financially and psychologically needed and wanted to work and described how symptoms frequently made them unable to achieve an adequate work environment (Dudley-Brown, 1996, p. 62)

A major part of being vulnerable and reliant on others entailed the acceptance of one's limit and reaching out for help. This was particularly difficult for some women, as they "did not want to impose on people".

One parent reflecting on her initial attempts to manage by herself said: Don't try to manage on your own...ask for help. You do have to ask, sometimes you feel belittled, but it's a good thing to ask for help (Participant quoted in Mukherjee et al. 2002a, p. 360)

3.3.1.3.3 Oscillating mood

Strong feelings of hate and despair due to IBD symptoms were shared by participants and their family members. The frustration, anger, hate and sometime depression were experienced as a result of the illness, which weighed heavily on the family in general. Three children spoke of feelings of anger, describing times when they had thrown things around their room or screamed and shouted in front of others. This was caused by dwelling on what it would be like if the parent died, having to stay indoors to keep the parent company, and restrictions placed on the

family's diet because of the parent's health. Furthermore, some mothers expressed being irritable and having mood swings as a result of the illness's treatment. Steroids in particular were reported to cause labile moods adding burden on the family.

I was depressed. I was worried about whether I could take care of my baby (Participant quoted in Kimura & Ohmori, 2015, p. 40)

On the other hand, one mother expressed how IBD squashed tension in her marriage during times of flare, but this truce soon faded as she recovered and went into remission.

He's been good while I've been ill (...) but once I get back home, he forgets he'll start again. He realises the drinking upsets me. Actually, it's not very nice to have a drunken husband. They don't treat you very well. But he's always marvelous when I'm ill. He's a wonderful husband when I'm ill. As soon as I'm better, he starts drinking once again, and I'm the slave in the house (Participant quoted in Liss & Sharma, 1970, p. 466)

3.3.2 Cluster 2: Coping

Participants described their struggles and attempts to manage IBD through the use of various 'practical strategies' such as diet, medication, and/or even surgery. When treatment would not work, participants battled the symptoms by confining themselves in or around the house/toilets. Some had to 'adjust to the new normality' by accepting their illness, taking perspective, and adopting a wait-and-see approach. 'Adjustments to their family life' were also made, for example, by monitoring closely the bowel movements of their children in the hope to detect IBD if it appeared early. In order to 'protect the overall family interests,' mothers altered their ideal desired number of children and prioritised the needs of the family over their own. A level of 'maturation' was perceived in children of IBD parents, who became more independent and caring of their ill parent as well as others. Lastly, participants coped through 'support and communication' from/with families and friends, which brought them closer and formed 'tighter bonds' within their networks. However, IBD was mostly concealed and only shared with a trusted few, often a family member or a close friend.

Table 7 Contribution of the Cluster 'Coping'

Cluster 2		Coping							
Themes	Negotiating Control			Adjustments to family life			Support and Communication		
Subthemes	Practical strategies	Toilet & household	Adjusting to new normality	Clothing	Protecting family interests	Maturation	Need for support	Tighter bonds	Selective Sharing
Author(s), Year									
Liss & Sharma (1970)	✓			✓	✓	✓	✓	✓	
Dudley-Brown (1996)	✓	✓	✓					✓	✓
Mukherjee et al. (2002a)	✓	✓	✓	✓	✓	✓	✓	✓	✓
Mukherjee et al. (2002b)	✓	✓	✓		✓	✓	✓	✓	✓
Lewis et al. (2009)			✓	✓	✓				✓
Cooper et al. (2011)		✓					✓		
Kimura & Ohmori (2015)	✓	✓	✓	✓	✓		✓		✓

3.3.2.1 Theme 1: Negotiating control

3.3.2.1.1 Practical strategies

Amongst the strategies used by mothers to restore control over their daily life were dieting by eliminating certain food known to cause bowel distress. Others took their medication at the first signs of IBD recurrence, arranged for their treatment to be taken at home to stay with their children, took pills before long car rides, or even tried complementary homeopathic treatments. In addition, some participants had surgically removed their bowel to control the symptoms and endless daily interruptions. Some participants had their treatments customised to be taken at home and one even wore adult diapers (referenced by the brand name 'depends') to leave the house without the worry of incontinence.

Oily or cold foods affect my abdominal condition, especially ice cream. So I don't eat it. I have dairy products with low fat (Participant quoted in Kimura & Ohmori, 2015, p. 42)

It was believed that stress acted as a trigger fuelling IBD. Thus avoiding arguments with partner, or running a healthy lifestyle with sufficient hours of sleep and good physical hygiene was deemed to be effective in coping with IBD.

Children of ill parents also played a part in coping with IBD by mainly performing house chores and staying home to look over their sick parent. They made snacks, distracted parents through conversation and demonstrated love and affection.

3.3.2.1.2 Toilet and housebound

In those instances where the treatments, and coping strategies were not sufficient to keep IBD at bay, mothers stayed at home and confined themselves (and the family) to activities in or around the house to avoid embarrassing themselves in public by having an accident.

I noticed trails of blood in the bed when I got up in the morning. Eventually one morning I woke up and just couldn't stop going to the toilet. I literally would wipe myself, get up and then run back again (Participant quoted in Cooper et al., 2011, p. 30)

Some mothers even fed their babies over the toilet to cope with both the demands of the child and their constant bowel symptoms.

The worst thing about this disease is that I have little time from when my stomach starts hurting to get to a restroom. So, I tried to only go to places where I could find a toilet easily (Participant quoted in Kimura & Ohmori, 2015, p. 40)

3.3.2.1.3 Adjusting to new normality

In their seemingly cyclical battle to restore or negotiate control, participants attempted to regain pre-illness normalcy. Others took some perspective on what it meant to have IBD; they tried to act as if they were healthy, adopted a wait-and-see approach, tried being more relaxed on health matters as well as using humour and positive thinking to cope.

They also tried to think positively about their situation and used jokes about the condition to diffuse tension in the family (Mukherjee et al. 2002a, p. 360)

To adjust even further to the new reality some participants with IBD fantasised about the future possibility to use genetic testing to decide which treatment would be more suited for them, and even possibly detecting IBD before it started.

I really think it would be nice if you could tell [through genetic testing] what form of treatment is going to work for people and you can tell (...) what their percentage possibly would be, whether they have certain environmental factors that make them more high risk or whatever (Participant quoted in Lewis et al. 2009, p. 498)

Coping and adjusting to the new way of life was well received and perceived by children when the parent's illness did not interfere with their everyday life.

Another [daughter] explained that the illness was just a normal feature of everyday life to her (...) [and] many stated that their family was managing well (Mukherjee et al. 2002b, p. 482)

It was noted for those who had a natural course of pregnancy that IBD was almost forgotten, and they led a normal life just like any regular healthy mother.

3.3.2.2 Theme 2: Adjustments to family life

3.3.2.2.1 Close monitoring

Parents who lived with the knowledge that IBD could be passed on to their children and mothers kept a close eye on the toilet habits of their young ones. The fear that an ordinary diarrhoea could be the beginning of IBD pushed mothers to monitor with an ‘eye of hawk’ every bowel movement of their children.

Furthermore, participants facing children acting out, in reaction to their illness, had to strike a balance between children’s indigestion, attention-seeking behaviours, and their personal fears of IBD.

Two [mothers with IBD] had children who had frequent bouts of diarrhoea, and they were uncertain about how to respond, and unsure as to whether their child was genuinely ill or simply copying them (Mukherjee et al., 2002a, p. 359)

Furthermore, anger and irritability were also enacted in children. For example, one mother reported how her eldest child sought attention by filling up his nappy when she was feeding his younger sibling.

The passing on from generation to generation of toilet-associated behavior patterns to express anger is unhappily exemplified in the patient's baby, Paul, putting his younger brother's bottle into the toilet (Liss & Sharma, 1970, p. 474)

One of the participants who expressed resistance and concern over the use of genetic testing: said: “*I feel it could create fear. Like everybody would worry if they find out they have the gene and then you’re going to be like watching the kids*” (Participant quoted in Lewis et al., 2009, p. 498).

In one study this close monitoring was depicted as early as during gestation, when gastroenterologist, obstetrician and patient were brought together to keep a close eye on the foetus development through regular scans.

3.3.2.2.2 Protecting family interests

Some participants stated that they would not let IBD change their family planning decisions; even if they could hypothetically have access to a genetic testing that would determine the likelihood of their offspring developing IBD. They rationalised that being forewarned is a means of being forearmed and they would be in the best position to provide and share information with their children about the illness if it occurred.

Others did form a family despite IBD; however, they limited having more than one child or spaced the time between the first and the second to better cope with the burden of IBD and caring for young ones.

Furthermore, mothers stated prioritising the family and carrying on despite the burden and interference of IBD. The children’s needs took precedence over the mothers’ individual needs.

You've just to get on with it, you have to. I mean even if it means, you know, I mean I've like changed nappies while I've been sat on the toilet, you know, while I'm busy the bairn still needs taking care of and when he's toddling about. I mean he was 18 months when the second baby came along, it's like making sure they didn't fall down the stairs all while you're on the toilet, do you know what I mean? Everything, you've got to put it on the back burner, you really have. I mean no matter how much pain you are in or what is happening, it's a case of you're in your own home, you know, you can clean up any mess, any accidents that happen but your kids have got to come first (Participant quoted in Mukherjee et al., 2002a, p. 360).

However, sometimes the illness came in the way and the 'best choice' was the one that suited the mother, the child, and family as a whole. The following quote illustrates this point:

I had to stay in hospital during the early period of childcare. One week after my hospitalization, my daughter was weaned from breast milk and began to take formula milk. But I think it was a good choice because I just had to do so (Kimura & Ohmori, 2015, p. 42)

In addition, shielding the family also meant shielding the child from the consequences of IBD, but also waving unnecessary burden from the ill parent. Mothers' instinctively tried to appear happy even when they felt poorly and limited visits to the hospital to prevent their children from witnessing the illness. Reciprocally, children expressed putting on a brave face even when they were feeling low to avoid causing worry to their ill-parent, however, some also reported that they enjoyed hospital visits as it allowed them to see their parents rather than worry about them alone at home.

3.3.2.2.3 Maturation

Children of ill mothers seemed to have sometimes developed independence as they took on more household chores compared to before the parent was ill. They also acted responsibly and stayed at home making sure to behave well when their parent was feeling poorly. Some even monitored their parents' medication intake and got upset when their parents would not conform to the prescribed dosage or properly store their drugs.

Parents also witnessed greater empathy and responsiveness on behalf of their children. The illness seemed to have sensitised them to become caring and loving. However, none reported that a role reversal had occurred where children acted as a main carer.

The most frequently mentioned positive effect on children was showing more care and consideration, both towards the ill parent and to people more generally. Children helped out and comforted parents when unwell, and encouraged them to do things they found difficult to manage (Mukerjee et al., 2002a, p. 360)

As for couples, in time of flare and remission, the dynamic of a couple seemed to vary. The illness placed a weight on the relationship and the carer suddenly became the cared for. The non-ill spouse or partner took over most of the responsibilities of the house including caring for children, and children old enough tried to lend a hand.

In one instance, a mother with UC regressed to a state of total dependence and needed her own mother to care for her (UC-mother) and her children. The husband of that same participant, was designated as an alcoholic, but he seemed to resume his caring role, giving up his careless behaviours, when his wife was flaring up.

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 (Husband of participant quoted in Liss & Sharma, 1970, p. 470)

In a few instances, participants mentioned that the illness made them appreciate life. When the symptoms were at bay, it forced them to do more with the children (going out, traveling etc.). Reciprocally, children were also aware of the impact of IBD on the family as a whole and grateful for their ill parent's attempt to manage it:

Young people were aware of the efforts made by the ill parent to cope with the condition included: taking medication; resting; eating or drinking the right things; having homeopathic treatment; going on holiday; taking their mind off it by working, reading or watching television; pushing the family to go out and enjoy themselves without the parent; and just trying to carry on with life as normal (Mukherjee et al. 2002b, p. 483).

3.3.2.3 Theme 3: Support and communication

3.3.2.3.1 Need for support

Mothers with IBD turned to partners, parents and extended family for practical and emotional help at times of struggle. In some instances, participants distinguished the type of help they could seek, notably calling one's own parent for childcare and having emotional and financial support from their partner. Emotional support as well as help in daily tasks were also met by older siblings who had left home, family friends, aunts and uncles, grandparents and sometimes neighbours. Furthermore, as previously mentioned in the subtheme 'feeling vulnerable', when no other resource was available, mothers reluctantly turned to social services.

As for children, they reported that usually the non-ill parents or extended family members provided support. Younger children sought comfort by hugging and staying close to their toys or the ill parent.

Other things that helped were talking to friends, being given information about their parent's health and medical treatment, having a friend in a similar situation, other people calming you down when upset (Mukherjee et al. 2002b, p. 483)

In their article, Mukherjee et al. (2002a) made a list of areas where mothers with IBD needed support and help, amongst the points underlined by the author that were not so far covered are the presence of a 'crisis unit' to assist parents in their daily role when they need to be hospitalised and a place to convalesce away from the family.

3.3.2.3.2 Tighter bonds

Both participants and their children said that the illness brought the family closer and strengthened the bonds between its members. Interdependence seems to have reinforced the relationships with some saying that “*IBD (...) improved parenting by: making people more aware of the child's needs and loving*” (Mukherjee et al., 2002a, p. 359).

Children recalled enjoying their parents reading to them bedtime stories when they (the ill-parents) were not feeling well and spending quality time at home. They abundantly demonstrated affection and care through humour and presence.

As for couples, none of them mentioned the impact of IBD on their intimacy, except for one husband who said the illness did not impede their sexual intimacy as it was already reduced due to previous discords

He felt that her colitis did not very much affect their sexual life since this was already restricted by the differences of opinion they had about contraception. He did not seem outwardly bothered by either of these problems (Liss & Sharma, 1970, p.470)

It seemed that in addition to witnessing their children develop empathy, as mentioned in the subtheme ‘maturation’, ‘tighter bonds’ was another positive by-product of having IBD.

3.3.2.3.3 Selective sharing

Discussing IBD and motherhood with a fellow other going through the same experience was deemed helpful in coping with life events. However, opinions were mitigated about how much (if at all) to share of the illness with children. Some mothers acknowledged that children appreciated their condition better once it was explained to them. Children also varied as to how much information they sought (if at all) about their parent’s illness. The amount of information and knowledge they pursued did not depend on their age but was related to their maturity and curiosity level.

Children also had different views on whether they should talk to friends about the parent’s health. A few spoke to friends when they were upset or worried about their parent. Others avoided telling friends, fearing that they would not understand or would make fun of them. As one 10-year-old explained: ‘No point telling them cause they wouldn’t understand cause they haven’t got a Mum with Crohn’s. People spread and talk to other people. We like to keep it quiet (Mukherjee et al., 2002b, p. 481-2).

Disclosing and sharing their illness with friends or neighbours was less common. Participants preferred to keep it in the family and only humoured jokes regarding IBD in closed intimate circles. One woman recalled an incident of rushing to the toilet and feeling misunderstood by those witnessing the scene, with the exception of a close friend who seemed to appreciate the urgency of the situation.

One night we went to dinner, a bunch of us at work, (...) I take my potty with me (...) all of a sudden, I start cramping (...) she [her friend] said take a Lomotil

(...) I have to go back to the restaurant. But I couldn't make it back to the restaurant – I had to go. Well, there were two other girls (from work) in the car who don't really know what it is to go. We pull into the alley, I go, I dump it out, she gets the wipes out. We're prepared! And they (the other girls) are looking at us, like ... and the next time I see them they say 'Are you feeling better?' well 'I wasn't sick... that's my life!' They didn't understand at all (Dudley-Brown, 1996, p. 63)

As for schools, parents who informed workers and teachers received full support and cooperation from the staff to walk children to and from their home when they could not afford to do it themselves.

Staff had provided access to school toilets and organized lifts to take the child to and from school when the parent was too ill to do so (Mukherjee et al., 2002a, p. 361)

Participants who mentioned wanting to receive results of genetic testing if it could identify IBD said they would like the results to be kept hidden and confidential particularly from their employer. They were concerned and fearful of others' discrimination and misconception of IBD. Hence, they opted to limit sharing the news with a close network.

I used to talk about my disease to my old friends because I didn't want to conceal it. It was easier for me. But, now, I don't tell my friends who are also mothers about my disease. I feel it is not necessary to tell them about my IBD (Kimura & Ohmori, 2015, p. 42)

Sadly, some mothers felt rejected and denied help to access toilet facilities even after disclosing the burden of IBD. The hidden aspect of their illness combined with a lack of knowledge amongst the general population (and sometimes medical staff) seemed to push mothers with IBD to remain silent about their condition.

Only a couple of parents in this study had sought help from social services and the local education authority, and those who had were refused assistance. Within the retail sector, lack of knowledge amongst shop assistants meant that it was difficult to get speedy access to toilets (Mukherjee et al., 2002a, p. 361)

3.3.3 Cluster 3: Conceptualisation and integration

IBD was, for the most part, 'conceptualised' as a result of genetic as well as environmental components. In one instance though, IBD was conceptualised as a result of a mother-child symbiotic dynamic. Participants also identified the specific 'triggers' that could exacerbate their illness, such as stress or specific foods. Most participants could further recount clearly and vividly the onset, duration, and time span between flares and remission phases. IBD was hence classified as a 'hidden illness' and ill mothers had to 'advocate for validation' of their symptoms. Participants were often relieved to receive a diagnosis as the ultimate proof of the legitimacy of the condition. The hidden aspect of the illness was further 'exacerbated', not so much by the 'disparity of knowledge' amongst the general public, but by that amongst generic medical staff leading to feelings of 'ambivalence towards healthcare professionals'. Lastly,

mothers stated their needs to enhance their care and experience of IBD by demanding a ‘centralisation of resources’ pertaining to motherhood and IBD as well as a ‘holistic approach’ to care during prenatal and postpartum years. The list of themes and subthemes elaborated under this cluster is detailed in Table 8.

Table 8 *Contribution of the Cluster ‘Conceptualisation and Integration’*

Cluster 3		Conceptualisation and Integration						
<u>Themes</u>	My IBD			Hidden Illness			Mums’ Needs	
<u>Subthemes</u>	Origins	Triggers	Vivid awareness	Advocacy for validation	Disparity of knowledge	Ambivalence towards HCP ⁵	Holistic approach	Centralisation of resources
Author(s), Year								
Liss & Sharma (1970)	✓	✓	✓		✓	✓		
Dudley-Brown (1996)	✓		✓	✓	✓	✓	✓	
Mukherjee et al. (2002a)	✓				✓	✓	✓	✓
Mukherjee et al. (2002b)	✓	✓		✓	✓	✓		✓
Lewis et al. (2009)	✓				✓	✓	✓	✓
Cooper et al. (2011)	✓		✓	✓	✓	✓	✓	✓
Kimura & Ohmori (2015)	✓	✓			✓	✓	✓	✓

3.3.3.1 My IBD

3.3.3.1.1 Conceptualisation and integration

Most individuals with IBD formed the understanding that the illness originated from a combination of environmental and genetic factors. Children had a similar understanding of the permanency and cyclical impact of the illness however, they conceptualised it on a continuum of wellness; IBD was perceived as serious but not ‘too’ serious.

I think it’s quite serious, well not life-threatening, but serious in that it almost ruined his life because he’s not as happy as he might be if he didn’t have it . . . 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., 2002b, p. 481)

Liss and Sharma (1970) formed the understanding that a significant loss in a person’s life could trigger UC. The symbiotic and dependent relationship formed between a mother and her daughter could prevent the daughter growing separate from her parent; and when a geographical and life change/separation was imposed (the participant got married) the first flare of IBD occurred. The authors of this article classified IBD as a psychosomatic illness as was

⁵ HCP: healthcare professionals

schizophrenia⁶. That said, the general understanding throughout the six other articles was that IBD was a chronic and hereditary disease.

I'd say probably genetics and environment. We suspect but can't verify that my grandfather had it on my mother's side, and I seemed to have my first symptoms right after I quit smoking, and from what I understand from research on the web and from some of the findings that you summarized, that both of those things could have played a part (Participant quoted in Lewis et al., 2009, p. 497)

3.3.3.1.2 Triggers

The conceptualisation and understanding formed around IBD extended to the triggers that would fuel IBD's onset. Mothers identified some specific foods or certain types of stressors that would upset their stomach, such as arguments with relatives as seen in the quote below:

She (Mrs Coleman) feels that exacerbations often correspond to the times of acute upset with her husband (...) She claims freely that her diarrhoea worsened with almost every problem she has faced such as conception, pregnancy and childbirth, and even daily shopping and household duties (Liss & Sharma, 1970, p. 468)

Children of IBD parents also monitored an awareness of triggers; they named stress triggers and doing more activity than recommended as potential risks of flares.

3.3.3.1.3 Vivid awareness

Mothers with IBD closely monitored the start, progression and remission of every flare episode. There was a vivid awareness of the timing of each flare and, for some, a description of the remission phase during their pregnancy. The participants detailed the type of symptoms, precipitating events, as well as number of bowel movements. Some mothers mentioned sudden onsets with no a-priori bowel history; whereas others recalled having a family member suffering from IBD.

There was no previous history of bowel problems and her first pregnancy had taken place without any significant event (...) 'It must have been about four months into my pregnancy when I started with diarrhoea. Not too much, but just so that you'd notice it was diarrhoea (...) My husband came home that night and I went to the toilet and it was like someone had slaughtered me in the bathroom (Participant quoted in Cooper et al. 2011, p.30)

The 'vivid awareness' was solely described by the ill individuals. As seen in Table 8, only three articles contribute to this subtheme.

⁶ This point was not elaborated on further in the article, except than to say that the mother-child relationship and generational patterns were both at the heart of researchers interests when looking into schizophrenia and UC origins.

3.3.3.2 Hidden illness

3.3.3.2.1 Advocacy for validation

One participant reported having insisted on being taken seriously by healthcare professionals. Her symptoms were misdiagnosed as piles as they co-occurred during her pregnancy. The prolonged time to receive a formal diagnosis was accompanied by feelings of humiliation and rapidly deteriorating health.

I kept saying to them [healthcare professionals], '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. It was like I was begging them to listen to me (Participant quoted in Cooper et al. 2011, p. 31)

She assumed she had cancer and felt relieved to get a diagnosis of IBD. Having a chronic illness seemed to be a lighter issue compared to the fear of cancer. This feeling was also shared by another participant, who talked about the respite of receiving a label for her symptoms.

Furthermore, there were a few occasions where local educational authorities and social services had refused to provide help to a few parents with IBD. One can argue that it is due to the lack of classification of IBD as a disability, or the recognition of the illness and its burden, that these establishments did not validate the need to help the distressed parents.

3.3.3.2.2 Disparity of knowledge

Mother with IBD expressed their concerns about the lack of awareness of IBD within the generic medical field. Medical staff and healthcare professionals seemed to lack training in IBD, rendering its depiction and diagnosis less likely.

Dr Smith [patient's doctor] explained that out of all the patients in my doctor's surgery, there might only be one other person who's got it [IBD], and that my doctors are not specially trained to pick it up (Participant quoted in Cooper et al. 2011, p. 32)

The information sought regarding IBD and pregnancy was sometimes contradictory, particularly with regards to what type of medication was safe to use during the gestation.

Limitation of information necessary during perinatal period: The participants searched on the internet for the effects of IBD on pregnancy and delivery while consulting their doctors' at all reproductive stages. They were confused by the lack and/or discrepancy of information (...) 'I felt that the internal medicine doctor's opinion was different from that of surgeons with regards to use of painkillers (Participant quoted in Kimura & Ohmori, 2015, p. 41)

Furthermore, this lack of awareness of IBD stretched to the family and friends who were unfamiliar with the illness. Mothers with IBD felt misunderstood and alone in dealing with the emotional burden of their illness. Children expressed a similar lack of awareness about IBD amongst their friends.

Others avoided telling friends, fearing that they would not understand or would make fun of them (...) 'No point telling them cause they wouldn't understand cause they haven't got a Mum with Crohn's (Participant quoted in Mukherjee et al., 2002b, p. 481-2)

Some mums assumed that 'It takes one to know one'; they hence tried to get in touch with others who shared the illness but said that the information was scarce. They then had to resort to the Internet.

I searched the web for information on how other women with IBD were dealing with difficulties during pregnancy and delivery because I couldn't get such information from other women with IBD. My doctor just gave me some papers written by other doctors (Participant quoted in Kimura & Ohmori, 2015, p. 41)

One participant expressed feelings about the lack of knowledge amongst people by saying "I think very few people in this country really know what the word 'Crohn's Disease' means. Even the slightest inkling of what part of the body is infected or what your symptoms are or what complications or anything" (Participant quoted in Lewis et al., 2009, p. 498). This opinion was shared by the authors of the article who reported that both ill and non-ill patients had very little knowledge regarding the complex aetiology of IBD.

3.3.3.2.3 Ambivalence towards healthcare professionals

Participants' relationship varied greatly from trust to mistrust due to the presence or absence of validation of IBD. Participants spoke about the lack of ability of *establishing trust* in medical staff who were not trained properly to recognise IBD onset. Therefore, some participants did not consult nurses and midwives regarding their disease-specific concerns.

I think that the midwives didn't care about my disease during pregnancy and the postpartum (Participant quoted in Kimura & Ohmori, 2015, p. 41)

One mother with IBD seemed to doubt the professional advice of her consultant to resort to surgery. She wanted to exhaust all other alternative treatments before having surgery. She hence opted to get a second opinion and switched consultants.

Mrs. Coleman has had several physicians during her 10 years of Ulcerative Colitis. She felt that she never really had much faith in any of them, since none of them ever paid enough attention to her or understood her well enough (...) Dr. Stern recommended surgery for her colitis, something which she claimed he had promised would never be necessary for her. She got quite angry with him and consulted another physician who recommended conservative medical treatment at his residential treatment center (Liss & Sharma, 1970, p. 472)

Establishing a partnership and a relationship of trust was restored once mothers with IBD felt attended to and received tailored medical treatment. Those specialists who monitored, followed up and answered questions relating to IBD and motherhood were the ones who gained patients' trust. Recognition and feeling heard seemed to be at the crux of establishing a partnership.

I always depend on my doctor. If I have any problem with the disease, I go to the clinic at any time. My doctor suggested a good time to get pregnant, with consideration of my condition (Kimura & Ohmori, 2015, p. 42)

3.3.3.3 Mums' needs

3.3.3.3.1 Centralisation of resources

As seen in the subtheme 'disparity of knowledge', it was difficult for women to find information regarding their transition to motherhood with IBD. Some reported finding information using a British national charity website, however, most complained that there was not enough 'out there'. The only way mothers were to get relevant information about pregnancy and IBD was if they were seen by different specialists at the same time.

Though the participants felt it was a bother to receive management by both an obstetrician and a gastroenterologist, they accepted the high-risk management as a safe system. My pregnancy was risky because I needed to be managed by both an obstetrician and a gastroenterologist. It was bothersome for me to have check-ups in two different departments. But I felt at ease to know that collaborative management was possible if needed (Kimura & Ohmori, 2015, p. 39)

Ideally, the integration of care, where a mother with IBD could be seen simultaneously by obstetrician and gastroenterologists, could prevent receiving conflicting medical advice and save time and travel costs from attending different appointments.

3.3.3.3.2 Holistic approach

The journey to motherhood with IBD led some of the participants to request a more holistic approach to their care. Medical doctors seemed focussed on attending to the symptoms of IBD and paid little attention to the interference of the illness on the mothers' role. Participants expressed the desire that the medical team, as a whole (GP, nurses, midwives, and consultants), take the family's needs into account by customising care and providing support before, during, and after birth.

With regards to genetic testing, if it were made available, patients preferred to receive pre- and post-counselling to discuss the interpretation and implication of the results.

[There are benefits to] approaches based on the concept of patient-centred care, one that aims to develop effective partnerships between patients and health professionals. It is important, therefore, that IBD specialists continue to develop strategies aimed at educating the health care community about the needs of IBD patients (Cooper et al., 2011, p. 33)

Most of the seven articles, included in this analysis, had in their conclusion the use of patient educational programmes or patient-centred approach to customise care to the overall needs of mothers with IBD or issues important to the family as a whole.

3.4 Summary and Discussion

3.4.1 Characteristics and content of articles

This meta-synthesis gathered qualitative studies pertinent to the transition to motherhood within the context of IBD. Although the search across the eight databases was not restricted to any specific date, most of the selected and relevant articles to the search topic appeared after the turn of the 21st century (Mukherjee et al., 2002b; Mukherjee et al., 2002a) with only one article published 30 years prior to that, which looked at the mother-child relationship and generational dynamics' role in UC (Liss & Sharma, 1970). In the latter article, the symbiotic relationship between mother and child across three generations was seen to be created and maintained around the illness. This aetiological perspective on the development and perpetuation of IBD is side-lined nowadays. Experts have yet to identify the causes and origin of IBD, however, it is accepted that multiple factors including predisposition and environment come into play leading to IBD (Fiocchi, 2015).

Interestingly, the aim and results of the seven selected articles were very centred around the challenges and experiences of individuals with IBD; however, the current meta-synthesis revealed three main clusters grouping the subjective living of mothers with IBD across the seven articles with only one of them tackling the 'burden (of IBD) on the family'. The other two clusters centred around 'coping' mechanisms and 'conceptualisation and integration' of the experience of the illness and motherhood.

3.4.2 Synthesis saturation & cluster discussion

3.4.2.1 Burden on the family

All the articles contributed substantially to all clusters, themes and sub-themes as seen from the contribution tables (Table 6, Table 7, Table 8) presented in the result section. Cluster 1 'Burden on the Family' is however, by far, the richer cluster with most articles contributing to most themes and subthemes. Particularly, the subtheme 'Feeling vulnerable' has been reported in all seven articles; and is extensively described by mothers with IBD who were burdened by their emotional, financial, and/or practical dependence on others. Mothers were also reluctant to ask for help in order to avoid imposing on others. These feelings went hand in hand with reported mental health issues such as anxiety and depression as noted in the subtheme 'oscillating mood'. Mikocka-Walus, Pittet, Rossel, von Kanel, and Grp (2016) showed a link between anxiety and depression with recurrent IBD symptoms. Not only were individuals experiencing depression and anxiety more likely to have cyclical flares, but the intensity of their symptoms was also higher compared to those not experiencing these mental health issues. The authors recommend screening all individuals with IBD routinely to prevent adverse progression and poor prognosis. Similarly, the inability to 'care, nurture and feed' young ones showed to be a significant burden for mothers with IBD. Cooper et al., (2010) also talked about the importance of the self-image

of health and ability of parents to perform their role such as taking the kids to school and maintaining a family routine as an important pillar for self-efficacy and control over IBD. Moreover, mothers with a chronic illness were plagued by ‘fears and concerns’ as well as ‘emotional load’ from living with a life-long and sometime life-threatening illness. Fear was contagious amongst family members and partners as well as children who dreaded that the ill-parent would not return home. Fears of death fuelled anxiety and frustration as well as attention-seeking behaviours within the family, making it difficult for the ill-parent to cope.

3.4.2.2 Coping

Looking closely at the contribution tables listed in the results section, one can see that five subthemes had only three articles out of seven populating them. Two of these subthemes, ‘tighter bonds’ and ‘maturation’ belong to the ‘Coping’ cluster⁷. Upon closer inspection, ‘tighter bonds’ and ‘maturation,’ tap more than any other coping subthemes into the positive outcomes of IBD and motherhood. It is possible that the time since diagnosis could play a part into when women can form acceptance and notice positive changes in family bonds. Some mothers were diagnosed for less than a year at the time of the interviews and perceiving tighter bonds might have been premature. In addition, some mothers had children of very young age, which would preclude them from witnessing maturation and independence in their children’s personalities at such an early stage.

The other listed coping strategies included diet restrictions, staying in the vicinity of bathrooms, and social restrictions (Cooper et al., 2010). Managing IBD through restrictions enabled feeling a sense of self-efficacy and control over the illness, however one could argue that individuals are losing control over the illness as they are letting the illness take priority over other life events. Participants in the Cooper et al. (2010) study also reported keeping a ‘fighting spirit’ in face of the seesaw struggle to control IBD; this theme resonated with the one depicted in the SRR where mothers attempted to adjust to their new normality and restore pre-illness functioning.

The original addition of this SRR was the theme of adjustment to family life, particularly the aspect of protecting family interests by placing the children or family needs first. Sometimes, protecting the family meant doing what is best for the mother, such as deciding to wean the child a little earlier than expected because her health is deteriorating. At other times, it meant limiting the number of desired children in a household which echoed with the findings of Selinger et al. (2013) about voluntary childlessness amongst IBD patients. However, in Selinger et al. (2013) it appeared that, even amongst members of a national Crohn’s and Colitis charity, a severe deficit in knowledge around IBD and pregnancy-related issues could have been at the root of the fears surrounding the transition to motherhood. In the

⁷ The three other subthemes are discussed in section 3.4.2.3

current analysis, participants seemed to strike a balance between receiving burdensome information and letting it dictate their behaviours, which implied their ability to navigate between their fears and desires to form a family. Notably, participants mentioned leaving a gap in the time between pregnancies to better cope with the demands of a newborn and young children.

3.4.2.3 Conceptualisation and integration

The other three subthemes that were least populated in the contribution tables were: ‘triggers’, ‘vivid awareness’ and ‘advocacy for validation’. These subthemes belong to the third cluster ‘Conceptualisation and Integration’. The relatively scarce representation of these topics amongst the seven articles could be due to the timing at which women were diagnosed. For participants living with IBD for a long time remembering or mentioning advocating for diagnosis validation struggles might no longer be relevant. Nevertheless, a comprehensive review of the burden of IBD on patients listed delays in getting a diagnosis and/or missed diagnosis as a common burden of the illness (Rocchi et al., 2012). The review also listed excessive costs of medication and inequitable access to healthcare as major issues faced by IBD patients but these were not addressed in the meta-analysis. As for ‘triggers’ and ‘vivid awareness’, they portrayed the unique impact of IBD with regards to monitoring the recurrence, escalation and number of symptoms during flares. These subthemes did not tackle the experience of being a mother with IBD and could have been side-lined as the interviews focussed on how participants made sense of all aspects of motherhood and IBD.

This proposed explanation is supported by the fact that all other themes and subthemes relating the joint impact of motherhood and IBD were mentioned in all seven articles. Indeed, three of the four most represented subthemes across the articles belong to this cluster; notably ‘origins’, ‘disparity of knowledge’ and ‘ambivalence towards healthcare professionals’ (the fourth being ‘feeling vulnerable’ discussed above). All articles mentioned either briefly or through longer quotes participants’ understanding of the origin of the illness, whether it was passed down from someone in the family or if it was a combination of environment and genetic factors. Forming an understanding of the illness seemed to be important to mothers with IBD.

Moreover, the theme ‘hidden illness’ and subsequent subthemes ‘disparity of knowledge’ and ‘ambivalence towards healthcare professionals’ are well documented in the literature. Rocchi et al. (2012) mentioned that IBD patients suffered from the lack of awareness of IBD amongst the general public. Ignorance around the implication of living with a chronic illness could lead to feelings of lack of collective support for people with IBD in the workforce and the society in general. Coulson (2013) found that individuals’ primary use of online forums was to gather information, particularly from others sharing a similar experience. There seems to be a strong need to find out more about living with IBD. This need for affiliation, and desire to feel understood, as well as to learn vicariously from others resonated in the meta-synthesis. According to Coulson (2013) forums allowed searches by topic and enabled daily exchanges of

a wealth of information. In addition, forums were sought out as an up-to-date platform where the most recent treatments were often debated with users' feedback. Emotional support was another main benefit of these online communities, which helped individuals develop a more positive perception of their illness. They reported feeling less lonely as a result of being part of this online community. However, mentioned pitfalls included post anonymity and privacy preservation which make it difficult to assess the credibility of participants, and the possibility to be bombarded with sad stories. Coulson did not report the likelihood of such events happening, only its potential detrimental impact on users trying to get answers to their struggles.

A mixed method study by Pittet et al. (2016) indicated that IBD patients were generally dissatisfied with the information given at diagnosis. Healthcare professionals did not communicate the importance of diet, prognosis, necessity of life-long treatment and other deemed crucial topics for the patients. Women with IBD were more likely than men to be dissatisfied with the information given by their physician, and CD patients were more likely to be dissatisfied with the given information compared to UC patients. Dissatisfaction creates mistrust and tension, as seen in the meta-analysis, patients went for a second opinion, changed consultant care and reported discontentment with the medical services. Moreover, the Pittet et al. (2016) study showed that nurses were not seen as a useful source of information; some participants criticised the lack of knowledge amongst nurses and midwives. Pittet et al. (2016) attributed the lack of credibility to the lack of specialist IBD nurses in Switzerland; however the studies included in the meta-analysis were conducted in countries where IBD nurses are available (UK, USA, Hong Kong, and Japan) and patients could have benefited from their knowledge if such specialists were part of their care.

Lastly, I noted the absence of mention of the impact of sexuality and sexual functioning amongst the selected articles. Timmer et al. (2008) surveyed 336 women with IBD (219 with CD) and found that 17% of the sample was not sexually active 'at all'. Participants reported a low sexual activity level and a low sexual interest level regardless of the disease activity. Disease activity (i.e., being in a flare), however, impacted frequency of intercourse and level of anxiety. Participants commonly reported lack of lubrication and pain during intercourse as factors impeding their desire to be intimate. Moreover, depressive mood and use of steroids were respectively strong determinants of low sexual functioning and low scores on pleasure and orgasm rating.

3.4.3 Reflection on the meta-analysis

I had to go through several iterations of the search over the course of the four years of this PhD. Initially, the names of clusters, themes and subthemes seemed to match the nomenclature used in subsequent analyses. After careful reflection on my tendency to use similar names for clusters, I opted to carefully read and reread the content of the analysis and adjusted the titles to ensure finding the most descriptive and appropriate name. Capturing the content of an analysis

is tricky as I was influenced by what I had read and heard during the interviews conducted for the PhD study. I kept an audit trail using excel sheets to show the progression of naming the cluster. It can be made available upon request.

3.4.3.1 Advantages

I tried to be as inclusive and exhaustive as possible in my keyword search terms to precisely avoid missing any published peer-reviewed articles. Also, the thorough and systematic search of all eight databases, some of them aggregator databases, added to the rigour of the method in this systematic research review. One could argue that since the search time spanned across such a long time (four years since the beginning of the PhD), new articles could have been released and inadvertently excluded from the SRR. To remedy this limitation, I ran a second search in November 2015 (five months after the initial search), and again in April 2017, to ensure the final count did not change. Last but not least, this meta-synthesis is, to the best of my knowledge, the first one to look at the qualitative peer-reviewed articles released on the topic of motherhood and IBD. It contributes to understanding caveats and gaps in research as well as some of the areas of common concerns for mothers with IBD.

3.4.3.2 Limitations

One limitation of this SRR was the single scoring of articles using CASP; however, I tried my best to be consistent in the grading and kept documents of passages in the articles reflecting why a particular score was given and kept records highlighting the failures of the study. The review would have possibly benefited from having two reviewers to support the quality of the articles and justify why no articles were rejected based upon the CASP score.

A second limitation was the plethora of articles that appeared to be related to the topic of interests but which were in reality just a false positive. This searching limitation led to an extended and delayed screening period that spanned over six months. However, as mentioned in the advantages section, an exhaustive list of 72 key terms was created and proofread by my two supervisors to ensure being as inclusive as possible. Thus, it was not the sophistication of the strategy that led to missing or targeting potentially irrelevant articles but the actual fact that very little research has been conducted on the subject.

A third limitation is the low number of selected articles, and the fact that only two of those articles truly targeted the attitudes and meaning of illness in parents (with only one of them only targeting mothers in its sample). This shortage of a targeted sample forced the inclusion of articles with a majority of mothers, or articles in which the content could be distinguished across sex, and even articles that had content relevant to parents with IBD from the perspective of their children (as explained in section 3.1.3.5).

Finally, it is worth mentioning that a meta-synthesis is somewhat similar to a secondary analysis of data. I did not have first-hand access to the transcripts of participants, only what the authors of the articles presented. Hence, any missing content relevant to the experience of

mothers with IBD might be a reflection of what the authors emphasised in their results and not a reflection of the narrative of participants of their study.

3.4.3.3 Future directions

Most of the articles were published in nursing journals, however, the transition to motherhood with IBD could benefit from a multi-disciplinary outlook and viewership from social care and policy makers. If IBD were to be recognised as a disabling disease it could grant mothers ease of access to disabled toilets or access to services for childcare whilst in hospital. Moreover, patient education seemed to be at the heart of all conclusions, which is pivotal to the improvement of the quality of life and experiences of mothers with IBD. However, educating and raising awareness of the general public on IBD issues is somewhat omitted. Individuals with IBD would benefit tremendously from not living in silence if the illness would be understood and accepted in a non-judgemental manner.

The next chapter will layout the method used to collect and analyse the accounts of mothers with IBD which formed the basis of the PhD thesis.

Chapter 4

Methodology

My PhD addresses the research question: ‘What is the lived experience of women who transition to motherhood within the context of Inflammatory Bowel Disease?’ This chapter outlines the methodology employed to answer this research question. Hence, it covers ethical approval and considerations, characteristics of the researcher of possible relevance to topic studied, recruitment procedures and sample characteristics, data collection, design and practical implications of the interview schedule, as well as the reasoning behind the choice of analytical procedures. In relevant places, the chapter also includes considerations of methodology: that is, the position I have taken, and decisions I have made, in light of the ‘theory of method’ informing this study. Hence, in most sections, I provide reflective insights into the processes and challenges of the research and the systematic, methodological reasoning behind my choices.

In brief, participants were invited to take part in a research interview to share their experiences of transition to motherhood with IBD. These interviews were video-recorded with their consent to allow me the opportunity to create YouTube medleys to share the results of the study.

4.1 Ethics

Braun and Clarke (2013) urged us to think about ethics not only at the micro-level of participants, but also at the macro-level of society. Hence, at the micro-level, I have written in this section all the steps undertaken to ensure respecting the BPS code of research ethics (BPS, 2009). I highlight below the ethical issues foreseen through fieldwork and lone working and how I remedied them. I also elaborated on the process of consent to respect the autonomy and dignity of my participants and underlined the areas where participants were likely to be at risk and/or benefit from their inclusion in the study. I made a sincere attempt to minimise the risks and increase the benefits and gave careful considerations to compensation, confidentiality, data protection and safeguarding from conflict of interests. As for the social responsibility, or ethics at the macro-level, it is important to reflect on how this study can impact society at large. I believe that the use of YouTube medleys, which comprise clips from interviews illustrating how women with IBD transition into motherhood, will help fulfil obligations to inform and support many women with IBD and their families. The details on how the medleys were created, their content, and how they were sent for approval feedback on a selective audience is provided in Chapter 8.

4.1.1 Fieldwork and lone working

The main foreseen ethical issues with regards to myself as researcher were fieldwork and lone working. Due to the nature of the IBD symptoms¹ and because all participants had, by definition, young children I decided to travel to participants' homes instead of having them come to the University of Leeds. Providing participants with the opportunity to meet in the comfort of their homes at their preferred time was deemed both appropriate and ethical, however, that meant I had to travel alone and sometimes outside working hours, in order to accommodate their preferences.

A Risk Assessment Form (RAF) was completed and approved by the Health and Safety Officer (Appendix D). In addition, a safety protocol was set in place detailing the steps of the "BUDDY system", developed by the Clinical Psychology Team at the University of Leeds to increase my safety working whilst outside university premises (Appendix E). This involved making sure that my lead supervisor knew where I was and telephoning her in front of the participant on my arrival – to showcase safety procedures – and again, after having left, to confirm my safe departure and return home. Consenting prepares the participant for what to expect when meeting me face-to-face, which in turn reduces the chance of surprises and/or disagreements. Hence, having a good process of informed consent was also part of aiding my wellbeing.

4.1.2 Consent

No elements of deception were used in this research and a multi-step consent process was used because informed consent is thought to be implemented from the moment of recruitment until the time of thesis submission. Two flowcharts detailing the conduct of the research, as well as the delivery of informed consent (verbal or written depending on the participants' choice of face-to face or Skype interview), have been created to facilitate visualisation of the process. *Figure 3* illustrates the multi-step consent process when face-to face interviews were held, Appendix F details the multi-step approach² for Skype interviews.

¹ As seen in the introductory chapters, IBD can cause fatigue and severe diarrhoea and one cannot predict when the symptoms will appear in order to plan around the illness.

² These charts were created to demonstrate the process of informed consent to the ethics board and to maintain rigour whilst conducting research. The charts were not distributed to the participants.

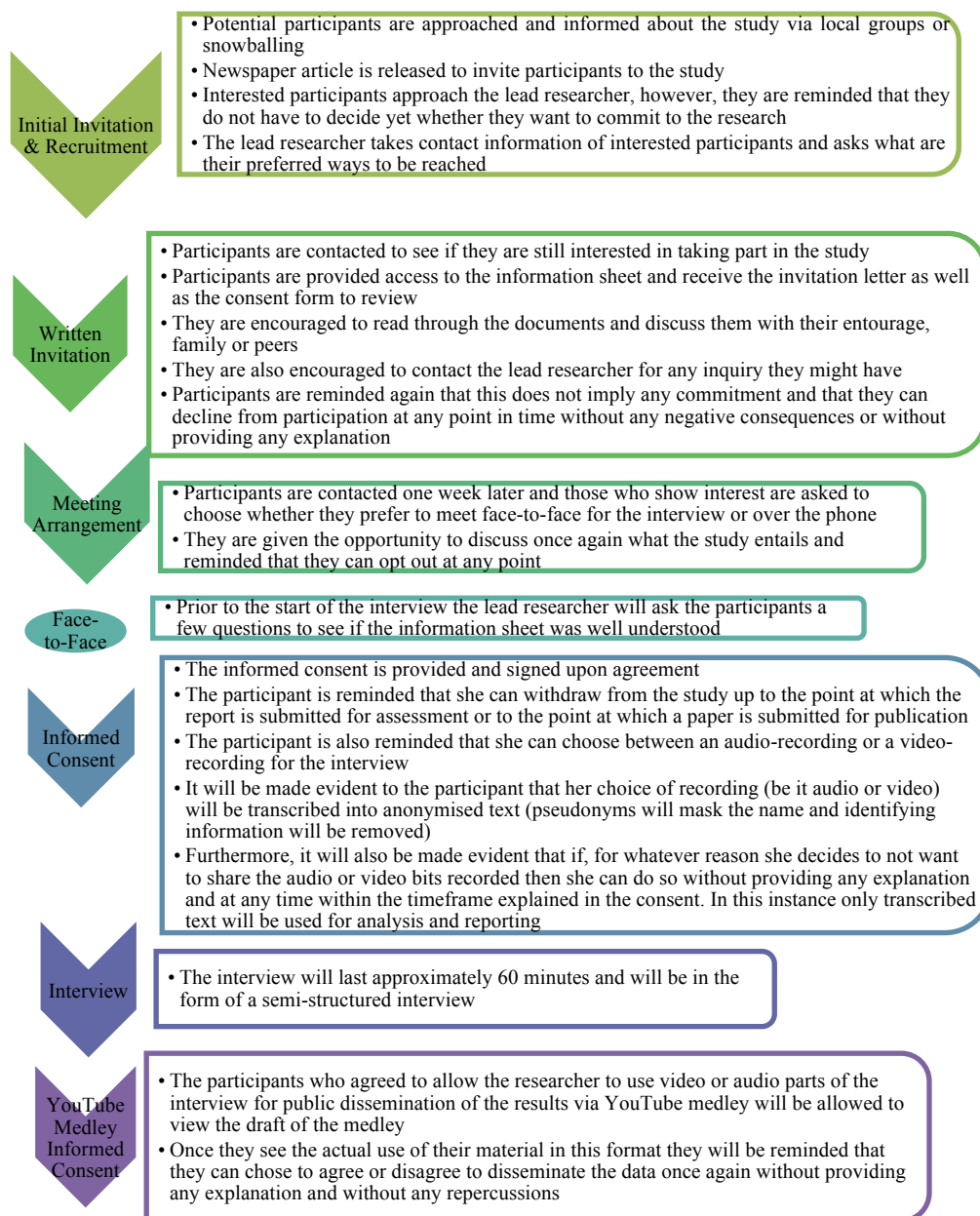


Figure 3. Flowchart of the process of consent for participants interviewed face-to-face

The participants were informed of all the aspects of the research when they received the study invitation letter (Appendix G) and information sheet (Appendix H). Both documents used lay-terms, non-discriminatory language and were reviewed by both supervisors to ensure the wording was appropriate. Upon receiving the information sheet and filling the demographic sheet (also referred to as the background information sheet, Appendix I) to ensure eligibility, each participant was given a minimum of a week's time to think about participation, after which, if they still showed interest, an interview date was set. All participants were given the opportunity to discuss the information received initially by email and later during the interview.

On the day of the interview, I systematically went through the information sheet asking random questions about the study to each participant to ensure she had a good understanding of its key features. For example, I asked if she knew how many times we were to meet, and how the video/audio recording will be used. I made sure to reiterate out loud that consent to use the audios or videos recorded on publically available channels (i.e., YouTube) will be sought again once the medleys have been drafted to allow each to visualise the material used and possibly retract consent. In addition, participants were also reminded that they could withdraw the data obtained from their interview at any stage of the study, up to the point that the dissertation is submitted for examination or a paper is submitted for publication. This information is clearly stated both on the information sheet and on the consent form (Appendix J).

Written consent forms were signed off and dated on two copies, one for each party's record. Informed consent provides some indication that participants have received adequate information about what the study entails, but one can never really assume that each participant has a full appreciation of how exactly data would be used and released (Corti, Day, & Backhouse, 2000). To the greatest extent possible, I tried to be mindful of this fact and did the best I could to respect the code of ethics. However, the understanding I will form of the material through the process of analysis and reporting of the findings can never be truly conveyed at the point of data collection.

4.1.3 Risks for participants

According to the BPS Code of Human Research Ethics, a vulnerable group is defined by one of the following criteria: "children under the age of 16, people with learning or communication difficulties, patients in care, people in custody or on probation, and people engaged in illegal activities, such as drug abuse" (BPS, 2009, p. 31). Based on this definition, mothers with IBD may not qualify as a vulnerable group, but that is not to say they cannot feel vulnerable at times because of their illness combined with their parenting responsibilities. For them, 'risk' also involves the potential discomfort of disclosing personal information regarding their transition to motherhood with IBD. Moreover, disclosure of some of this information will be available on YouTube and could potentially cause some stress to the participants in anticipation of its public release.

To mitigate such potential risks: (a) a clear informed consent process was conducted so that participants are aware of the nature of the study including potential topics of discussion and how it will be disseminated; (b) participants were reminded that their contribution is entirely voluntary and that they can withdraw at any point during the interview without giving any justification; (c) as mentioned in the consent section, participants' approval for being recorded and releasing of recorded clips to the public, is sought twice and they are reminded that they can decline consent for the latter; (d) if a participant wishes the clip to be removed after it has been released, I would abide by removing the uploaded video; (e) also, during the interview, open-

ended questions were used allowing each individual to divulge as little or as much as they want, and; (f) I attempted to minimise expressing opinions, thoughts, or making judgments on any comments made by the interviewees and adopted a general approach of acceptance. Lastly, (g) in order to prepare for the unlikely event that a participant ever revealed any intention of harming herself or others, or discussed involvement in a serious criminal activity, I had written in the information sheet that I would have to immediately report this and divulge the content of the conversation to my lead supervisor and would consult with her about taking appropriate action. However, the information sheet also stated that the interview schedule will not pursue such information and participants are made aware of all these details ahead of the interview date. This situation never occurred during the interviews.

4.1.4 Benefits for participants

One benefit of this research for participants is that they have the opportunity to talk about themselves to a sympathetic and interested listener. This discussion may allow participants to explore their experiences and possibly help make sense of them. The interview explores how participants cope with their transition to motherhood so brings to the fore their resilience. The interview strategy is to end on a positive note, and I make sure to direct the participants to the free sources of support on the information sheet if they feel the need to seek support (Crohn's & Colitis UK service line and information line numbers are written down along with times of availability of these services, see Information Sheet, Appendix H). As an additional resource, the lead supervisor was always aware of the timing of the interview and was available by phone so as to provide support for both the participant and/or myself if need be.

4.1.5 Compensation

Reasonable compensation for travel expenses was made available in the event that participants living in Leeds preferred to meet at the University of Leeds rather than at their home. However, this scenario never presented itself and no compensation of any nature was provided to any of the participants who took part in the study. The topic of motherhood and IBD is considered to be of a sensitive nature, and I only encouraged those women whose primary motivation to take part appeared to be an interest in sharing their experiences, to allow me to develop knowledge, without expecting any particular secondary gain. In addition, I recruited a diversified sample, with some women from relatively poor economic backgrounds. Compensation under these instances could be thought of, according to the BPS ethical guideline (BPS, 2009), as coercive rather than compensatory.

4.1.6 Confidentiality

Anonymity and confidentiality were attempted by all means possible within the transcribed and safeguarded data. Personal information, such as names and places, were disguised using pseudonyms and other potentially identifying material were omitted or changed slightly in the

transcripts. One of the anonymising strategies used for the video-recording was the removal of family photos from filmed backgrounds prior to the interview and audio removal of names and/or places mentioned during the interview by masking the sound.

The pseudonyms were scripted to reflect the participants' type of IBD, their order in the interview list, and the number of children they had. Furthermore, to discriminate between pilot and main study participants the letters "Pi" were added to the pseudonym for the pilots, and the 'p' letter was inserted at the end when participants were pregnant at the time of the interview. For example, *CDMumPi02C01* referred to the second pilot participant (Pi02), who was diagnosed with Crohn's Disease (CD) and had one child (C01). Similarly, the pseudonym *UCMum03C01p* meant that this participant had Ulcerative Colitis (UC), was the third participant to be interviewed after the two pilots (Mum03), had one child and was pregnant at the time of the interview (C01p). All reasonable means were used to maintain the broad anonymity of the participants in the transcripts and notes, as well as, YouTube medleys (that is, to those who do not already recognise them visually or by voice) and consent was obtained to use the clips (visual or audio) after the participant had seen and/or heard the proposed clip to be used (details are provided in Chapter 8).

All the interviews were sent in audio format (.mp3) to 'The Typing Works Limited', an independent company³ working in collaboration with the University of Leeds. The transcribing company signed my confidentiality agreement form and requested my signature on their form (See Appendix K and Appendix L). They signed to commit to treating all material as confidential and that no person other than the transcriber will have access to the audio recordings. Upon completion of the transcription and conveying it to me, all digital recordings and transcripts were deleted from their system.

4.1.7 Data protection

Participants' text-based data and signed consent forms were stored in a locked cabinet. All non-anonymised data (e.g. audio and video-recordings) were stored on a university password-protected and encrypted laptop drive and were backed-up on two separate encrypted hard drives. The audio and video data were temporarily held on the iPad during the transfer from data collection site to University of Leeds and subsequently deleted from the iPad. As for data on my personal laptop, they were only stored short-term up until their final transfer to the protected University-drive for the long-term storage. All electronic devices used to collect data were encrypted and/or password protected. Moreover, following the guidelines of the Data Protection Act (ICO, 2016) "personal data processed for any purpose or purposes shall [will] not be kept for longer than is necessary for that purpose or those purposes" (p.37); thus, all research related data will be safely stored for up to 10 years after the final publication of this research in order to

³ The company is independent in that it is not involved in the research for other purposes than transcription.

fulfil the audit obligations. As for material published, they will be available in perpetuity, or for as long as the publisher makes them available and can be found, along with the thesis document, on the University of Leeds website data repository.

4.1.8 Declaration of conflict of interest

The study was externally funded by Crohn's & Colitis UK (CCUK) charity. CCUK is the working name for the National Association for Crohn's and Colitis (NACC) which is a British Charity that supports individuals diagnosed with IBD as well as their families, friends, and care providers. They provide both information and funding for research that enhances the wellbeing of all those affected by IBD.

Neither of my supervisors (Professor Anna Madill and Dr Peter Branney), nor myself or our respective institutions⁴ have received any incentives for taking part in this research over and above normal salary and costs of undertaking the project. There are no other sources of conflict of interest and CCUK does not have control of publication of findings. CCUK only requests to be alerted to publications within 8 weeks of expected publication date, and the charity does not interfere with academic freedom in any way.

4.1.9 Ethical approval

The study received ethical approval from the Ethics Committee of the School of Psychology at the University of Leeds (ref no: 14-0141) on August the 8th, 2014. However, the interview schedule and some recruitment advertisements were later revised and the study received its second and final ethical approval on November the 21st, 2014 (ref: 14-0280).

4.2 The Researcher

A few details of my autobiography are worth disclosing to contextualise my engagement with the research and point out how I share both similarities and differences with the participants (Le Gallais, 2008). First, in terms of differences, I started the PhD when I was 29 years old and during the four years of the programme I remained single and have not experienced motherhood. I do not suffer from Inflammatory Bowel Disease or from any other chronic or punctual illness; by all definitions I am considered to be a healthy person. I am also relatively younger than the average mother at the time of the interview and come from a middle to upper class family background. I have had a strong preference for researching how women remain resilient despite facing serious health problems and during my previous two Masters I looked at the impact of breast cancer on recovering women and their entourage.

⁴ Professor Anna Madill and myself are affiliated with the University of Leeds and Dr Peter Branney is affiliated with Leeds Beckett University.

These broad characteristics and past history place me from the very start as an ‘outsider’ relative to the participants (Ergun & Erdemir, 2010). Except for being a woman and having the potential and desire to be a mother one day, I share very little experience with the participants who entered the study, and it often appeared in the interview that the participants were on a mission to convince me about the severity, challenges of their illness and later pregnancy. Even in terms of cultural and educational background, I experienced a distance with the interviewees given that I was born and raised in Lebanon, possess strong Middle Eastern values, and have taken my education up to the point of conducting research for a PhD. Initially I suffered from cultural shock. For example, when entering a participant’s home, I noticed I carried assumptions about what it meant to become a mother. I thought I would find their house in a relatively clean state, or that the participants would be somewhat enthusiastic – as was I – about the research. Both assumptions were strongly tested as I progressed in the research. It made me sometimes feel unwelcome, as in Lebanon it is custom to greet any visitors with a tidy house which conveys a respect for the other person’s comfort. Moreover, as English is not my native language, I did have some apprehension about understanding and being able to convey my thoughts both during the interview and the analysis. Reading and writing in English is a constant challenge for me to perfect and improve upon. However, I have had English classes and courses since I was 12 years old and all my degrees (BA, M.A, M.Sc., and now PhD) have been in English allowing me to overcome this initial anxiety. That said, I did struggle a bit with the accent of some of my participants, particularly the ones from Scotland and Northern Ireland. Hence, having the transcripts sent to The Typing Works for professional transcription really helped in terms of having an additional Native English person, listening and reporting verbatim and staying faithful to the words participants chose.

As for my personal inclination towards the topic, aside from it relating to my previous interests regarding women and challenges to their health, I was interested to conduct this research for several reasons. Having lost my mother from a pulmonary autoimmune disease at the age of 9, I was automatically drawn to study and delve into research on motherhood and chronic illnesses, particularly autoimmune illnesses. Investigating pregnancy and transition to motherhood is, in a way, a sublimation of my desire to know more and to find some answers as to what it means to have and become a mother. As for IBD itself, it has unfortunately touched the lives of friends and relatives around me and, although they do not currently have children, I am sure that one day they will want to cross that bridge. Thus, researching IBD and pregnancy is a cathartic process to me; it allows me to cope with life events that have directly affected the people I love and hence indirectly affected me. During the interviews, tears were often shared and I recall one particular interview with UCMum11C01p where we both cried at the end. It was very difficult not to share and empathize with her pain and I had to contact my supervisor right afterwards to deal with the emotional valence of the experience

My position as an outsider or insider further extends to my initial knowledge about qualitative research. Previous to this PhD I had only conducted two projects involving qualitative research, both of which did not involve meeting participants face-to-face and both using a different analytical approach than the one used here. I was a novice with regards to Thematic Analysis and the method of conducting data collection. I underwent a summer school training: *Qualitative Research International Summer School* led by Victoria Clarke and Virginia Braun at the start of the PhD to enhance my knowledge and skills (July 28 to August 1, 2014, University of West England, Bristol, UK). On the positive side, I found that being an outsider gives me some advantage in terms of having to scrutinise my behaviours and use my former training in quantitative research to systematically consider the data and apply the same rigour whilst looking at every transcript. I purposely opted to avoid reading the literature on the topic of IBD and motherhood until I had conducted and analysed the first five interviews. I was hoping to come up with some of the preliminary coding and possible themes before my thinking was possibly swayed by prior knowledge. Hence, it was not until the second year of the PhD that I started the SRR which took two years to complete. I cannot help but notice that once I delved into the literature, some of the subthemes resulting from the SRR permeated the analysis of my interviews. Notably, I mentioned in the SRR *disparity of knowledge* and *ambivalence towards healthcare providers* as subthemes of Hidden Illness, both of which appear as themes in Chapter 6 *Transitional Challenges*. I opted to slightly change the name of *disparity of knowledge* to *Burden of Knowledge* in my analysis and kept *ambivalence towards healthcare providers* as is. The priming of the literature crossed-over at other instances as well, notably with the subthemes of *maturation* and *close monitoring* found in the SRR and also reflected in Chapter 5: *Blurred Lines* (termed respectively *need for maturity* and *close scrutiny*). Keeping a reflective diary allowed me to underline these instances of overlap and be mindful of them.. Of course, this is not to say that these topics were not in my data. By the time I had completed my data collection – at least in terms of knowledge and understanding – I was much better informed and had learned a lot from my participants and the literature about what it means to live with IBD and become a mother. The last interviews resonated with me more deeply and I was no longer in the dark with regards to lexical terms or experiences that were shared. I felt somewhat less of an outsider, although I cannot consider myself any greater part of this group.

Moreover, I kept a reflective journal through the process of research. This allowed me to pose a very important question at the beginning of the research: *Am I the right person for the job?* I had a lot of assumptions about illness and, particularly, the roots of chronic illness. I used to think of illnesses, in general, as somewhat a result of an interior or psychological dis-ease with the illness being a physical manifestation of this ‘mal-être’. I also used to believe that physical illness would remain or even progress as long as a balance within the self is not restored. I have changed since then in my position. I have come to accept the illness more at face value and, although IBD does not have a known cause, I adopt a multifactor approach that

it is a consequence of genetics and the environment. Seeing the suffering of my participants, hearing their stories, and reading the literature made me reconsider my beliefs.

Also I had doubts with regards to my limited knowledge in qualitative research. Was I qualified to do this work? I had to delve into the culture of the qualitative world. Thinking like a qualitative researcher meant I had to let go of a lot of my quantitative assumptions and readjust what I thought counted as knowledge and the concept of reality and truth. I sought meaning and not statistical significance and embraced my subjective perspective in terms of identity, context, and politics and reflected on how I might have influenced the findings within an epistemology which embraces contextualised understandings rather than a search for seemingly objective truth. This reflection is not intended solely to justify and defend the production of the findings but is an acknowledgement of my interactive role with the research and the researched. Moreover, I will use reflexivity throughout my thesis as an intersubjective reflection showcasing how my position as a researcher influenced the decisions I made and the analysis generated (Finlay, 2002).

4.3 Recruitment Aims

4.3.1 Target sample size

The research aimed to recruit 20 to 24 women from diverse backgrounds and different lived experiences through maximum variation – explained below – to reach data saturation upon which it is likely that further data would add little to the results (Marshall, 1996). Patton (2002) recommends a sample of 20+ participants for large qualitative research projects. My target sample size takes into consideration also the time available to conduct the study (3 years), my resources, study design (one interview per individual), and the research question that is experiential in this case. Moreover, Morse (2000) states it is important to look at the quality of the data as some interviewees might be able to self-reflect more than others; thus having more interviews does not always equate to richer research or analysis, and data saturation can be reached with fewer interviews when participants are very articulate. The following two subsections detail how participants were selected (inclusion and exclusion criteria) and why data saturation was plausibly achieved.

4.3.2 Inclusion criteria

The inclusion criteria are that participants are mothers who self-report as having a *medical diagnosis* of IBD, who are at least 18 years old, living in the UK, and who have at least one biological child – that is, a child to whom they gave birth – aged (roughly) between two and seven years old. The upper age limit of the child allows for discussion during the interview of a relatively recent transition to motherhood. The lower age limit permits the retention of only women who have had sufficient time since delivery to reflect back on the process of becoming a

mother with IBD. Some case-by-case judgement calls were made when the first-born child's age fell slightly outside the set age range.

'Biological child' did mean I excluded women who had adopted or in other ways become a mother without going through pregnancy and birth. This implicit exclusion was appropriate because the process of pregnancy and birth are of central importance to women with IBD given their illness experience. This is not to say that becoming an adoptive or, perhaps step-mother, with IBD does not have its challenges, but it would involve a slightly different research question. Participants had to be fluent in English because there was no funding to provide for translation. The demographic sheet filled prior to entering into the research allowed collection of geographical location, socio-economic status (SES: as derived by me from the household income brackets provided, refer to Appendix I), number and age of children, and the IBD diagnosis of each participant.

4.3.3 Exclusion criteria

Women who did not meet all of the above criteria were not admitted to the study. Also, some women, meeting all the inclusion criteria, were deferred from entering the study when it was recognised that they did not add to the diversity of the sample. For example, the study aimed to recruit a demographically-diverse sample; however, from the initial pool of participants who contacted me, and who were subsequently entered in the study, too many were diagnosed with CD (given my aim to recruit an equal number of women who had Crohn's Disease and who had Ulcerative Colitis – and with some 'unclassified' cases). I therefore prioritised women with UC diagnosis and IBD unclassified to enter the study in the mid-phase of recruitment. Furthermore, by the time 14 women were recruited, I noticed that only two were in full-time employment, all were married or in long-term relationships, and only one was from an ethnic minority group (Indian British) and another North American. Hence, I began to prioritise full-time working mothers with IBD and broadcasted an ad via social media to recruit single mothers as well as mothers from ethnically diverse groups. As a result of this ad, four more women from different ethnic backgrounds were recruited amongst which one was also a single mother. The section on sampling techniques elaborates further on these selection points.

It is my belief that the final sample size (N=22), detailed in full in Sample Characteristics section below, provided the best chance of reaching data saturation because the sample was diverse in pertinent characteristics to the lived experience of mothers with IBD (Curry, Nembhard, & Bradley, 2009). Sampling diversity (as detailed in the Sampling Techniques section) enabled me to enrich the analytical goal whereby different women with different perspectives, backgrounds, and treatments provided rich data about their lived experiences as mothers with IBD. I will elaborate on this point further in the discussion section relevant to the method.

4.4 Recruitment Strategies

I made use of several gateways and channels to advertise the study and recruit as many and as diverse a sample of participants as required. All advertisements used lay terms, eye-catching phrases, visually pleasing graphics as well as informative content to capture the interest of potential participants. Materials were all pre-approved by the ethics committee.

4.4.1 Press releases

Two recruitment articles detailing the research in the CCUK's quarterly newsletter ("News") were released in the Autumn 2014 and Winter 2015 issues (Appendix M and Appendix N). The press releases were deemed effective to inform potentially interested participants about the study. A third article was also posted on Mumsnet: a website aiming to facilitate exchange among parents through sharing of articles, blogs and chat rooms (Appendix O). Lastly, three more articles were released on IBD-related websites; the first two were released on the Jewish Digest on the 6th of July 2015 and the 7th of June 2016 to also promote the research in diverse communities and minority groups throughout the UK (<http://www.jewishdigest.org/doctors-digest/research-study-in-leeds-on-ibd-and-mums-to-be/>; <http://www.jewishdigest.org/lifestyle/experience-of-becoming-a-mum-with-ibd/>) and the last one on the CCUK website on June 23rd 2016 (<https://www.crohnsandcolitis.org.uk/news/research-opportunity-for-mothers-with-ibd>).

4.4.2 Social media

The study was further promoted on the CCUK Facebook Groups (National and Local) as well as on a Facebook page and a twitter account created specifically for the purpose of disseminating information about, and results from, the study (Facebook Page: "IBD and Mums-To-Be"; Twitter: @IBDandMumsToBe). Each of these interfaces had a link to a YouTube video launched to promote the study (<youtube.com/watch?v=P9F0-l-717I>). These interfaces were also linked to my Academia profile (<https://leeds.academia.edu/JihaneGhorayeb>) where all the study related documents and material presented at conferences can be found. The social media interfaces allowed its viewers to find out about the latest updates of the research, how many participants had been recruited, and results made available as the study progressed. The usefulness and impact generated through the use of these social medias is addressed in the Discussion, Chapter 8.

4.4.3 Social events

CCUK support groups were contacted to request if I could attend local events supporting IBD in Leeds to advertise the study (i.e., morning coffees, "Get your belly out", CCUK Forum in Leeds, Lunch and Learn in St Albans, London, Patient Engagement Day, and IBD fundraising night). At these various meetings and events my supervisor and/or myself have distributed

hardcopies of the invitation letters, information sheets and consent forms as well as flyers (Appendix P) to promote the study. I have also given talks and presented the findings as they were being released at various stages of the PhD to inform CCUK and other interested parties about the ongoing progress of the study (See Appendix Q for a list of the conferences and talks given).

4.4.4 Recruitment issues

IBD is often a ‘silent’ disease in that it is not visually obvious. A few people disclose having this illness, and even surgical interventions – such as having an external stoma bag – can be hidden to the naked eye (Defenbaugh, 2013). Hence, mothers with IBD would certainly qualify as a ‘hard-to-reach’ group. This meant that I had to approach as many local support groups as possible, and reach out to groups scattered all around England, Wales, Scotland, and Northern Ireland to recruit my sample⁵.

4.4.5 Selection rate and online survey

The adverts led to 98 participants contacting me, of which 57 returned the demographic sheet and continued to show interest to take part in the study after reading the information sheet (See Appendix S, Recruitment Map). The demographic sheet contained a general inquiry asking participants “How did you hear about the study IBD and Mums-To-Be?” which allowed me to identify which channel was most effective in reaching potentially interested candidates, the most commonly stated being ‘CCUK News’ (Table 9). It is impossible for me to know how the other 41 applicants were reached, as they did not state in their emails where they saw the ad for the study nor did they return the demographic sheet. A total of 28 participants met the inclusion criteria and ongoing need for diversity and, hence, were invited to enter the study. This amounts to a selection rate of about 30% of the total amount of responses received.

In order to avoid any disappointment, I generated a reasonably short online survey, covering most of the interview topics, to allow those 29 women who were not included in the study to share their stories. The survey allows the women to retain the benefit of their interest and, ethically, to provide an alternative way in which they could participate. The survey was designed and launched using the Bristol Online Survey portal on February 3rd, 2015 (URL://<https://leeds.onlinesurveys.ac.uk/ibdandmumstobe>). It was sent to three pilots, one of whom replied and provided positive and constructive feedback on her experience of filling in the questionnaire and the two others dropped out. The final version of the online survey was thus used as compensation to those who were prevented from entering the study. The survey was closed on June 30th, 2017 and 11 mothers with IBD out of the 29 who received the online

⁵ Appendix R details the map of the geographical location of all the participants who have entered the study (red pins).

survey filled in the questionnaire. The details of the sections of the questionnaire as well as the brief description table of the sample who answered the survey can be found, respectively in Appendix T and U.

Table 9 *Advertisement Success Rate*

	Frequency	Percentage (%) ⁶	Valid %	Cumulative %
CCUK 'News' Article	16	48.5	48.5	48.5
CCUK Facebook Group	11	33.3	33.3	81.8
CCUK Support Website	4	12.1	12.1	93.9
Word of Mouth	1	3.0	3.0	96.9
Missing	1	3.0	3.0	100
Total	33			

4.5 Sampling Techniques

Three broad types of sampling techniques were used to recruit the current sample: convenience sampling, purposive sampling and theoretical sampling. As Rapley (2014) argues, one needs to choose people carefully and for good analytical reasons as the claims made by qualitative research questions are often based on a relatively small sample.

4.5.1 Convenience piloting (n=1)

In the initial stages of the study, the testing of the timeline, the interview schedule (detailed in the Data Collection section), and the video-recording equipment were conducted with the first pilot *UCMumPi01C01*. This pilot participant was identified through convenience sampling: that is, a mother with IBD of my acquaintance who was willing to let me test data collection procedures with her. Review of this pilot led me to the following changes:

- rephrase the wording of some of the questions in the interview schedule,
- delimit how much time I must give for the participant to settle into the interview process and sign the consent sheet,
- and to purposely press the voice or video-recording button after the consent was taken.

A similar convenience approach was used to select the second pilot *CDMumPi02C01* who was referred to the study through Word of Mouth from the director of the Leeds CCUK charity group. This second pilot was included in the sample and analysis. Small changes were again made to the interview schedule and sequencing of interview process as a result of this second pilot, the number of revisions of the interview schedule along with the details of the change is discussed in *Designing the Interview Schedule and Conducting the Interview* (section 4.8).

At that point in time of the study, (2 months post start date) it was difficult for me to assess how long it would take to reach and recruit participants using community channels. I also could not tell which participants would be easy or difficult to reach. For example, I suspected

⁶ All percentages and frequencies are rounded up to the first decimal.

that women living in rural areas might have less visibility to the advertisements and could be less attuned to social media. I thus decided to start recruitment as soon as possible to avoid any delays in the PhD.

4.5.2 Purposive sampling: maximum variation and intensity sampling (n=6)

The first phase of sampling included six participants based on their differences in geographical location, who were hence in the care of different healthcare authorities (see Table 12 for chronological selection of participants and city of residence). Women were recruited from different areas of England, such as Leeds, Barrow-in-Furness, Crewe, Lancashire, Solihull, and Dumbarton (Scotland). This subtype of purposive sampling is referred to as *maximum variation* as it selects each case to be substantially different from the other. Participants were different notably on geographical location, thus access to, and service organisation of, care. Maximum variation reports the uniqueness of each case on the heterogeneous key dimension (Patton, 2002). The six interviews were conducted during the months of October to December 2014 and led to further refinements to the interview schedule (see section 4.8). Another selection criterion for recruitment during this phase was variation of the women's life events: thus, one participant was pregnant at the time of the interview, another had been living with an external stoma bag for over 23 years, and a third was classified by medical experts as 'IBD unclassified'. This type of sampling is referred to as *intensity sampling* "where the phenomenon of interest [notably, total bowel removal, IBD type, and current pregnancy] is manifested intensely" (Patton, 2002, p. 234).

4.5.3 Purposive sampling: maximum variation and criterion sampling (n=13)

The second phase of recruitment occurred at the beginning of the month of February 2015 until the end of May 2016. During the months of February and March 2015, three participants were selected who were living in and around the South of England (near London). This rendered geographical variation from those recruited earlier and contributed in one way or another to the diversification of the sample. I had, at that point, more women diagnosed with CD than UC and hence decided to recruit a few women with UC and another with IBD unclassified⁷. Two of the women included were pregnant at the time of the interview. Also, I was mindful that most participants entering in the first phase were from middle to upper SES, thus one participant with

⁷ Although the participant had self-reported having IBDu in the demographic questionnaire, I found out in the interview that she was initially diagnosed for UC and 15 years later received a diagnosis of CD. I consulted with Dr Christian Selinger – a gastroenterologist at St James Hospital, Leeds, and he recommended considering her as having CD "I would describe this women's IBD as CD rather than IBD-U. There is usually firm evidence for a diagnosis of CD when we [medical doctors] switch from one [UC] to another [CD]" (personal communication, 10 October, 2016). She was henceforth considered as having CD.

a low SES was intentionally added in this second phase, who also happened to have been living with an external pouch for a few years.

During the month of April 2015, a woman from a South-Asian community contacted me and I immediately included her in my study as up until now I did not tap the experience of a participant from a non-White ethnicity. Lastly in May 2015, I recruited two women from Northern Ireland and undertook Skype interviews. However, only one was later included in the study who also happened to be pregnant with her second child at the time of the interview⁸.

4.5.4 Theoretical sampling (n=2)

The third and last phase of recruitment started in June 2016 and ended in October 2016, leading to the addition of the last two participants. After conducting some analysis and reaching the conclusion that the support network – particularly husbands/partners – were of extreme importance to many mothers with IBD, I thought of reaching for single women, and women from ethnic minority groups, who also might be on a different par with regards to support systems into which they can tap. I recruited two women – *CDMum22C02* and *UCMum23C02* – who were both from ethnic minority groups. The first woman was from Guyanese nationality and was raised in the UK, she was also a single mum. The second was a Black British Caribbean woman who was married. This concluded the recruitment phase of my main PhD study.

I must add that I had to refer a few women who met the inclusion criteria to the online survey as they did not meet the specified criterion (for example, age of child) or did not manifest the intensity of the phenomenon of interest. Hence, when a few women from the same geographical region contacted me, one or two were recruited and the others were referred to the online survey. Similarly, in the last phase, if a woman was not from an ethnic minority group, or if she was married, she was referred to the online survey. The total number of women who did otherwise meet the inclusion criteria but were deterred from entering the main study was 29.

4.6 Sample Characteristics

4.6.1 Sample size

Although 28 women were invited to take part in the interview, only 25 interviews were conducted. Three participants declined to enter the study, after setting an appointment date and time, due to ill health. I encouraged them to contact me once they felt better, but they never reached out and I respected their wish to refrain from participation. An additional three interviews were not retained for analysis. The first one was my initial pilot (*UCMumPi01C01*). I consulted with my lead supervisor and it was deemed that the interview schedule was too

⁸ The retention of only one of the two Skype interviews was mainly due to a limited transcription budget.

preliminary and that I was still testing my researcher skills for the first time. The second one was a Skype interview conducted with a woman from Northern Ireland (*CDMum18C01*). This was not included because I was able to schedule another interview by Skype with a woman from the same geographical region who was pregnant at the time of the interview (*CDMum19C01p*) and my lead supervisor and I opted to have the latter one transcribed and analysed as, unlike the first, she had agreed to the video-recording for both research and dissemination purposes. Hence, I made the decision to use the transcription budget for only one and go back to transcribe the other if I found it difficult to find participants with UC. I had more women with CD than UC and had to prioritise including equal numbers. The third participant who was not included was *CDMum21C03*. This was due to a technical failure with the recording device. The interview data was lost as the iPad recorded the session without the sound, even though I had conducted my usual test just prior to the interview. Despite my best efforts to involve technicians and Apple-knowledgeable friends, the video's sound could not be restored.

4.6.2 Description of included participants

The characteristics and description of the sample entered in the study (N=22) are provided in the two tables below (Table 10 and Table 11)

Table 10 *Description of Participants Age, at Gestation and Pregnancy, and Their Children's Age*

	Mum's age at 1st born	Mum's age at 2nd born	1st born age⁹	2nd born age	Mum's Age
Mean	31.32	32.33	4.24	2.82	35.82
Median	31.50	32.00	3.50	3.00	35.50
Mode	32.00	31.00	2.00	3.00	34.00
Std. deviation	4.06	2.61	2.69	1.59	3.42
Minimum	25.00	28.00	8 months	7 months	29.00
Maximum	39.00	37.00	10.00	5.00	42.00

⁹ The children's ages and mothers' ages are given relative to the time of the interview.

Table 11 *Description of Participants Age at Diagnosis, and Years living with IBD and Children*

	Diagnosis age	Years lived with IBD	Time from diagnosis until 1st born	Time from diagnosis until 2nd born
Mean	23.77	12.09	7.55	11.33
Median	22.00	11.00	7.50	12.00
Mode	13.00	3.00	-2.00 ¹⁰	.00
Std. deviation	8.79	8.84	8.60	8.02
Minimum	10.00	1.00	-6.00	.00
Maximum	41.00	25.00	22.00	24.00

The sample is composed of 16 White UK-residents, 1 South-Asian UK-resident, 1 Guyanese British, 1 Caribbean British, 1 Jewish British, 1 French British and 1 North American British. Eleven women have CD, ten UC and one IBD unclassified. They were for the most part educated at college level (50%) with another 8 women having an Apprenticeship level of education. Their average age at the time of the interview was 36 years (M= 35.82). These women have lived on average 12 years with IBD, with a range of 1 to 25 years. At the time of their first pregnancy, most women were in their early 30s with a range of 25 to 39 years of age at first-born child. This means that they had been living for about 7 years with IBD on average by the time they were pregnant for the first time. The entire sample was either married or in a long-term relationship, except for one participant who was divorced and were predominantly working part-time or stay-at-home mums.

It is worth mentioning that all women are, or were, in heterosexual relationships and, although no attempt was made to recruit mothers with a particular sexual orientation, it seems that participants who came forth were, most likely, heterosexual. The combined household income was affluent with the majority of the sample (n=17) earning 30,000 GBP or more annually. One could argue that it might be unethical to categorise women according to income or race. However, these delimitations were made to respect the contextualisation of the analysis and broaden the scope of the analysis to diverse background, although no attempt was made to classify or compare women according to race and SES per se in the analysis.

Most women had received their diagnosis prior to their pregnancy(ies), four women had received it during either the first (n=2) or the second pregnancy (n=2), and four participants were pregnant with their second child at the time of the interview. These latter four participants were respectively, 8 weeks, 13 weeks, 20 weeks, and 32 weeks pregnant when they contacted

¹⁰ The mode represents the most commonly given answer and -2 means that, more commonly (N=2), women were diagnosed two years after the birth of their first born. This is not to say that in my sample women were commonly diagnosed after the birth of their first child, as the median shows that more than half received their diagnosis 7.5 years prior to the birth of their first child. The mode just reflects that two of them received a diagnosis exactly two years after the birth of their first child, the rest of the sample had it at different times. Similarly, the mode is equal to zero in the following column as some women (N=2), have had their diagnosis during their second pregnancy or just upon birth of their second child. So, the time of diagnosis and birth are the same and they cancel each other out.

me to enter the study. At the time of the interview they were mostly in the second trimester, except for one who was already in her third trimester.

Table 12 *Description of Sample Characteristics*

		Frequency	Percentage (%)	Valid %	Cum. %
Ethnicity	Caribbean British	1	4.5	4.5	4.5
	Indian British	1	4.5	4.5	9.1
	Guyanese British	1	4.5	4.5	13.6
	American British	1	4.5	4.5	18
	French British	1	4.5	4.5	22.7
	Jewish British	1	4.5	4.5	27
	White	16	72.7	72.7	100.0
Marital Status	Single/Divorced	1	4.5	4.5	4.5
	Married/Long-term relationship	21	95.5	95.5	100.0
Education Level	Secondary School	1	4.5	4.5	4.5
	Apprenticeship	8	36.4	36.4	40.9
	Bachelor	11	50.0	50.0	90.9
	Master/ PhD	2	9.1	9.1	100.0
Work Status	Full Time ¹¹	5	22.7	22.7	22.7
	Part Time	13	59.1	59.1	81.8
	House Person	4	18.2	18.2	100.0
Household Income	Above 45,000 GBP < 30,000 GBP > and > 45,000 GBP	12	54.5	54.5	54.5
	15,000 GBP > and > 30,000 GBP	5	22.7	22.7	77.2
	Prefer not to say (prob. low SES)	2	9.1	9.1	86.4
	Missing value (prob. low SES)	2	9.1	9.1	95.5
		1	4.5	4.5	100.0
City of Residence	CDMumPi02C01: Leeds	1	4.5	4.5	4.5
	CDMum01C02: Leeds	1	4.5	4.5	9.1
	CDMum02C02: Solihull	1	4.5	4.5	13.6
	UCMum03C01p: Barrow in Furness	1	4.5	4.5	18
	IBDuMum04C01: Lancashire	1	4.5	4.5	22.5
	CDMum05C02: Crewe	1	4.5	4.5	27
	CDMum06C02: Glasgow (Scotland)	1	4.5	4.5	31.5
	UCMum07C02: Surrey	1	4.5	4.5	36
	CDMum08C01: Harrow	1	4.5	4.5	40.9
	CDMum09C02: Watford	1	4.5	4.5	45
	CDMum10C02: West Berkshire	1	4.5	4.5	49.5
	UCMum11C01p: Liverpool	1	4.5	4.5	54.5
	UCMum12C02: Huddersfield	1	4.5	4.5	58.5
	UCMum13C02: Birmingham	1	4.5	4.5	63
	UCMum14C01p: Chelmsford	1	4.5	4.5	67.5
	UCMum15C02: London	1	4.5	4.5	72
	CDMum16C01: Lewes	1	4.5	4.5	76.5
	UCMum17C01: Bicester	1	4.5	4.5	81.8
	CDMum19C01p: Lisburn (Northern Ireland)	1	4.5	4.5	86.4
	UCMum20C01: Claygate	1	4.5	4.5	90.9

¹¹ Two women were currently on maternity leave due to return to full-time work.

	CDMum22C02: Chard	1	4.5	4.5	95.5
	UCMum23C02: London	1	4.5	4.5	100
Number of Children (per household)					
	Single Child	10	45.5	45.5	45.5
	Two Children	12	54.5	54.5	100.0
Time of Diagnosis (relative to pregnancy)					
	Before pregnancy(ies)	15	68.2	68.2	68.2
	During first pregnancy	3	13.6	13.6	81.8
	Post-delivery/Between pregnancies	2	9.1	9.1	90.9
	During/ Post-delivery of second pregnancy	2	9.1	9.1	100.0
Number of Miscarriage					
	No miscarriage	13	59.1	59.1	59.1
	One miscarriage	9	40.9	40.9	100.0
IBD Type					
	Crohn's Disease	11	50.0	50.0	50.0
	Ulcerative Colitis	10	45.5	45.5	95.5
	IBD unclassified (IBDu)	1	4.5	4.5	100.0
Type of Treatment (current and past)					
	Medication ¹²	22	100.0	100.	N/A
				0	
	Surgery	7	31.8	31.8	N/A
	Dietary Management	15	68.2	68.2	N/A
	Therapeutic Counselling	6	24.5	24.5	N/A
	Treatment During Gestation	15	68.2	68.2	N/A
Currently Pregnant					
	Yes	4	18.2	18.2	18.2
	No	15	68.2	68.2	86.4
	Attempting	3	13.6	13.6	100.0
Time Elapsed to Conceive (1 st Born)					
	Unplanned	5	22.7	22.7	22.7
	1 to 3 months	7	31.8	31.8	54.5
	3 to 6 months	2	9.1	9.1	63.6
	6 to 12 months	3	13.6	13.6	77.2
	Between 1 to 2 years	1	4.5	4.5	81.8
	More than 2 years	3	13.6	13.6	95.5
	Not Mentioned	1	4.5	4.5	100.0
Time Elapsed to Conceive (2 nd Born) ¹³					
	Unplanned	2	9.1	9.1	9.1
	1 to 3 months	5	22.7	22.7	31.8
	3 to 6 months	2	9.1	9.1	40.9
	6 to 12 months	1	4.5	4.5	45.5
	Between 1 to 2 years	1	4.5	4.5	50.0
	More than 2 years	1	4.5	4.5	54.5
	Not Mentioned	3	13.6	13.6	68.2
	N/A	7	31.8	31.8	100.0
Child Gender					
	1 st Born Male (out of 22)	12	54.5	54.5	N/A
	2 nd Born Female (out of 12)	8	36.4	36.4	N/A
Recruitment Channel					
	CCUK Support Website	3	13.6	13.6	13.6
	CCUK "News" Article	9	40.9	40.9	54.5
	Facebook CCUK Group	8	36.4	36.4	90.9
	Word of Mouth	1	4.5	4.5	95.5
	Missing Value	1	4.5	4.5	100.0

¹² Only three women were on no medication at the time of the interview.

¹³ Only 12 women had two children at the time of the interview but an additional four were pregnant were their second child which allowed the estimation of the number of months it took them to get pregnant the second time (total count 15). The woman who had twins was only counted once.

4.7 Data Collection

The data was collected interactively using face-to-face semi-structured interviews (except for two that were conducted via Skype) consisting of open-ended questions. An interview is defined as a conversation with an aim (Briggs, 1986) and semi-structured interviews are the most widely used approach to collect data in the social sciences, particularly in qualitative research using a thematic procedural categorization (Hugh-Jones, 2010; Madill, 2012). Semi-structured interviews are a good tool to capture the perceptions and experiences of women becoming mothers within the context of IBD as it allows making use of open-ended, non-leading questions to promote insight into the participants' views. The interview generates a dialogue between myself and the participant but its main aim is to promote relevant monologues from the interviewee consisting of extended rich description and narratives which provide me invaluable data. I will discuss my role as an interviewer in Designing the Interview Schedule and Conducting the Interview section below.

The interviews were video-recorded using an iPad video-recorder placed on a tripod for height-adjustments and linked to a tie-microphone for sound enhancement. The participants were also sent, prior to the interview, a "Guideline to High-Quality Recording" sheet suggesting 'dos and don'ts' in terms of accessories and clothes on the day of the interview (Appendix V). According to Gibbs, Friese, and Mangabeira (2002), digital technology is used as a main data collection tool for two reasons. First, it is a ubiquitous technology, nowadays used by most people to record their own videos whether to remember their holidays or moments in everyday life, making it a tool both familiar and comfortable to most interviewees. Second, it is cost effective in terms of time, effort and money as the camera can capture words and facial expressions saving the interviewer time and effort from taking hand-notes. This also ensures the preservation of precious moments within the verbal and nonverbal dialogue. Third, the technology has come to be relatively cheap with time rendering it more mainstream and intuitive to use. Lastly, having the recording in .mp3 audio format as well as .mp4 visual format allows for an easy transfer from the recording to YouTube channels to construct the medleys.

The interviews were, for the most part, held at the participants' preferred location (their home) and were all video-recorded except for one participant who expressed the wish to be only audio-recorded. As mentioned, one of the Skype interviews was video-recorded using the screen-recording option on the laptop. That said, two of the women who were video-recorded agreed to it on the condition that I would be the only ones to see the video. In summary, I collected 19 videos for which I had permission to use for the medleys, 1 audio-recording and 2 videos for research purposes not to be shared with the public.

4.8 Designing the Interview Schedule and Conducting the Interview

Several drafts were generated and refined before finalising the first interview schedule for pilot testing. The original schedule (see Appendix W) had several common questions drawn from readings on the impact of IBD within the nuclear family (Cooper et al., 2010, 2011; Mukherjee et al., 2002b; Mukherjee et al., 2002a). This first draft was later refined and polished by the input from a Facebook brainstorming group composed of some of my relatives and close friends¹⁴ (Appendix X). The various answers and concerns expressed by the group prompted the need to have a timeline inserted at the beginning of the interview and to organise the sequence of questions in order of pre-pregnancy, pregnancy, and post-partum time. The schedule tested with the two pilots had seven sections and comprised a total of 23 questions with probes and prompts (Appendix Y). After receiving feedback from the second pilot, the interview schedule was again updated and used in its third version for the following five interviews (see yellow highlights in Appendix Z). In addition, assessing this set of questions at the start of the second phase of recruitment led to the insertion of three more questions and a few more prompts. Lastly, upon the third phase of recruitment, interviewing a single mother led to the rewording of the intimacy question in the sixth section of the interview schedule (Appendix AA) from “how did this transition to motherhood and IBD impact your couple’s intimacy?” to “how did this transition to motherhood and IBD impact your intimacy with men?”. In this way, the interview schedule was refined four times before obtaining the final version.

The language used for the questions was clear, precise and, to the best of my knowledge linguistically, appropriate. For example, I had used the term “labour day” to ask how the experience of giving birth was, but I noticed that often women were puzzled with the term so I had to rephrase it to “delivery day” during the interview. It is possible that my initial training at the American University of Beirut in Lebanon came in the way of my speech and led to some adjustments to tailor the dialogue to the British idioms.

4.8.1 Aim of schedule

All the questions in the interview schedule were designed to address the research question capturing the essence of the experience of women with IBD transitioning into motherhood. The questions promoted open exploration of the thoughts, feelings, and lived experiences of the participants.

4.8.2 Question types

The schedule comprised feeling questions (e.g. “How did their reactions make you feel?”), sensory questions (i.e., “How did you feel physically?”), as well as thought and knowledge

¹⁴ Although the brainstorming group (N=45) was free from any chronic illness, they were all women who had undergone the transition to motherhood and who could provide insight into their experience.

questions (i.e., “Did you have any expectations about becoming a mother with IBD?”). The interview starts with a background question as an icebreaker (i.e., “Can you tell me about when you discovered that you have IBD?”), although, most of the background questions would have been previously gathered from the demographic sheet.

4.8.3 Construction and sequencing

The schedule made use of non-leading questions, such as “Can you tell me about the background of your pregnancy?”, as well as prompts (“Were you on any type of treatment at the time of your pregnancy?”) and follow-up questions (“Can you elaborate on what you mean by [corresponding word insertion]?”) inserted to make sure I ask about the full range of the participant’s experience. Probing questions phrased as “why-questions” were not used and were, to the extent possible, avoided while conducting the interview as they might imply blame or judgement at times, or force the participants to provide a justification or ad hoc rationalisation at other times (Madill, 2012). I preferred to use the phrase “How come?” or “How so?” to promote the participant to give me a bit more detail on a particular topic.

The interview starts with the more neutral¹⁵ questions and progressively moves to the possibly more sensitive questions. The interview also balances between negatively toned and positively toned questions, such as “Can you tell me about the most difficult aspects of becoming a mother with IBD?” followed later on by “Can you tell me what have been the most positive aspects of becoming a mother with IBD?” Throughout the process of designing the schedule I reflected upon the sensibility and sensitivity of the questions by echoing, “How would I feel if I were asked this question?” This simple self-reflective exercise permitted the elimination of blunt or insensitive questions initially placed in the demographic section as well as in the interview schedule. Needless to say that, at times, sensitive questions had to be asked; for example, when a participant reported having a miscarriage. I usually tackled the question with a disclaimer saying: “I am going to ask you a sensitive question and please feel free to decline to answer if you don’t want to answer. In the demographic sheet having had more than [adequate number] pregnancy(ies), I was wondering if you could tell me about the other(s).”

The interview concludes with three ‘clean-up’ questions aiming to provide a positive summarizing tone to the interview and generate any new ideas that could have been missed during the process. The questions are: “If you were to describe one thing you know now you wish you knew before you became a mother with IBD what would it be?”, “If you could provide tips, do’s and don’ts, to other mums about to embark on the journey with IBD what

¹⁵ One ought to keep in mind that the words ‘neutral’ and ‘sensitive’ in reference to the nature of questions are relative to the context of chronic illness. A neutral question within this specific context is seen as asking when IBD was diagnosed; and a sensitive question would be one asking about how the person felt when she found out she was pregnant with IBD.

would they be?”, and finally “Is there anything important to becoming a mother with IBD that we have not covered that you would like to add?”.

4.8.4 Timeline

The timeline was perceived as a useful tool to generate contextual data at different periods of the transition to motherhood. Key dates were gathered from the demographic sheet prior to the interview and a timeline with the dates printed were presented to the participant at the start of the interview (see example from first pilot in Appendix BB). Each participant was asked to take a few minutes to check the timeline and mark any additional important events that were significant to her transition to motherhood. This gap of time before the start of the interview was considered good practice as it enabled participants to organise their thoughts and, to the extent possible, ensure that they talk about all aspects deemed important. Later on, as I was entering data into SPSS to present the results of the demographic sheet in a table (see in text Table 10, 11 and 12), participants’ notes and/or corrections they made helped me make better sense of the occurrence of their life events (e.g., which surgery happened when, when symptoms occurred, and diagnosis was established). Participants sometimes filled out the demographic sheet leaving blank answers although the option “prefer not to say” was provided. However, I was often able to retrieve the missing information by reading the transcripts and using the timeline to trace the sequence of events in their lives.

4.8.5 Practicalities and preparations

I made it a point to double-check the recording equipment the day before the interview and to follow at all times the appropriate security steps as laid out by the BUDDY system detailed in Appendix E. On the day of the interview, I also tested the tie microphone whilst placed on the participant’s clothing to make sure all recordings were well captured. Furthermore, I made sure I dressed appropriately and opted for a casual-smart attire to avoid creating distance between the interviewee and myself while still conveying professionalism. For similar purposes, I also avoided using any jargon or medically-laden terminology to avoid an atmosphere of dominance or to over-intellectualise our exchanges. Despite all these preparations, and double-testing the microphone on the day before and immediately before starting the interview, the iPad did glitch during one interview and no sound was recorded for the entire hour of recording. Unfortunately, this interview could not be transcribed and had to be excluded (CDMum21C03) from the study.

I also had to do some planning around interviewing scenarios. For example, I had to rehearse what I ought to do in case the participant: (a) asked me questions about my thoughts during the recording, (b) seemed unable to answer a question, or (c) had a distressed reaction (e.g., cries). In the first instance, I opted to politely decline from answering any personal or general questions during the interview and say that I was happy to discuss this after the interview is finished.

CDMum16C01: [...] with the food reintroduction as well (.) the food became you could have one thing this week so it's potato all week (.) then the next day you could have one thing this week so it didn't become a joyful experience (.) of (.) ooh let's have a roast dinner (.) it became (.) well [CDMum16C01] can have mashed potato and that's it (.) you know (.) [CDMum16C01] can have only pears this week(.) so it became quite a (.) it was quite a defining thing (.) and nothing about eating was enjoyable at all (.) is that quite a standard thing(.) have you found that (.) I guess you can't answer that question but is that something that you've found from other people?

I: Um (.) May I answer that maybe a little after (.) do you mind?

CDMum16C01: Okay (.) no no (.) not at all (.) no (.) that's fine (Line 875)

In the second instance, if a participant seemed unable to answer a question, I encouraged the participant to make their own sense of the question and provided any relevant information, however limited or apparently tangential if they were still unable to answer.

I: Did you during that journey seek to discuss you know (.) being pregnant with IBD with anyone around you?

CDMum06C02: Do you mean with other people with IBD or?

I: What is your first thought?

CDMum06C02: I certainly did discuss it with my close family and friends(.) um I don't know anybody else that's got (.) um Inflammatory Bowel Disease and I don't (.) I have got a friend that's got a stoma um but she's never had any children (.) um so I didn't have anybody that I could to that I know would know what I felt physically or otherwise (.) but certainly yeah I did (.) and I've got close family and friends that I could speak to about what I was concerned about and how I was feeling (Line 348)

In the last instance, that is, if a participant expressed a distressed reaction, I asked her if she would like to take a break from the recording and gave her as much time as needed. In the unlikely event that the distress persisted, I had planned to ask if she wished to stop the interview altogether, but that scenario never presented itself even though some participants did burst into tears and the interview was interrupted for a few minutes.

CDMum02C02: [...] I had to (.) I only popped over to the retail park which is five minutes away (.) we all got in the car(.) I was absolutely fine (.) I thought I was gonna be OK(.) we pulled up at the retail park (.) I couldn't (.) I was just about to get the little one out the car and I had to put her back in the car as quick as I could (.) drive back to the house as quick as I could 'cos I knew I was gonna have an accident 'cos I thought I can't physically get them both out the car (.) get into the store and get to the toilet as well as not have a complete accident (.) So I had to come home and they both had to sit on the bathroom floor while I sorted myself out and had to get back in the shower (.) I've had to throw so many clothes away but it's just awful that they get to see that ((starts crying)) sorry

I: Would you like us to pause for a minute?

CDMum02C02: Yeah please

I: Of course (Line 553)

Reflecting on the instances of participant distress, I can say that initially I used to jump to stop the interview partly because the participant's reaction was very uncomfortable for me to witness. With time and experience, I started to wait a little bit longer, respecting their feelings and wish to stop talking at that moment, before interrupting to stop the interview. I noticed that this slight pause often resulted in participants wanting to continue talking and they often declined to stop the recording. It is very humbling to be a part of their lives and to have the privilege to hear their stories, and I developed the utmost respect for my participants who fought through their respective diagnosis and life events.

4.8.6 Pros and cons of face-to-face semi-structured interviews

Both face-to-face and semi-structured approach to interviewing has several disadvantages and advantages (Braun & Clarke, 2013). In terms of disadvantages, having to meet participants and asking relatively open-ended questions can be considered a time-consuming experience for both the researcher and the interviewee. Notably, the interviews I conducted lasted on average 71 minutes with some just short of 2 hours. Also, I mostly had to travel long distances to reach the participants' homes. During the travel time, I wrote reflective notes of the interview to retain as much detail of the day as possible and went back to the University of Leeds to store the data safely. The whole process usually took me two days. Sometimes, I also had to stay over for a few days and travel from a central point to interview participants who were living relatively nearby. I never had more than one interview per day but these trips were taxing physically and emotionally. Another downside to face-to-face semi-structured interviews is that it lacks anonymity as the interviewer and interviewee often meet, which might deter some participants from agreeing to take part in the first place. This was not the case in my experience, as almost 100 women came forth after viewing the advert of which 60% were still willing to take part after reading that the interview would entail video-recording (see Appendix S Recruitment Map). Lastly, asking open-ended questions, in a non-leading way requires expertise to juggle the response of the interviewee, whilst keeping in mind the aim of the study and the other probes and questions of the interview schedule. I have sometimes missed a question during an interview. Also, sometimes participants were not as talkative or elaborate in their answers which forces the interviewer to sit in silence to encourage them to develop their answer and ultimately probe more whilst avoiding being too directive and structuring the orientation of the questions.

On the other hand, in terms of advantages, using semi-structured interviews allows for the generation of rich, contextualised data tapping into the lived experience of the participants using a relatively small sample size. It also allows flexibility and researcher control over the interview sequencing and breadth of questions. I was not rigidly adhering to the interview schedule in terms of order or type of question, but I tried to remain close to the wording on the schedule for consistency across participants. The popularity of semi-structured interviews stems from the similarities it shares with everyday conversation, and I was able to choose to skip

questions previously covered by the participant and expand on newly arisen areas relevant to the research questions. For example, in one instance, a participant, *CDMum05C02*, mentioned using genetic testing to determine the likelihood of having a child with IBD, so I took the liberty to ask a few questions around this particular experience which was outside the interview schedule. This flexibility enabled me to remain close to the research question and aim of the interview while respecting the freedom of the participant to say as little or as much as they want on relevant experiences. These unanticipated avenues were a mark that the interview process was provoking rich and relevant material.

Moreover, conducting a semi-structured interview, within a critical realist stance (which will be detailed in the Analytical Procedures section), allows the interviewer – when there is only one interviewer – to develop their own style and way of asking questions (Rubin & Rubin, 2005). Developing a personal style enables the researcher to establish rapport, which is defined as the “quality of relationship (...) which encourages respondent to speak as freely and frankly as may be, without at the same time diverting the interviewer from his [her] reportorial duties or compelling the continuance of the relationship beyond the optimal point” (Benney, Riesman, & Star, 1956, p. 143). I was mindful that it was my responsibility to monitor my tone, wording, and body language while conveying my questions to help the interviewee feel at ease and relax during the interview. I believe my previous Master of Arts and training in clinical psychology was extremely useful in this process.

Lastly, interviewers are usually trained and encouraged to say as little as possible to reduce their influence on the participants’ responses (Madill, 2012) and even then, the interviewer’s influence whether through conversation, facial expressions, or the type of questions asked cannot be separated from the process of data generation. It was challenging to maintain momentum, and at the same time remain in silence when need be to invite the participant to talk more. However, I made use also of non-evaluative backchannels, such as “mhm” and “hm”, to encourage the participant to speak while remaining as quiet as possible to maintain the flow of their thought and to not inadvertently suggest to them particular responses or answers.

4.9 Analytical Procedures - Thematic Analysis

The transcripts were analysed using Thematic Analysis (TA) as outlined by Braun and Clarke (2006). The following sections will elaborate on data preparation (transcription level) and definition of TA. I will give some considerations to the epistemic, ontological and axiological stance in this research and elaborate on the steps taken to conduct the analysis. The last section will discuss some of the pros and cons of using TA.

4.9.1 Transcription level

Transcription was orthographic, which is a verbatim transcription of what was said during the interview with the use of pauses, hesitations, false starts as well as visual elements of the conversation (Braun & Clarke, 2013). In relation to the latter, only through looking at the video can one truly situate the spoken language and interaction into contextual form and, thus, adding notes to the transcript on pertinent non-verbal behaviour facilitated my interpretation of the material. This level of transcription is considered appropriate for TAs (Braun & Clarke, 2006), as the emphasis is slightly more on what was said rather than the specifics of how it was said. I followed Hugh-Jones and Madill's (2009) 'Jefferson-lite' notation key for transcription which includes some prosodic and paralinguistic behaviours such as crying, short pauses (.), longer pauses marked in seconds (3), laughter ((laughs)), [omitted words], [masked words] (i.e., [Daughter's Name]), loudness (NOW) and stressed or accentuated words (immediately). I also denoted the onomatopoeias found in the speech (um, oh etc.). I thus conveyed non-semantic sounds, slangs and vernacular terms without 'cleaning'. For example, one participant used to call her medication Azathioprine Azos, and another referred to "wee man" to mean her son. Hence, I kept the transcription as close as possible to the terminology used by the participants.

Each transcript received from the independent transcriber was reviewed twice for accuracy: first listening to the audio while going through the texts to correct any mistakes or omissions and a second time while looking at the video (when available) to ensure the interpretation matched. I removed all comas and full-stops as one cannot really delineate punctuation in a verbal dialogue. Reported speech was delineated with ' '. So, for example, if a participant was reporting what the doctor told her, I would use ' ' to mark the difference with her words. The independent transcriber sometimes left blanks [15:45] with minutes in brackets where she couldn't decipher what was said. I was able to fill these blanks from memory as I could vividly remember what was discussed in the interview.

Nevertheless, no transcription is unselective (Kowal & O'Connell, 2014) or a facsimile of what was discussed in the interview. The specification of level of transcription is merely an attempt to present the process of transcription as transparently as possible and also to acknowledge awareness of the inherent limitation of the process. Moreover, one can argue that to be immersed with the data, one should do the transcription of the data and sit with it from beginning to end (Kowal & O'Connell, 2014). This shortcoming in the research is mitigated by having two set of eyes, myself and the independent transcriber reviewing the transcripts. Also, the independent transcriber has the advantage of being trained in the art of transcription compared to myself – a novice in the field of transcription. Having that other expert set of eyes reduces the chance of omitting fillers or repetitive words leading to a change and maybe loss of the meaning. Moreover, as stated, I checked the transcript very carefully and reviewed also the video footage as part of this process.

4.9.2 Thematic Analysis defined

Thematic Analysis, is a method that codes, analyses and depicts patterns across a given *dataset*, or throughout a *data corpus* in order to address a particular research question, in this instance, ‘What is the lived experience of women who transition to motherhood within the context of Inflammatory Bowel Disease?’. TA was first developed by Holton (1973), however Braun and Clarke clearly delineated the terminology and elaborated a step by step approach to conduct TA. The terminology used in TA is the following:

- *Data corpus* represents all the data gathered for the study, here 22 transcripts;
- *Dataset* represents a lesser number of interviews, so less than 22 interviews that depict a specific pattern;
- *Data item* represent a single unit of transcript, so one interview;
- *Data extract* is a passage or chunk of data taken from a particular interview for illustrative purposes;
- *Code* is a title attributed to a specific passage, or data extract, because it has meaning and significance to address the research question: that is, it captures the gist of an idea;
- *Sub-theme* constitutes an amalgam of several codes that define one aspect of a larger theme;
- *Theme* is a ‘prevalent’ pattern of responses that captures the essence of the research question and could encapsulate two or more sub-themes;
- *Concept* is an overarching idea encapsulating two or more themes.

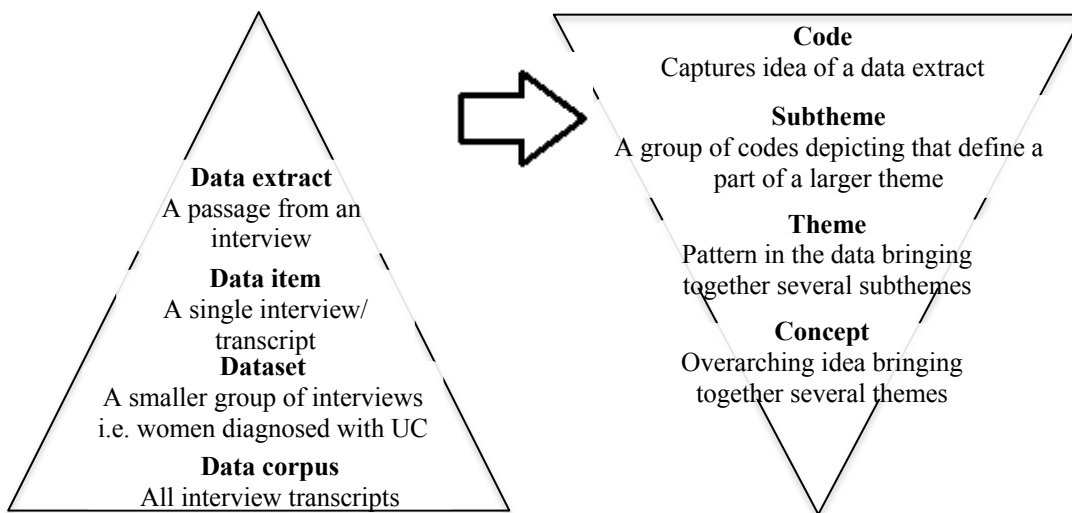


Figure 4. Visual mapping of the terminology used in Thematic Analysis¹⁶

¹⁶ The layout of the triangles reflects quantity of the discussed terminology, i.e. data corpus represents a larger quantity of interview compared to a dataset. Similarly, there would be many more codes generated than sub-themes and themes. However, if one was to look at the applicability of the

The main premise of TA rests on the active role of the researcher in identifying the patterns in a given dataset and does not conceptualise themes as ‘emerging from’ the data. The latter perspective implies a passive role for the researcher and a fatalistic approach that anyone who seeks to analyse a dataset using TA will eventually reach, more or less, the same conclusions since it posits the assumption that the themes in some way ‘pre-exist’ in the material and are not generated by the researcher.

4.9.3 Dialectics

According to Braun and Clarke (2006), an important aspect of conducting TA is to provide an explicit description of the choices that I had to make as a researcher both before and whilst doing the analysis. In this section I will describe the various dialectics and questions that Braun and Clarke (2006) recommend considering and outline in some detail the analytical procedures I used. The section will thus cover: (a) what counts as a theme; (b) my use of both latent¹⁷ and semantic thematisation; (c) why I chose an inductive, as opposed to a theoretical, analytic approach; (d) which of my analyses represent a rich description of the entire data corpus and which analysis represents a detailed account of one aspect of the data; and lastly (e), the epistemology and ontology adopted in this research. It is worth noting, the dialectics of each analysis reflected in the three Chapters 5, 6 and 7, will be iterated at the introduction of each chapter to ease the reader into the respective level of analysis provided.

4.9.3.1 Theme delimitation

As mentioned earlier, keeping a reflexive journal and having coding tables and excel sheets were good practice to help me trace back the steps I took, and choices I made, in creating my themes and concepts. For convenience, I will describe what constitutes a theme in my research using examples from my first and second chapter of analysis (Chapters 5 and 6).

A theme “captures something important about the data in relation to the research question and represents some level of patterned response or meaning within the dataset” (Braun & Clark, 2006, p. 10). In my research, I considered a theme to be a recurrent experience, description, or explication of thoughts conveyed by the participant relevant to their transition to motherhood with IBD. The word ‘recurrent’ does not imply a specific frequency or denote a particular prevalence within a data item, set, or corpus. I did not quantify ‘how much’ a pattern, depicted through codes, ought to be reflected in the data corpus to be considered relevant or sufficient to become a theme. It was important, however, that the themes that were refined and labelled as such did appear a number of times across the data corpus or datasets. However, sub-

terminology then the pyramid on the right-hand side would have to be inverted as concepts would enclose meaning and applicability across the data corpus.

¹⁷ The terminology in this section is progressively elaborated as each question is addressed in the following paragraphs.

themes that constitute various aspect of an overarching theme did not always appear consistently across the data items.

Take for example the Concept of *Blurred Lines*, detailed in Chapter 5, which captures the ways in which having a diagnosis of IBD parallels experiences lived in the transition to motherhood. Looking closely at the three themes of this concept labelled *Need for Readiness*, *Lifestyle Changes* and *Monitoring Personal and Physical Development*, one can note that the theme *Need for Readiness* is found throughout each data item and across the data corpus, and comprises five subthemes: *shocks and secrets*, *need for maturity*, *identifying blame*, *fear of mortality* and *seeking others' experience*. If participants contributed to a subtheme, each did so in a different way. In order to clarify visually this point, I have placed in Appendix CC, Appendix DD, and Appendix EE contribution tables for each of the three themes elaborated in the concept of *Blurred Lines*. Each theme and respective subtheme were depicted at the level of the data item and marked with an "X" when found in the data, whether it was in a sentence, in a word, or several pages. The themes and subthemes appeared in most interviews between 20 to 22 data items. In this analysis, prevalence is reflected at the level of the data item and across subthemes, themes and concepts.

Looking more closely at the subtheme *fear of mortality* (refer to section 5.1.4 page 136), one can see that not all participants contributed to it and those who did, expressed it in quite different ways. Some women conveyed a fear of labour complications, others a fear of foetal deformities or survival and the comfort of echography scans during pregnancy, and some even spoke about the fear of dying. Hence, although actual content could be quite different, what was important in determining a theme and subtheme was that I perceived, and could provide an argument for, shared *meaning* in relation to the central concerns of my research: in the example given, there were parallel features between the transition to motherhood and having IBD.

4.9.3.2 Latent versus semantic

A latent theme is one that is conceptualised or inferred from the data, that is, derived from ideas that are relatively implicit within the participants' descriptions. A semantic theme is one that is data-driven – 'bottom-up' – and hence derived closely from participant descriptions, including the actual words they used. Referring back to Appendices CC, DD, and EE, one can notice the letters (L) and (S) at each level of the concept of *Blurred Lines* to depict whether the themes and subthemes were predominantly¹⁸ more semantic (S) or latent (L). Most of the themes in the *Blurred Lines* concept are semantic, meaning that the codes, which constitute the cornerstone of the themes developed from the interviews, are predominantly data-driven. For example, the theme of *Lifestyle Changes* has all eight subthemes coded semantically: *regime alterations*,

¹⁸ I had to use the word "predominantly" as there are always exceptions, rarely does one subtheme or theme strictly abide by one coding system.

libido loss, dependence, financial and career implications, relationship and network changes, sleeplessness and fatigue, constant worry, and adapting to uncertainty. Moreover, the subtheme *sleeplessness and fatigue* has its name directly derived from participants' extracts, the subtheme depicting – as the name implies – how both IBD and motherhood have reduced their sleep and exacerbated their fatigue.

When I was in [South of France City Name] I woke up (.) it was time for feeding (.) and I felt horrible (.) it's just (.) I couldn't do it anymore (.) and I felt very (.) not guilty (.) but a bit guilty about it (.) and I thought if I don't stop (.) I'm going to go into depression (.) because I was that tired and that, so (.) um(.) I stopped (.) but I didn't stop totally (.) I kept two feed (.) so I just (.) introduced the bottle slowly (.) so that better for my boobs to go down and um (.) I didn't feel that guilty then, so I was only doing the (3) one-twice a day (.) I think (.) That's how I fed (.) that's how I (.) But the feeding part was quite good actually (.) I did enjoy it (.) Up until this point (UCMum17C01, Line 441)

On the other hand, the subthemes *fear of mortality* and *seeking respite*, taken respectively from *Need of Readiness* and *Monitoring Personal and Physical Development*, they are mostly coded latently as shown in the following extract:

It was whether I'd be able to look after the baby if something did go wrong in the birth whether I'd be able to look after the baby afterwards if they'd accidentally cut my bowel or (.) 'cos when you have the forms for an emergency section it does actually say (.) you know (.) they're not responsible if they accidentally nick your bowel or (.) you know (.) or your bladder (.) you know (.) all these warnings that are obviously they're extreme but you do take it all in (CDMum02C02, Line 121)

I coded this excerpt latently as *fear of mortality* given the phrase “if something did go wrong” because: (a) giving birth, whether naturally or not, still carries risks for women's life, even though medical advances have reduced this risk; (b) it is reasonable to assume many women will avoid stating directly the appalling idea of dying in childbirth, hence alluding to it obliquely; and (c) other participants did make this fear explicit in similar descriptions of possible complications during birth. Braun and Clarke (2006) state that “a thematic analysis typically focuses exclusively or primarily on one level” (p.13) and in this thesis a semantic level of theme depiction was used primarily, possibly given the relatively ‘concrete’ embodied experiences and chronological events my participants were asked to describe. However, I had to alternate sometimes between latent and semantic thematisation to conceptualise beyond the data-driven meaning – in the example of *Blurred Lines* focused on here – in order to capture the often-metaphorical parallels between having IBD and being pregnant.

4.9.3.3 Inductive vs. theoretical

The codes, subthemes, themes and concepts can also be produced in one of two ways: inductively or theoretically. In the inductive approach, the themes are driven by the data collected in the interview. In the theoretical approach, the themes are driven and/or framed by pre-given, ‘top-down’ conceptualisations and interests. In this thesis, the patterns have been

identified using mainly an inductive or bottom up approach, with one instance of imposing theoretical structure to the analysis. The reason for favouring an inductive approach is that not enough research has been conducted on the topic of motherhood and IBD, thus imposing a specific frame could be premature and lead to the loss of important patterns and meanings in the interviews. In Chapters 5 and 7 the analyses are entirely derived from the data and were not approached through the lens of a prior theory or pre-existing frame. However, in Chapter 6 *Transitional Challenges*, the themes, subthemes and codes, are inductively derived, but also structured around a top-down imposed framework. I looked at my data through the lens of the naturally occurring trajectory of pregnancy, notably, from the pre-pregnancy or nulliparous life, to conception, gestation, birth, and early years of motherhood. Although these phases are not based on a theory, they rather reflect the chronological events that women go through whilst becoming mothers, it is still considered a theoretical top-down approach as I deliberately imposed these structured cut-off phases to form my analysis. I named these five phases: *Nulliparous Life*, *Planning for Pregnancy*, *Conception and Gestation*, *Labour and Breastfeeding*, and *Early Years of Motherhood with IBD*. In each of the phases, four themes, and their respective subthemes, forming the concept of *Transitional Challenges* are revealed: *Burden of Knowledge*, *Weighing Decision-Making*, *Blame and Guilt*, and *Ambivalence towards Healthcare Professionals*. This was the only instance where a top-down approach was used in the thesis.

4.9.3.4 Rich description vs. detailed account

Furthermore, parts of the analyses were depicted as a rich description of the data, that is a description of the entire dataset and/or corpus, and parts were more reflecting a detailed account of a particular theme of the analysis. This distinction allowed me to split my analysis into the three chapters *Blurred Lines* (Chapter 5) and *Transitional Challenges* (Chapter 6) and *Reflecting on Others* (Chapter 7). Chapters 5 and 7 tackle themes and subthemes which apply across the entire data corpus. They both reflect a rich description across all 22 participants. Conversely, Chapter 6 details the Concept of *Transitional Challenges*: it is an account, as the name implies, of the challenges women becoming mothers with IBD face. The challenges include a burden of information, making decisions, feeling blame and guilt, as well as feeling ambivalent towards healthcare professionals. The analysis hence focusses on detailing the specific challenges and presents a timeline of looking at those challenges and the claims made from the analysis. This timeline is unique and specific to the dataset of women who have received a diagnosis prior to their pregnancy (the analysis is derived from 15 participants). However, the timeline also incorporates examples of how it could apply somewhat to women diagnosed during, between, or shortly after their first pregnancy. The analysis also points out that participants having their diagnosis after their last pregnancy fall outside the proposed timeline of *Transitional Challenges*.

4.9.3.5 Epistemology and ontology

Epistemology is defined as the theory of what constitutes knowledge as well as its limits (Carter & Little, 2007). All research takes an epistemic stance, whether it is made explicit or not, in that, assumptions are made about what constitutes knowledge and what does not. Similarly, all research will posit an ontology – theory of being – which will encapsulate assumptions made about the nature of the material objects of study or structures of the social world (Carter & Little, 2007). In this study, I position myself as a critical realist (Maxwell, 2012). Critical realism can be understood as having a realist ontology and relativist epistemology. Hence, in terms of epistemology, I take the stance that my participants provide me their reality and lived experience through words and, subsequently, that they must draw on the available reservoir of linguistic resources to them to convey the meaning they give to their lives. Linguistic resources are complex and creative and allow many different ways of conveying information. They are, however, at the same time constrained in terms of time and place: that is, historically and culturally. Moreover, linguistic resources are not a neutral medium of communication but contribute to constructing the meaning given to raw experience through the words and concepts available to do so. Thus, as a relativist epistemology, critical realism takes the stance that knowledge is partial and culturally situated.

In terms of ontology, I am assuming the real existence of physical bodies that can experience illness and, when female, are usually, in the woman's fertile years, capable of conception and giving birth. I take a deliberate stance in accepting that my participants' IBD is real and that the symptoms experienced and reported by them are a physical manifestation of the disease. Similarly, I accept my participants' reports of becoming a mother and that their children are a physical manifestation of their transition to motherhood.

From an ethical, or axiological, point of view taking a critical realist position was appropriate to my work. I asked my participants to self-define as having a medical diagnosis of IBD and children of the age required for my study (realist ontology), but I did not seek further proof and considered it respectful to take their description at face value. In terms of knowledge, I respected my participants' accounts during interview as their reality and truth while accepting also that different participants may have different truths and experience different realities to each other – and to me. I also accepted that their accounts may not be always internally consistent and may change over time given that they may use the interview to 'work out' a meaning and that this meaning may change in the light of future experiences. A relativist epistemology allows me to make knowledge claims in terms of my understanding of my participants' truths as conveyed to me at the time of interview. This is still knowledge even if it is defined as always provisional.

In summary, there are many decisions that needed to be made in how to operationalise TA in my study. I have explained the main decisions shaping my analysis in the above paragraphs including the delineation of themes as a pattern that is recurrent across each data

item, the predominant use of a semantic level of analysis, and an inductive approach. I further delineated the chapters of the analyses based on how rich/wide or specific a description they portray of the data and stated my epistemic and ontological stance as critical realism.

4.9.4 Phases of TA

In order to conduct a TA, Braun and Clarke described in their research paper *Using thematic analysis in psychology* (2006) six phases to guide researchers through the process. Diagram 1 below illustrates these phases.

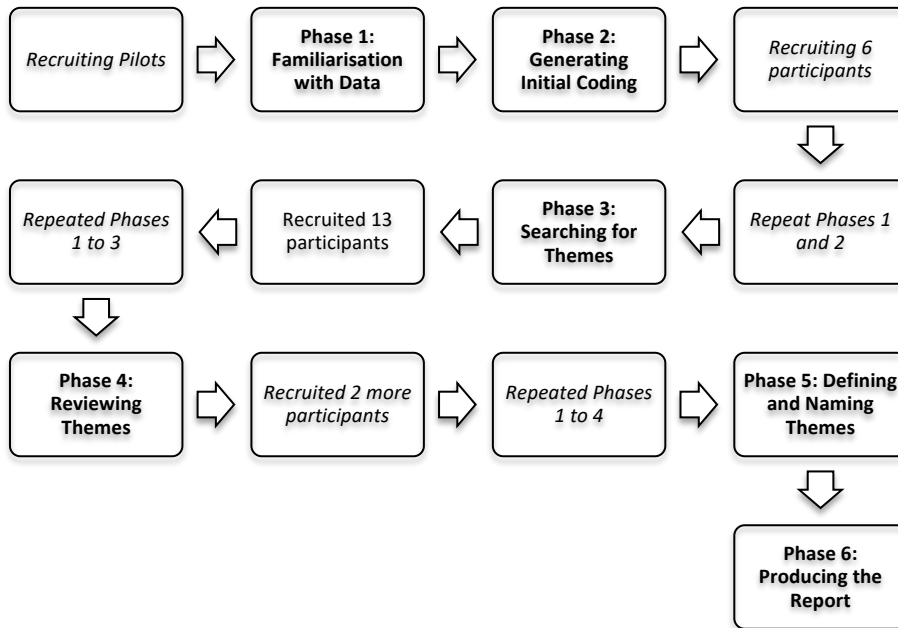


Figure 5. Looping navigation across the six phases of Thematic Analysis

Following their recommendations, all 22 transcripts were printed with a line and page numbering as well as wide margins on each side. I then systematically went over the six-phase guide, which are combined here for clarification:

First, I familiarised myself with the transcript. This phase involved listening to the audio-recording and also watching the video as soon as possible after the interview was over and reading the transcript over and over again making notes on the side margins. I also took handwritten notes of my thoughts and initial ideas on paper to complement the side notes made on the transcript. There was often not enough space on the margins to elaborate on my thoughts and the extra paper allowed me to write and reflect more on my initial notes. I took handwritten notes for the initial 10 participants after which the process became faster and smoother and I did not need to take hand notes to code the data. I became familiar with the available dataset; writing on the margins of the transcript was enough. It is my belief that being consistent is fundamental to conduct TA, however it is not a recipe for a successful analysis. I had developed

at that point, an analytical sensibility to my data and was able to move past taking extensive notes.

Second, I generated preliminary codes by initially jotting them on A4 paper. The codes generated were both semantic, or data driven, as well as latent or implicit content based. This however, turned out to be too time consuming and I had to juggle too much information. I came up with the idea to divide the transcripts into a grid where each meaningful passage of the transcript would be assigned a corresponding code (see Table 13). I left two additional columns where I could write more comments and possible budding themes. I kept the research question at the top of these grids to remind myself not to code everything but rather to code meaningful passages that inform me of the research question.

Table 13 *Example of Transcript Coding*

UCMum14C01p			
What is the lived experience of women who transition to motherhood within the context of IBD?			
Text Excerpts and line number	Comments	Codes	Themes
I was just being told 'No it's IBS it flares-up if you're stressed etc.' um (.) and I just assumed that that was the case 16	GP qualified? Training?	Confounding diagnosis IBS	
And I just assumed that that was the case 16		Trusting experts and authority	
Um (.) I think it sort of uh quite cross really because it probably could have saved me a bit of suffering over the years and um (.) actually by the time I was diagnosed um (.) my flare-up was really quite bad and I was in quite a bad way um (.) and the last couple of months of my pregnancy were really quite awful 19-24	Delay in diagnosis causally related in their minds to deterioration of symptoms	Blaming doctors for wrong diagnosis and spiral down of symptoms	Mistrust of medics

Using word documents allowed me to place all the files next to each other and compare on the screen across the dataset. I then created an outline per participant summarising the codes as well as a general outline made of bullet points summarising the similarities and differences across a set of participants. For example, in an individual outline I noted the specific comments and themes recurrent in the transcript such as the consideration of adoption as a coping mechanism for delayed conception with IBD (*UCMum03C01p*). As for the general outline, I would note commonalities reflected across several interviews, such as the way women commented on how shocked they were that conception happened so quickly.

In the third and fourth phases, identifying the initial themes and revisiting the themes, I underestimated the time it would take to generate themes. Once I was done with the coding I wrongly assumed it would flow naturally to form a theme and subthemes. My initial technique to form grids in word documents was useful to visually distinguish each code but it was too effortful to generate themes and notice the slight nuance amongst each excerpt. I had to retain in my working memory too much information across participants and repeat this process every time new information was added to the budding theme. To unburden myself, I thought of

inserting all the codes in an Excel sheet where each line would represent a participant and each column a different code. In each cell, at the intersection of a column with a row, I placed the excerpts that illustrated the code with its corresponding line numbers. This little trick allowed me to trace back to the transcript if I needed to remember the context of the excerpts. Having in a single column all the excerpts reflecting a particular code, allowed me to notice the fine differences in each participant's interview. Furthermore, the software allowed me to easily shift one column closer to another and I could swiftly link several sets of columns into a theme and rename accordingly.

The last two phases, (fifth and sixth) involved defining and naming the themes as well as writing the resulting analysis in a coherent report. These phases came hand in hand whilst I was writing the results. The very process of writing challenged me to better formulate my argument and make sense of the data even further. I was able to move away at times from the data and review it the next day with a fresh set of eyes. Needless to say, these last phases led to countless drafts of revision that were sent to my supervisors for input and kept being iterated to improve as much as possible the content, evidence, and argument constituting my analyses. I found it most difficult in this phase to stop myself from analysing the data further and put an end point to it all. The difficulty particularly occurred when I happen to have noticed something new in the data and felt the urge (almost itch!) to find all the other instances in the previous transcripts where this idea did (or did not) appear. Talking to my supervisors about the iteration process and keeping in mind the timeline to complete the PhD in four years were key determinants in placing an end to the analysis and completing the writing.

4.9.5 Pros and cons of Thematic Analysis

The main advantage of using TA is its intrinsic a-theoretical flexibility (Braun & Clarke, 2006). TA does not place itself within a specific epistemic paradigm such as positivism or constructionism. Its theoretical freedom grants adaptability to the current dataset and research question, which is experiential. Also, because the study is by its novelty exploratory, my approach will be inductive which leads me to be driven by the data with patterns or themes mirroring the content of the data. However, I must acknowledge my limitation in being purely inductive: one can never be entirely driven by the content without some input of pre-set notions and concepts. For this reason, I refrained myself, as much as possible, from delving into the literature review, and left it for only after the preliminary results were formed.

Another major advantage of TA is that it allows comparing and finding commonalities across a given dataset. It is not preoccupied in identifying unique meaning within a single transcript but it tries to make sense of how a topic is discussed across all the data corpus. Although this could be considered a drawback in cases where the idiographic meaning is sought, in this analysis, looking at the overall patterns and differences across the lived experiences of mothers with IBD permits a fuller understanding of their lived experience. This

method is particularly useful in the current study because I interviewed a sample of 22 women which can be considered a medium to large sample in qualitative research (Baker & Edwards, 2012; Braun & Clarke, 2013).

Furthermore, TA can result in the generation of numerous codes and themes. It has been my role to highlight those that are relevant and meaningful to the research question. Indeed, codes that were not pertinent to the research question were not added to the analysis and consequently themes not pertinent to the lived experience of mothers with IBD were not generated.

4.10 Summary

In sum, all the method and methodological details elaborated in this chapter permitted me to explore the lived experience of women who transition to motherhood within the context of IBD. The study received ethical approval to ensure the research respected BPS ethical codes and was safe and useful for the participants, myself, and the public. Various recruitment strategies were used including social media, blogs, and newsletters to recruit participants. The size and constitution of the sample was adequate for the aim and purpose of the research, and the video-recorded interviews allowed for the generation of data and use of the recording to produce YouTube medleys to disseminate the findings. Lastly, I have described the analytical method – Thematic Analysis – and provided a rationale for its suitability to address the research question: What is the lived experience of women who transition to motherhood within the context of Inflammatory Bowel Disease? As for rigour and quality check of the method, these will be addressed in the Discussion (Chapter 8). The next chapter – the first chapter of analysis – will elaborate on the concept of *Blurred Lines* which will explore the resonances in transitioning to motherhood with some of the experiences women have while receiving a diagnosis of – and living with – IBD.

Chapter 5

Blurred Lines

There were many parallels that can be drawn from the participants' accounts between the experience of becoming reconciled to having IBD and that of becoming a mother. The transition from a 'healthy' life – or 'nulliparous' life – to one with a chronic illness – or to having a child – requires many adaptations and lifestyle changes. In both respects, the participants were focused on personal development and physical changes. I elaborate in this chapter on the parallels and, hence blurred lines, between the two 'conditions' central to being a mother with IBD.

People don't realise or didn't realise you're actually coping with another medical condition on top of your pregnancy (CDMum19C01p, Line 296)

The analysis is structured around the concept of *Blurred Lines* and the following three sections reflect the themes that make-up *Blurred Lines*: that is, *Need for Readiness*, *Lifestyle Changes* and *Monitoring Personal and Physical Development*. Each theme consists of several sub-themes as indicated in Table 14. Appendices, Appendix DD, and EE show the contribution of each participant across the themes and subthemes. Analytical and interpretative points are supported throughout by quotes from the interviews.

Furthermore, as described in detail in the Methodology (Chapter 4), transcripts were analysed using Thematic Analysis (TA: Braun & Clarke, 2006). In brief a reminder, the type of TA presented in this chapter is: *critical realist* (Maxwell, 2012), meaning that, while knowledge is considered partial and culturally-situated, I accept that physical bodies and social structures exist and have real impacts; a *rich description* in that it draws from across my 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 appendices listed above also indicate the semantic subthemes and themes using the letter (S) and distinguish them from the latent ones denoted by the letter (L). In particular refer to Appendix CC for the contribution of each participant to the first theme and its respective subthemes both latent and semantic.

Table 14 Overview of the Themes, and Subthemes of the Concept Blurred Lines

Concept: Blurred Lines	
Theme 1: Need for Readiness	
<u>Subthemes</u>	Shocks and secrets Need for maturity Identifying blame Fear of mortality Seeking others' experience
Theme 2: Lifestyle Changes	
<u>Subthemes:</u>	Regime alterations Libido loss Dependence Financial and career implications Relationship and network changes Sleeplessness and fatigue Constant worry Adapting to uncertainty
Theme 3: Monitoring Personal and Physical Development	
<u>Subthemes:</u>	Close scrutiny Weight changes Symptom confusion Seeking respite Identity change

5.1 Theme 1: Need for Readiness

All of the participants contributed to the theme *Need for Readiness*. However, the way women with IBD coped with receiving the news that they have a chronic bowel condition and the news that they were pregnant differed. Each subtheme with its specific manifestations is detailed in the paragraphs below.

5.1.1 Shocks and secrets

There were parallels between how women with IBD spoke about coming to terms with the news of having an illness and how they spoke about finding out they were pregnant. In both instances, participants expressed a state of shock and remained secretive, if only for a while, about their condition. Receiving a diagnosis of Inflammatory Bowel Disease left participants in a state of shock, daze and denial followed by acceptance of the news.

*So I was really shocked when they told me I have some kind of bowel disease
(UCMum03C01p, Line 15)*

*I was walking round thinking like 'oh I'm just a bit ill' (.) you know (.) 'it's not an
issue' [...] when I first got diagnosed I went a bit wild for a bit and I was out
drinking a lot (.) I suppose it's your twenties anyway though isn't it
(CDMum02C02, Lines 31; 727)*

Some participants shared the shock also expressed by their husbands upon receiving the news that their wife had IBD.

I think he was probably just in as much shock as me um (.) And didn't really know what to say or to do to try and make it [Diagnosis of UC] better (UCMum12C02, Line 159)

Others reported a delayed reaction as they had initially assumed the illness was only a treatable disease and it was not until the recurrence and realisation of the chronicity of the condition that they manifested their shock.

I've been 10 (.) about 10 years without any issue (.) so in my head I was cured (.) so I was quite disappointed when it reappeared ((laughs)) I didn't realise that you could have it again (.) but I think because I didn't have it for such a long time (.) that I didn't think that it was coming back (.) and I thought it was a disease not a condition that you have to have all the way through your life (UCMum17C01, Line 45)

Similarly, some interviewees described feeling shocked to know they were pregnant, and some reported their spouse's astonishment also at hearing the news. And, although most planned their pregnancy, for those who had received a diagnosis of IBD prior to planning for a family, the shock of discovering they were pregnant was because the couple assumed it would take much longer to conceive.

I just (.) it's just it's just a really big shock and I don't think anyone can kind of (.) you can't understand what that feels like until you do it (.) What a big shock it [the pregnancy] is to find that out (CDMum01C02, Line 76)

One participant decided to carry on as if nothing had changed and another said it took a long time to wrap her head around the idea that she was pregnant suggesting, therefore, also a kind of denial of the news in some cases.

We were quite it took a long time for it [the pregnancy] to sink in (.) it took a long time for it to become real because we couldn't quite believe it because we'd expect it to never ever happen (CDMum06C02, Line 176)

It is worth mentioning that there was also, similarly to the delay in shock with regards to having IBD, a delay in reaction with regards to being pregnant – particularly in those cases where women were afraid to emotionally digest the news of the pregnancy due to previous miscarriage(s).

It was difficult with [First Daughter Name] when we found out because we'd lost a baby (.) I remember just looking at the pregnancy test and my husband going 'fine (.) you know (.) pregnant' and I just went 'OK great (.) what do you want for dinner' and he was like 'what (.) are we not gonna talk about' and I was like 'no (.) let's not talk about this (.) we'll talk about it at the scan' [...] (post scan) 'Oh my God, we're having a baby! This is a bit of a shock now, sort of almost it was a bit of a delayed 'oh this is actually going to happen now' (UCMum07C02, Line 137)

Upon receiving the news of IBD and of pregnancy participants tended to come to terms with it by keeping the information from relatives and friends. In relation to IBD, I noticed that participants first kept their experience of symptoms and sometimes even the diagnosis to themselves. Only

after living for some time with the illness (sometimes 6 or more years) were they more relaxed about disclosing it to others (friends, colleagues and relatives). In fact, one participant – UCMum13C02 – had lived with IBD for 7 years and, although she mentioned feeling the need and desire to talk about it with others who have the illness, she feared the repercussions from her South Asian (Indian) community. It would be like opening “a can of worms” (Line 915). She also was one of the few who refused to share the interview’s video clips on YouTube.

I know of people who have been diagnosed with colitis since (.) and I just think (.) ‘Ah (.) I’m going to tell them about my experience (.)’ but I don’t because I think I’ve kept it a secret now (.) it’s just opening a can of worms (.) and the whole wide world will know (.) and it’s not going to achieve anything really other than make my conscience feel better (.) but (.) um (.) so I don’t even care if people know now (.) but I think it’s come to a point where I don’t even think it matters whether they do or don’t (.) I guess it’s (.) And before I didn’t want anybody to know (.) and I think it was the right thing at that time (.) but now as I get older (.) I don’t care (.) um (.) But (.) at the same time (.) I can’t be arsed to tell (.) explain to everybody what it is (.) so (.) forget it ((laugh)) (UCMum13C02, Line 913)

Women who had lived around three years or less with their diagnosis at the time of the interview were more likely to keep the illness to themselves or selectively share the diagnosis with specific individuals such as their partner, parents, siblings, or close friends. It was one such participant who also refused to share the video of her interview. The only exception was IBDuMum04C01 who had lived with the illness for about two years at the time of the interview and although, like the others, initially she kept her symptoms to herself, she informed everyone around her once she actually received the diagnosis:

I didn’t know what was wrong with me because I didn’t have a diagnosis so I didn’t really tell that many people about it but since my diagnosis everybody’s aware (.) all my network are aware so people fully understand (Line 329)

This participant was 42 years old when I interviewed her and it could be that, having received the diagnosis later in life, as well as being NHS staff, accelerated the process of disclosure to others. Specifically, she felt comfortable talking about her illness once a label could explain the symptoms.

As for motherhood, apprehension about telling others of the pregnancy before the first baby scan was often mentioned in the first pregnancy, but not in the second, and was more vividly described where women had experienced a miscarriage and, hence, were reluctant to trust that gestation would progress to term. In total, eight participants had one miscarriage prior to their first successful pregnancy and one woman – UCMum15C02 – had more than 11 rounds of IVF (in vitro fertilisation, aka artificial insemination) to get pregnant, which amounted to over 10 years trying for a baby. The fear of disclosing her pregnancy was particularly extreme in her case:

I just didn’t (.) I think that I was just constantly thinking ‘Okay (.) it’s not really going to happen (.) so don’t get too excited (.) it’s not really going to last’ So (.) I was very (.) I played it all down (.) I think that was my sort of way of dealing with

it (.) if it did all go wrong then I wouldn't at least have got my hopes up [...] My mum didn't know I was pregnant (.) I never (.) I never actually confirmed that I was pregnant ever until she saw [5 months later] that I was pregnant (Line 236)

The state of shock, denial and secretiveness with regards to IBD precludes a drastic health condition and in the case of pregnancy a happy event. However, there were interesting parallels in the participants' use of language to describe these very different, but life-changing, events.

5.1.2 Need for maturity

Whether receiving a life-long diagnosis of IBD or becoming pregnant, women reported retrospectively how they took the news in relation to their age and level of maturity at the time. There was a latent understanding that both illness and motherhood require individuals to be mentally mature enough to cope with such events. A *need for maturity* was broached by all participants. Although some expressed this only in relation to IBD, others simply in relation to motherhood, some considered maturity as relevant to both IBD and motherhood.

Many participants alluded to their relatively young age and implied their inability to comprehend and assess the severity of their illness at first given their assumption that illness is a burden of age not a custom of youth. Participants were on average 36 years of age at the time of the interview but were, on average, diagnosed with IBD in their early twenties (around 24 years of age). This gap of time allowed for those who had been living longer with the illness to assess retrospectively how young and fragile they were when they discovered they had IBD. Youth exacerbated the initial shock of diagnosis, and seven women in the sample knew they had IBD before the age of 18. In one instance, CDMum06C02 expressed overtly how receiving a diagnosis at 13 and later a pouch at 15 “made [her] grow up too quickly [...] [she] was like an older person” (Line 85). However, most of the time, the necessity for maturity was more subtly and covertly expressed in the interviews.

Even participants who were diagnosed later in life – post-marriage, or post childbearing – mentioned their fear of passing on IBD to their children, particularly the fear that their child would have an early onset. Moreover, they sometimes expressed gratitude that they had already met their partner and did not have to go through adolescence or university years whilst dealing with IBD.

Um (.) wanted to make sure that there wasn't a high possibility of having another (.) of having a child that did have Crohn's Disease (.) particularly earlier on (.) I knew that I'd managed to overcome it and you know (.) feel better with the right medication so it wasn't so much if in later life a child got Crohn's Disease (.) it was more (.) when they were really young and perhaps it could stunt their growth that was a major concern (CDMum05C02, Line 46)

The *need for maturity* was echoed in relation to becoming a mother in terms of being ready for the responsibility of caring for little ones and some reflected on their feeling of being quite young when they had their first-born. The *need for maturity* was entangled in the discourse of

participants even though, for most of them, the pregnancy was a planned decision that was carefully thought through in terms of timing and personal development.

So maybe I think mentally I wasn't quite ready (.) um (.) and it [first pregnancy and miscarriage] happened [...] and I think I was more mentally prepared second time round [First-born boy] (.) yeah (.) I do want this baby and I'm ready for it (UCMum13C02, Line 17)

On the other hand, some participants felt ready to become a mother and welcomed the transition with open arms. They felt that they had reached a point in their life where they desired and planned to have a family with their partner.

I was ready to become a mum (.) so I felt mature enough to (.) to handle the challenges that (.) you know (.) I may face (.) so (.) yeah (.) it was quite a good time (UCMum14C01p, Line 111)

Hence, whether feeling ready or not, participants oriented to the *need for maturity* in approaching motherhood and in dealing successfully with IBD. Looking closely at the ages of women who felt ready to have a child and those who thought they were a bit young, I cannot see much of a difference. The feeling of readiness was irrespective of the years of age and was more of a personal journey. This subtheme of the *Need for Readiness* made me reflect on my own readiness to become a mother and how even though I am 31 years old at the time of my final year thesis writing, I am yet to feel the preparedness and willingness to become a mother.

5.1.3 Identifying blame

Both IBD and pregnancy news, whether separately or in conjunction, were accompanied by a feeling of *blame and guilt* directed towards the illness or motherhood.

Participants used strong metaphorical language through words like “freak”, “not normal”, “bag full of poo” or even personified IBD referring to “its ugly head” to point the finger at the many ways the illness has unjustly deprived them from leading a ‘normal’ life or being a ‘good mother’.

At the age of fifteen I mean I was devastated (.) I just thought, because it's a time that everybody wants to look the same and be the same and fit in and obviously you're getting interested in the opposite sex and you just, you want to be attractive and then somebody's telling you that you're going to have to walk about with poo in a bag, um it just sounds horrific (CDMum06C02, Line 70)

It appeared that through this harsh description of her external pouch this participant, blamed the illness for putting her at lower par compared to other girls of her age who do not have an illness. She later also pointed out how the illness also placed her at a disadvantage in her attempt to fulfil her mother-role:

So can you tell me about the most difficult aspect of becoming a mum with IBD? ((breath in)) I think probably being in pain (.) and (.) then not being able to cope physically (.) being able to do all the things you want to do (.) like going out (.) and take (.) because kids want to go out and they don't do physical things and active things and if you're in pain and you're energy's affected (.) , it's really

difficult to then do that [...]at that point that I wasn't being the mum that I should be [...] my older boy's got Autism as well so developmentally [...] I thought a lot of that was to do with the fact I wasn't interacting with him enough and I wasn't doing enough things with him (.) I wasn't being a good enough mum (CDMum06C02, Line 619)

Some participants started to flare-up with IBD whilst pregnant with their first or second child and, subsequently, blamed the pregnancy for triggering their IBD. Two participants – UCMum12C02 and CDMum22C02 – admitted this, bluntly accusing their second pregnancy for developing IBD. UCMum12C02 even considered termination because she was struggling to cope with the illness. She then felt guilty realising what she would have missed had she not had her daughter.

Drained (.) Really drained (.) At some points to be really honest with [Second Daughter Name] (.) um (3) and I hate to say it now (2) but I could have terminated the pregnancy [...] if I'd have known that I would have been that poorly [...] Some days I just didn't want to get out of bed (.) Um (.) 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 (UCMum12C02, Line 236)

As for CDMum22C02, she initially felt blamed for not wanting to be pregnant, her entourage assumed the process to be “a bit messy” (Line 340) for her and hinted at her selfishness for not wanting children: “I think everybody thought we wouldn't have children because I think they just thought we were quite our own kind of couple” (Line 338). In addition, when she later experienced the early symptoms of IBD during her second pregnancy, before she got diagnosed, she remembered her “sister kept saying [...] ‘it's because you're so old¹ having babies’” (Line 202). Although CDMum22C02 did ask herself “‘if I hadn't had her would I have got Crohn's Disease? I don't know (.) I think it was the strain on my body just was like can't do this’” she added “I'd still go through it again to have her [daughter]” (Line 953).

5.1.4 Fear of mortality

Receiving a diagnosis of a chronic illness, and embarking on the journey to motherhood, led participants to reflect on their mortality and sometimes that of their child. This was so particularly given that some symptoms of IBD, bloody diarrhoea, weight loss, and stomach pains (NHS, 2017), can be misinterpreted as bowel cancer and because mothers felt responsible to care for their child until a certain age. Furthermore, mothers were also, often for the first time, keenly aware of the impact their demise could have on a beloved and vulnerable other. For example, one 30 year-old-mother described a flare in a dramatic way explicitly highlighting how symptoms of IBD made her fear for her life: “I thought I was going to die (.) I did ((laugh)) I was that ill I thought I was going to die” (UCMum11C01p, Line 125). In addition, some

¹ CDMum22C02 was 29 years old when she had her first child and 31 years old when she had her second.

participants joined support groups through Facebook or Forums for IBD and described hearing about deaths as a result of IBD surgical complications or other kinds of IBD-related ‘horror stories’. One woman, CDMum09C02 described her near-death experience at the age of 21, and how she “wouldn’t be here” (Line 57) had she not received a bowel removal and external pouch. Another talked about nearly dying due to a stroke possibly caused by IBD.

at the time I had a 50/50% chance of surviving [...] you’ve always got (.) I’ve got this kind of (.) I might not be there (.) if anything happens (.) It went 50/50 last time (.) if any of those (.) those experience and thrombosis happen again (.) I might not go on the right way this time (UCMum17C01, Line 564)

Furthermore, having IBD and, more specifically, taking Immunosuppressants was perceived as a risk factor to develop other illnesses due to the lowered immune system.

My biggest concern [for being on Immunosuppressants] is that I’m a dentist and I’ve had quite a few needle sticks in my past and I’m exposed to HIV patients (.) Hep B patients (.) Hep C patients and I’m just worried that I (.) if I get a needle stick then I’ll be more prone to getting their disease and I won’t be able to fight it off (UCMum13C02, Line 404)

Similarly, becoming a mother, and feeling the responsibility of having a dependent, raises the urgency of being well and even the consideration that one needs to survive to support one’s child.

When you’ve got a child you start thinking I’ve got to be there for them at least for a certain point (UCMum03C01p, Line 621)

Some were faced with the harsh consideration of whether or not to terminate their pregnancy due to the serious health problems it might cause them or the impact of their IBD treatment on the foetus. For example, one participant (CDMum01C02) fell pregnant a few weeks after bowel surgery and did not know whether it would be possible to keep the child. Another fell pregnant shortly after being diagnosed and whilst receiving medication counter-indicated for pregnancy (UCMum11C01p). These situations placed women in the untenable position of deciding whose wellbeing, and even whose life to put first – theirs or the child’s.

I was concerned that I wouldn’t be able to carry the baby through of course [...] you know (.) the reassurance of once you’ve had the 12-week scan okay you’ve got through the immediate risk of miscarriage (.) but not to say that there still couldn’t be things wrong (CDMum08C02, Line 115)

In other instances, interviewees were faced with the *fear of mortality* of their child as soon as they were aware they were pregnant. This fear was often expressed in descriptions of the first scan (at 12 weeks) and considerations around disclosing the pregnancy before knowing for sure that the foetus was developing well, particularly for those who experienced a miscarriage.

It was difficult with [First Daughter Name] when we found out because we’d lost a baby (.) [...] so because I didn’t want to get excited ‘cos I’d been so excited the first time (.) and then it had all gone wrong so I was just ‘I’m not getting excited (.) I’m not even gonna think about it’ (UCMum07C02, Line 137)

In relation to the scan, foetal anomaly screening revealed to two participants that Down syndrome was high risk. Healthcare providers offered some the choice to terminate, but both women faced with this decision opted to keep their baby. CDMum19C01p said that although she did not face this choice herself she knows of others who have, and the option to terminate the pregnancy would not apply because of the abortion laws in Northern Ireland where she was living. When I raised the issue, she pointed out that had she ever been in that position and wished to terminate – although that was against her moral and religious values – she would have had to travel to England.

I didn't even realise that that would happen (.) but if you have a high risk (.) ((Breath in)) for Down's they counsel you because at that point you can decide to terminate the pregnancy (.) and I just couldn't believe that that would be an option (.) it certainly was not an option for us but I couldn't believe that that would be an option for anybody (.) that you can abort a baby because they've got Down's (.) but you can (.) and we said no (.) absolutely not (.) they said we could have an amniocentesis which would definitely confirm a diagnosis of Down's but obviously that's got risks associated with it (.) there's a risk of miscarriage from an amnio (.) which is very small but it was a risk too much for us (CDMum06C02, Line 313)

Moreover, one participant mentioned her fear of dying during labour, being afraid that something “might go terribly wrong” (CDMum02C02, Line 401). And this was a very real possibility for a participant who experienced a haemorrhage during labour.

I remember feeling like I was slipping away at one point um (.) Not necessarily (.) it sounds (.) that sounds really dramatic doesn't it but like as though I was going into unconsciousness and part of me was but part of me was saying 'wake up (.) you need to wake up (.) You need to stay awake (.) Just stay awake' and I remember people like the anaesthetist trying to feel for my hand to get a vein in my hand to get a drip in and um (.) just in case I needed to have a blood transfusion and things like that (UCMum12C02, Line 430)

Lastly, I found that even in the early years of caring for a child, mothers often expressed that they managed to keep the child ‘alive’ as an accomplishment and reflection of the hardship of being a mother. The lexical terminology was indicative of a latent fear of not being able to cope and ‘survive’ those, often, difficult times of caring for a dependent child.

I think six months is a (.) right (.) I've got this far (.) she's still alive ((laugh)) and then you get to a year and she's still alive (.) it's also good (.) I'm doing something right (.) (UCMum20C01, Line 677)

5.1.5 Seeking others' experience

Finally, in terms of the *Need for Readiness*, in relation to both IBD and/or motherhood, many women sought advice from others who had already faced these challenges.

Some interviewees attend support groups for IBD through charities, IBD consultants or other medical professionals, dieticians, or even joined online forums to discuss their concerns. Some participants spoke to friends who had a chronic illness other than IBD to their share

experiences. Also, participants consulted other resources to seek information such as encyclopaedias, books, and the Internet to become knowledgeable about their condition.

Well I was on a forum um (.) and that can be a good thing and can be a bad thing 'cos you find that a lot of people on forums are in the worst place (.) and whereas the other ones that aren't on the forums are usually the ones which have come away from it for a bit and just getting on with their lives (.) so when you go on a forum it's very much a lot of people have got issues and then you start worrying even more (.) so I kind of just stepped away from that really (CDMum10C02, Line 124)

Similarly, with regards to pregnancy and becoming a mother, women had recourse to their own mother/mother-in-law, gynaecologist, friends who had already become parents, and/or conducted their own research to get the latest advice. For example, UCMum03C01p found out she had to take folic acid by digging through the Internet and advocated against using bed bumpers in the baby cot because she had read they were dangerous. Amongst mothers who wanted to breastfeed, they had recourse to either an association that supports breastfeeding, YouTube information, or midwives to support them in their attempt.

When it came to participants who became pregnant after being diagnosed with IBD, they also turned to medical experts such as consultants and midwives as well as consulted online forums to look up, for example, the impact of medication on the foetus or what happens to an external pouch during pregnancy. However, the general conclusion was that most GPs, midwives and non-specialised nurses were not aware of the research around pregnancy and IBD. Moreover, they discovered that there was less – if any – targeted information at the time of their pregnancy(ies) than there is available today for mothers with IBD².

I went to the midwives and they were like, 'mmm, well we haven't ever had anybody with Crohn's and a stoma so we don't really know' (CDMum06C02, Line 187)

Several participants referred to the term “horror stories” to depict the overwhelming amount of information about labour with IBD. Hence, many found it useful to stick to just a few sources of information and to filter out advice from friends, families, and healthcare providers, which did not seem to take account of their IBD. For example, one woman disregarded the advice of midwives on breastfeeding because she could not have breastfed with the medication she was taking³.

I read all these different books but the books quite often contradicted them [midwives](.) each other and (.) you've got your grandma telling you you know 'well that's not how we used to do it in my day' and it's quite confusing (.) But yeah (.) I remember I had one midwife (.) She was really down to earth and she

2 A lot of the women complained that until this day, although there is a bit more information, the lack of breadth of research and definite answers on which course of treatment to take during pregnancy or what to expect is worrisome. This point is further discussed in Chapter 6.

3 Many made an explicit decision to focus on their own journey and avoid comparison with others. This point will be elaborated on in Chapter 7.

just said 'you've got to you know follow your instincts and do what you think is right' and that's true (CDMum05C02, Line 266)

Lastly, a few participants suggested that it would have been useful to have had psychological support, such as counselling, and others mentioned having recourse to therapy to deal with depression whether prior to having children or once they had their child.

5.2 Theme 2: Lifestyle Changes

Whether receiving a diagnosis of IBD, or learning that one was pregnant, a change of life was imposed and, with both 'conditions', these changes were usually permanent. The repercussions of this were that, in dealing with IBD and with becoming a mother, participants faced making significant adaptations in their lifestyle. The overlaps in *Lifestyle Changes* noted in participants' experiences are outlined in this section. Appendix DD identifies the contribution of each participant to this second theme and its respective subthemes.

5.2.1 Regime alterations

Upon receiving a diagnosis of IBD and when planning, and becoming pregnant, participants made changes in their food consumption, activities, and leisure time.

Regime alterations were very evident in terms of diet. Most participants accommodated to the chronicity of their illness by, for example, eliminating foods such as wheat, milk, or alcoholic beverages as well as fibrous foods. Unfortunately, sometimes women talked about giving up food, or eating very little quantities and/or only drinking fluids at times of flare to manage the uncontrollable diarrhoeas. In other instances, an expert imposed the change, notably a dietician or IBD consultant who recommended treatment through elemental drinks or asked participants to eliminate specific foods to help determine which food triggered their flares.

I was having a really restricted diet as well because before I had my surgery I had a really restricted diet because they wanted to make sure that there was nothing that was making my symptoms worse (.) So I had set foods that I was allowed to eat and that I wasn't allowed to eat (.) So I couldn't go out with my friends to a take away and have the normal food that they were having because I had to have certain foods and I wasn't allowed anything with kind of artificial ingredients or (.) there was very much a core set of foods that I was allowed to have and then over time I was to introduce each of the foods (.) sort of food groups if you like (.) so it was maybe milk one week (.) tomatoes another week to see if any of them made any difference to my symptoms (.) So that was really hard (CDMum06C02, Line 104)

Typically, in pregnancy, participants referred to their adapted diet in terms of being mindful of healthy eating: increasing the consumption of fruits and vegetables and cutting down, or eliminating sometimes altogether, alcohol, caffeine, and fatty foods such as bacon. An interesting parallel was that some beverages that were counter-indicated in gestation, such as alcohol and caffeine, seemed also to "upset" participants' bowel and caused more symptoms.

However, one participant – IBDuMum04C01 – stopped smoking in her attempt to have a baby and maintaining cessation during pregnancy appeared to make her IBD symptoms worsen⁴.

On the other hand, the alterations of regime at times of flare involved reduced physical activity. Some would not go out of the house or for a walk if their symptoms were active due to fatigue but also fear of needing the toilet urgently. Instead participants focused on relaxing activities such as reflexology or going to a spa to manage their stress level and, subsequently, their IBD. Such activities were typically explored as an alternative approach to medicines to find relief from IBD.

Anything that I could try and we [family and participant] were desperately tried so many different things (.) different diets and everything but nothing really seemed to help [...] acupuncture (.) um (.) I tried wheat free dairy free (.) um (.) the specific carbohydrate diet I tried um (.) hypnotherapy um (.) reflexology I've tried a lot of (.) I would say the majority of all the alternative therapies out there (UCMum15C02, Line 72)

In parallel, during pregnancy and the early years of motherhood, some participants talked about the benefits of yoga and meditation, also, when energy levels allowed, even starting a new exercise routine such as running.

I did a hypnobirthing course to try and (.) because I (.) I found with my Crohn's over the years (.) and with my arthritis that (.) you know (.) you can (.) that to manage pain there are (.) you know (.) you can use your mind (.) oh this sounds really airy-fairy ((laugh)) but just that there are things you can do to help yourself manage pain (.) and umm obviously there's all the breathing (.) but also just about kind of umm (.) keeping yourself calm and keeping yourself as centered as possible and it's often when we panic or lose control that things becomes more difficult and more painful (CDMumPi02C01, Line 365)

In a way, for a few participants who were diagnosed with IBD before their pregnancy(ies), they seemed to have been 'ahead of the curve' in terms of readiness for pregnancy and motherhood changes because they had already made healthy lifestyle choices and *regime alterations* due to their IBD.

5.2.2 Libido loss

Some participants discussed how sexual intimacy with their partner was reduced, or practically non-existent, during the first few years of motherhood as well as during flare phases of their disease. Also, some interviewees discussed how the illness and motherhood impacted how attractive they felt, and the implication of appealing to the opposite sex.

Some participants were, however, able to tell when it was IBD that was affecting their sexual activity irrespective of their transition to motherhood.

⁴ As explained in the "Protective and risk factors" section of Chapter 1 some evidence supports that smoking cessation can worsen symptoms of Ulcerative Colitis. However, this particular participant has received the diagnosis of IBD unclassified type.

I think colitis as well [as motherhood] completely impacts on that (.) I think the intimacy came back quicker after having [First Daughter Name] the first [time] [versus] having [Second Daughter Name] and being diagnosed with UC (UCMum12C02, Line 615)

The symptoms of IBD, having a sensitive stomach, constant bloody diarrhoea, vaginal and mouth ulcers as well as losing weight put a damper on their libido. Some participants who had their first flare during their early adolescence reported not developing breasts at puberty and feeling different than other girls their age as well as less attractive.

Others reported that their sexual activity was unaffected by their illness but that early years of parenting did prevent intimacy. In these cases, it was deemed a combination of feeling unattractive whilst wearing “big pants”, the lack of sleep, the differences in work schedules amongst partners, and the feeding routine and caring for their children, came in the way of sexual intimacy.

Maybe in the beginning because (.) You know (.) everyone's tired with a baby crying constantly but I wouldn't say IBD has affected (.) Anything [referring to intimacy level] (UCMum11C01p, Line 665)

However, sometimes it was difficult to know if it was IBD or parenting that was the true culprit in this loss or absence of libido.

I don't think I feel very like attractive or I feel like getting sexually intimate when you know (.) the toilet (.) I've been in the toilet so many times or I've got a pain or my stomach just feels sensitive or (.) if I'm just having a really bad day with it (.) That can really affect how I feel in general (.) But it's more often than not often and I think that can affect your sexual activity anyway can't it (.) So it's quite (.) I feel quite sorry for him most days ((laugh)) But I don't know whether that's to do with being a mum as well and just feeling generally tired and not letting anybody near you ever again after two of them ((laugh)) So I think that kind of is a bit of the IBD and motherhood (.) I think they go together (CDMum02C02, Line 861)

One can see that the link between being extremely fatigued in the early years whether due to IBD or caring for a child and having a reduced intimacy. Although the *sleeplessness and fatigue* parallel is discussed a few paragraphs below, it is interesting to see some overlaps in these subthemes. Also, losing too much weight and hence their feminine figure due to a flare, or an increase of weight attributed to pregnancy, was linked to how attractive women feel. Either can damage their body image and impact their libido. The link between *weight changes* and attractiveness is discussed in the following theme *Monitoring Personal and Physical Development*.

5.2.3 Dependence

Having IBD, or being a mother, can place women in a state of dependency and vulnerability whether financially, emotionally, and/or practically in terms of everyday tasks.

Participants diagnosed at a young age, or during their university years, mentioned relying heavily on their parents for support. Participants' mothers were said to advocate for

them and to research latest treatments for IBD. Even in adulthood, participants could feel as if they had regressed to a childlike state when dependent through illness on others for emotional and financial support, but also when incontinence was a problem. For example, one woman wore adult diapers to allow her to walk her children to and from school. Interestingly adult diapers can be referred to as ‘depends’ pants, emphasising even more this experience of regression and a role reversal to a child-like state.

I'm 34 years old, I should not have to wear incontinence pants but the choice is one or the other [being incontinent in public] (CDMum02C02, Line 327)

Similarly, in pregnancy, participants’ mothers and their partners were referred to as the main sources of help, especially if participants had a C-section and could not drive or perform household tasks until they had recovered. However, geographical and practical considerations played a major role. If the participant’s mother or parents lived far away, or if their partner worked at night or abroad, then she sought recourse to friends or other close-by sources for support. Furthermore, newly-born children were completely and utterly dependent on their mother, particularly if she had opted to breastfeed, and this reinforced the feeling interviewees had of needing help and needing to stay well for their child⁵.

It's such a big responsibility to have a child you know that relies solely upon you for absolutely everything (CDMum05C02, Line 92)

Hence, both IBD and motherhood increased at times participants’ sense of dependency on others. However, this was exponentially the case for mothers who experienced major IBD surgery around the time of birth as well as a flare while caring for young children. One participant vividly described her experience of needing help after having a C-section and then a bowel resection shortly after giving birth.

So I couldn't drive for six weeks 'cos of the C-section and then I only really had my independence for six weeks before I then had surgery and couldn't drive again for another eight weeks so I was a bit restricted as a sort of new mum in terms of what I could do and I couldn't lift him so I had (.) we arranged a rota of friends and family to come every day to help so that I wasn't lifting washing and sterilising and stuff [...] so you know not lifting and not doing washing and having to accept that [husband's name] might not hang the washing out the way I like it or people cooking meals for me that weren't necessarily my favourite but they're doing it out of the kindness of their hearts to help me you know (.) Silly things like that that you just have to just go with I found quite difficult (CDMum08C01, Line 495)

Of more general relevance to mothers with IBD, was the *dependence* on toilet facilities which impacted family activities such as visits to retail parks, malls, and even schools depending on availability of facilities and distance of travel. This was over-and-above the need of a mother to plan activities around children’s sleeping and feeding schedule.

⁵ The complete *dependence* of the child on the mother links back to the previous subtheme *fear of mortality* and exacerbates her concern of needing to be around until the child is of a certain age.

The hardest bit is just the interruption in your normal life when you've got to keep going to the loo (.) And the same when you're out and about when you've got a new baby and you just want to go shopping or something (.) And I pretty much know where the best toilets are in the city centre because I've been to all of them and I know (.) I knew the ones that I get a pushchair in (.) You know all the practicalities that come with having to know where toilets are all the time (CDMum01C02, Line 347)

Most women reported having great support from their partners with regards to taking turns to watch over children, doing the night-feeds, or taking them out to play. This solidarity brought couples closer and tightened the bonds of the family. There was only one single mother in my sample but three women did describe themselves as acting “like single mothers” because their partner was unhelpful or working abroad. These women formed their network strongly around their mother, or geographically close relatives, and mentioned having close friends or siblings helping with the tasks of raising their children while they coped with IBD.

5.2.4 Financial and career implications

Some participants chose to work part-time, or to discontinue or plan around their studies, to look after their health and/or their children.

Participants clearly denoted the impact of IBD in their career development. In terms of academic or school studies, having IBD imposed a temporary, and sometimes more permanent, sojourn as well.

I couldn't really do much [due to the illness] so I stopped university (.) I had to move back home [at] my parents and take Prednisolone for as long as I needed to (CDMum09C02, Line 18)

What I failed to discuss was the serious impact the disease had on my professional development at work (.) On my return from maternity leave I found it extremely difficult to concentrate and focus on my work due to the constant interruptions of toilet duties and my suffering with extreme numbers of mouth ulcers (.) This left me feeling extremely vulnerable with my peers (not being able to consistently offer 100%) and felt that I could not progress with my career until I received a diagnosis and a treatment plan to manage the suffering physically and psychologically (.) There were job opportunities (.) which I had to let pass me by because of the illness (IBDuMum04C01, Email communication, November 26, 2014)

Such interruptions and shifts in jobs could have monetary implication and some had to rely on their family for support and, hence, financial hardship could affect extended family members also.

[During the first week of returning home after delivery UCMum11C01p experienced a flare and was hospitalised for a few weeks] My mum had to take (.) you know unpaid leave off work (.) to care for me daughter because me husband just couldn't afford to take the time off you know we couldn't have paid the mortgage if he didn't go to work (.) It was tough on everyone (Line 89)

Due to IBD, some participants had to take several leaves of absence, whether for medical appointments and check-ups or to recover from a flare. Although some had flexible hours and

the support of their workplace, others feared that their repetitive absences and leave would cost them their job. Hence, they managed by shortening – against medical advice – their stay at the hospital or opted to go to a closer and less specialised hospital to minimise the time of travel to and from their medical appointments. Only two participants touched upon the financial costs of medication for IBD, one participant saying that she had to rely on her parents and refrain from eating out to afford getting all her treatments and another mentioned waiting for funding to receive an IBD drug.

Yeah (.) so initially family helped me out until I went to uni and then got a job (.) I'm lucky I've had good jobs working in the pharma-industry and stuff but it's just been using my savings (.) If you asked me about savings (.) I've got nothing um(.) because it's all gone (.) you know (.) for that (.) I sort of replaced going out (.) holidays (.) you know (.) people have coffees (.) you know like little habits (.) smoking (.) whatever (.) I don't do any of that (.) drinking (.) I barely drink as well (.) I drank when I was at uni but when I go out on a night out I don't drink so yeah (.) it's (.) the little pleasures in life have all sort of gone because I've had to save that money (.) so yeah (.) even that's been quite difficult (UCMum23C02, Line 233)

Similarly, mothers who took part-time jobs, or who concentrated fully on parenting and homemaking, had to depend on someone else to 'put the food on the table'.

I do feel very dependent on my husband and I do still now knowing that he's gonna be the main breadwinner (.) you know (.) and he probably always will be (.) but it's kind of really (.) I have to kind of bring myself back into this old-fashioned way of thinking that that's how we're gonna be (CDMum02C02, Line 189)

An intriguing observation is the relative absence of discussion in the interviews of the financial implications of having children per se. This consisted of one participant mentioning how expensive it was to bottle feed, and another stating that she resumed work part-time because day-care was extremely expensive. Two out of the three women who used IVF briefly commented on the cost of having in vitro treatments. Furthermore, going on maternity leave was a particular source of concern for one participant as she was not sure she would get her job back upon return. She underlined the differences between herself and her husband on how much impact having a child has on the mother compared to the father. Not only was the child utterly dependent on the mother for breastfeeding, as noted in the previous subtheme *dependence*, but the "mother's life changes absolutely" (UCMum20C01, Line 465) in terms of career as well.

A few participants emphasised the combined stress of IBD and motherhood and their impact on their ability to pursue a career.

*I knew that wouldn't be (.) that wouldn't be viable for me at all. I knew that I probably wouldn't ever be able to work full-time hours because of my Crohn's Disease umm (.) and also obviously the tiredness and just the sheer exhaustion of looking after a child **alone** (.) never mind going to work full-time (laugh) as well 'cos I didn't cope with working (.) when I worked full-time I was always really tired (.) I'd get home from work, fall to sleep on the sofa as soon as I got home (CDMum02C02, Line 157)*

5.2.5 Relationship and network changes

IBD and pregnancy both opened the door to a new range of friendships with people who shared similar experiences. Overall, all participants reported feeling supported by at least one person in their current network. Most often it was their partner, but they named their own mother or other friends who were also mothers as key supports. Having a friend who suffers from an illness, whether IBD or not, was also helpful and part of their support system.

After disclosing to others that they have IBD, participants often met others who had the illness. Networking through charities or forums also provided opportunities to meet new people with knowledge about and experience with IBD.

It's also meant I've made an awful lot of friends through IBD (.) Some of my closest friends also have Crohn's (.) So I've met lots of new people through it [volunteering through Crohn's and Colitis UK Charity] as well (CDMumPi02C01, Line 664)

Participants who had a supportive partner reported feeling closer to them and more connected as they had been through some of their worst times together. However, IBD also pulled participants away from some relationships. Particularly due to the association of food with pain, some women refrained from socialising and eating out; three participants felt bullied at school for their skinny or bloated appearance; and two mentioned pushing 'judgemental' people away when the latter ones appeared to be embarrassed by the participants' symptoms.

Similarly, for mothers, baby groups, breastfeeding clubs, antenatal or pregnancy yoga classes and school events were all opportunities to meet and make friends with other women on the same journey.

It's [motherhood] going to be (.) expensive (.) it's going to change your social life [see friends less] etc [...] And when you're a mum you want to get out and about (.) you want to meet other mums (.) you want your children to socialise with other children (CDMum16C01, Line 689)

Motherhood was also a door to a new kind of social life built around children, although it did make some women say they were less social and outgoing than during their nulliparous years, and that they preferred staying home or favouring family time over couple or friends' time. Becoming a family unit brought most couples closer together with one dyad deciding to move in together and get married upon the news of the pregnancy. However, the closeness felt by couples can also be tied with strains and arguments around raising children. In addition, not all newly formed relationships were welcome, and one participant reported feeling "harassed" by the 'Bosom Buddies' who went to the extent of knocking on her door to recommend breastfeeding.

Some women mentioned that their husband 'wrapped them in cotton wool' and were particularly protective of them because of pregnancy and IBD.

Yeah (.) I think you end up (.) sort of relating and communicating more by text messages and [laughs] rather than (.) actually physically seeing each other (.) or

leaving little notes on the kitchen side um (.) and your communications tend to be more about the children and your stresses end up being about the children (.) so your arguments end up being about the children (.) Um (.) But then on the other side it brings you closer together as well because you've got that other thing that you both share in to bring up together (UCMum12C02, Line 598)

Women whose husbands were less supportive, or worked abroad, felt left alone to raise their children whilst dealing with their illness. Nevertheless, they did manage to find networks of friends for support.

5.2.6 Sleeplessness and fatigue

It can be highly taxing to bare the symptoms of IBD: rushing to the loo several times a day and night, and excessive fatigue. Sleep disturbance and extreme tiredness resonate particularly with having a small baby: getting up several times at night for feeds, changing diapers, and dealing with the full-on challenges of caring for children throughout the day.

Um (.) probably the fatigue [is the most difficult aspect] ((laugh)) because it's [motherhood] exhausting anyway and then being exhausted [due to IBD] on top of that is really hard (CDMumPi02C01, Line 489)

Sleeplessness was associated with going to the toilet several times a night, but also possibly induced as a side effect of taking steroids during times of flare. Fatigue, on the other hand, resulted partly from the lack of sleep and was also associated with being pregnant: the first trimester being particularly tiresome and/or the third causing women sleep disturbances due to discomfort of carrying an almost fully developed baby. Fatigue could also have been a result of pregnancy – or IBD – generated anaemia, as well as morning sickness and having to rush to the toilet, either to vomit or have diarrhoea, which really ran some women down.

People laugh at me at work now people sort of said 'you've put us off pregnancy for life' 'cos of how bad I (.) was (.) I'd be sat at my desk and I'd have to ((hand on her mouth to prevent from throwing up)) we had a digit-code to get into the toilet and I'd be trying to put the digicode in and um (.) but then as you were sick you were nearly (.) I felt as if I was gonna have diarrhoea as well which was even more embarrassing (.) um (.) and all that out of your body was just exhausting (.) Some days I just didn't want to get out of bed (.) Um (.) 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 (UCMum12C02, Line 238)

It was difficult if not impossible to know if tiredness was pregnancy, IBD related, or a combination of both. It caused anxiety to not know if the symptom was “normal” to anyone who undergoes a pregnancy or if it was more a reflection of the illness and needed to be addressed. Some women formulated the burden of having IBD and pregnancy with relation to fatigue as a bigger burden than a non-IBD mother.

And to all new mums, Umm you know, you know it's going to be hard because you listen to everybody else, however with IBD thrown into the mix it becomes a lot harder, extremely hard and it's hard to cope with (IBDuMum04C01, Line 147)

Some women mentioned that having an ‘easy child’ who slept and fed at regular times made their sleep and tiredness less. But for those who had a second child, getting up to do the night feeds and then having to care for a toddler during the day was still very overwhelming.

Second time around was just pure hell ((laughs)) ‘cos going from one child to two was just a huge shock to the system (.) with small age gap as well, um (.) and so yeah it was hard (.) it was really hard [...] oh gosh (.) um (.) well first time around you can obviously sleep when the baby sleeps (.) um (.) second time around I had (.) and also [First Boy’s Name] did sleep quite well at night (.) whereas with [Second Boy’s Name] he was up every two hours so I was literally (.) had no sleep during the night and then had to get up and run around after a toddler in the day (.) so (.) it was 24/7 (.) I don’t know how I’m still here to be honest (CDMum10C02, Line 520)

Clearly it is impossible for any woman to compare her pregnancy load to that of others’ experience. This comparison merely indicated the burden and weight that mothers with IBD were experiencing for having the illness and pregnancy in conjunction.

5.2.7 Constant worry

A permanent concern and anxiety with regards to their IBD symptoms flaring and the wellbeing of their children plagued the daily life of participants. For example, they feared ‘having an accident’ in public and this concern overwhelmed them every time they needed to leave their home. In addition, participants were equally anxious to stay stress-free to avoid exacerbating IBD and having to recourse to surgery or hospitalisation. They also expressed concern about the impact of ‘strong’ drugs on their own health in the long run for years and some throughout the course of their lives.

As a mum you think about the future and whether or not there’s (.) you know (.) more risks involved with having Crohn’s Disease and you know (.) the risks involved in the medication that you take and you know (.) certain medications and Crohn’s itself can have (.) you know (.) slight heightened risk of having cancer and you know (.) generally to have a disease that if it was as active as it was when I first got it (.) over a long period of time it would seriously affect your health (CDMum05C02, Line 538)

In addition, a sense of responsibility and constant concern for the welfare of the child was ever present and parallels their concerns for their own health and the impact of IBD. Participants described worrying daily about whether their children were properly fed, safe, and cared for.

I think it’s very much (.) every time I want to go to a meeting (.) every time I want to go out (.) every time I want to (.) you know do (.) anything (.) it’s me and them (.) it’s not just me (.) You can’t think in the same way (.) you can’t just do something now (.) you have to think about what happens with them at the same time (.) once you’ve had a baby (.) I think (.) perhaps if you’re feeding them (.) because you’ve birthed them (.) you feed them (.) you’re in tune with them (.) you’re linked with them (.) it’s (.) they can’t be apart from you if you’re breastfeeding (.) so you’re all very much together anyway (.) and I think (.) after that you’re very much it’s all (.) it’s you and them as one [...] Whereas if I’m going out it’s (.) okay (.) well (.) I’m going out but I’ve got to think about who looks after the children and whether I get a babysitter der der der der der you

know (.) it's all very much (.) I think you think differently (CDMum09C02, Line 513)

Furthermore, knowing that IBD has a genetic component, filled participants with worry about the possibility of passing the illness to their children. This plagued them, even when they were reassured by their consultants or through research that the likelihood is quite low. Their fears led them to monitor the bowel movements of their child and forewarn them about the signs of IBD⁶.

I was concerned about passing on the Crohn's (.) but you don't always find that out at birth anyway (.) you know (.) my Crohn's came on at 22 so (.) even now I think about [Son Name] and I think (.) okay (.) he's got to four (.)he hasn't had it yet (.) let's hope that he doesn't (.) but I'm ever aware that (.) there's a risk that at some point it can [...]Um (.) It does worry me (CDMum08C01, Line 120)

Lastly, participants worried about the impact of having a flare on their children and feared being separated through hospitalisation to get treatment or surgery. The welfare of their children came first in their mind and even when under excruciating pain they always tried to anticipate how to make sure the children were taken care of:

I could barely stand up at that point it was so bad (.) but all you think about it (.) you just want to make sure that you've sorted out the children (.) because they're the most important thing and it doesn't matter how bad it is (.)they have to be looked after (.) somebody has to look after them and if I couldn't do it because I was too ill then my friend (.)would have to do it (.) there would be nobody else that could do it for me (CDMum01C02, Line 196)

5.2.8 Adapting to uncertainty

Adapting to the uncertainty and changes that were brought through chronic illness allowed some women to feel ready to meet similar challenges in their transition to motherhood. For example, dealing with the unpredictability of IBD symptoms was somewhat preparative for the ever-changing schedules of newborns.

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 and that there will be times where one day you might have organised something and you really want to do it but you wake up and you're incredibly ill and you can't (.) And I've got used to kind of trying to adapt my life around my illness more over the years and really I think that is a very helpful skill for the baby as well because I think people aren't prepared for how massive (.) what a massive change it is to your life and umm(.) and then it's about being adaptable and you know babies do not do what you want them to do ((laughs)) They have their own routine and it (.) if anyone's child's like mine she changes it every day so ((laughs)) I don't know what's going to happen on a day-to-day basis but I'm much more used to I think to being adaptable and trying to work around things than perhaps (.) I think (.) you know especially in modern society we're all (.) we all get quite set into our routines and what we do and I think that's quite a hard shift for people when they

⁶ These two points are discussed in the following theme, particularly in the subtheme *close scrutiny*.

have a baby but it's the same shift you have to make when you've got a chronic illness I think (CDMumPi02C01, Line 513)

Being used to handling unpredictable, sometimes unpleasant, events and having faced the idea that in life there were many unknowns, many participants alluded to the realisation that they could not control everything and adopted a 'wait-and-see' attitude or 'day-by-day' approach to manage their worries and accept the things they could not change. A lot of participants used the expression "you get on with it" or "you just do" when I asked how they coped with having IBD, being a mother, and dealing with two events simultaneously.

But if you think about it and put that in perspective that (.) to accept that before having my first child (.) to accept that could be the worst thing that would probably ever happen when you're on a day out with your child and not looking for the nearest toilet is probably one thing you should accept before you even think about having any children is that's the worst thing that could happen to you and carry some spare clothes for you as well as the child ((laughs)) (CDMum02C02, Line 878)

There seemed to be a drive – a force – that pushed them to carry on and get things done whether this was in relation to their IBD or to their parenting responsibilities. They also mentioned not having the time to think, or purposely avoided "reflecting back", to deal with the uncertainty and unknowns in their coping with IBD and their young ones all at the same time.

I found it interesting, and in parallel to the experience of any mother with young children, that my participants often carried spare clothes but, unlike other mums, for themselves as well as for their children. This reminded me also of the use some people with IBD make of adult diapers. One participant also mentioned carrying a potty which she could use, as well as her child. The use of her child's potty emphasises once more how some of the mothers with IBD adapt to, what might be considered, child-like behaviours or use 'family' facilities to avoid having public 'accidents'.

I have (.) I feel safe in my car (.) so um (.) I have a travel potty for the kids which works a treat (.) So if the kids' potty (ironic tone) (.) however (.) I'm not a very big person (.) and I can (.) um (.) you know (.) accommodate it to a bedpan should I need to (.) but I try not to (.) I try to stop places if I can (.) um (.) But you don't always get places or you can't always wait (UCMum13C02, Line 428)

5.3 Theme 3: Monitoring Personal and Physical Development

This last theme composing the concept of *Blurred Lines* reflects how the experience of motherhood and of having IBD involves paying attention to personal development and physical changes by monitoring psychological and somatic impacts. There was a *close scrutiny* on the two conditions' manifestation and a great focus on *weight changes* as an indication of health, as well as *symptom confusion* between IBD and gestation, such as pains during pregnancy and/or labour and flare pains. In this theme one finds also the idea that having a child can sometimes exacerbate, or conversely relieve, IBD symptoms whether during pregnancy or after delivery

and participants were permanently *seeking respite* from the demands made on them. Lastly, the theme tackles *identity change*: losses and gains brought about through the illness and through motherhood, particularly with regards to how mothers with IBD perceive themselves and their body. Appendix EE depicts the contribution of each participant to the third theme and its respective subthemes.

5.3.1 Close scrutiny

There were parallels between how closely participants monitored their body at times of disease activity, and how they monitored throughout pregnancy their bodily changes and the foetus's development via regular scans. For example, when their IBD was active, women described undergoing MRIs or colonoscopy to closely monitor the digestive tract for traces of inflammation. Moreover, participants often counted the number of bowel movement they had per day, sometimes reporting in minute details their symptoms to their GP. One wrote down in a diary the number of bowel movements, the shape and form of the stools, how much blood was lost, how much weight was lost or gained with incredible detail.

Some days I was going to the toilet probably nine (.) ten times a day [...] [but] the toilet is down to sort of three times a day (.) two to three times a day (UCMum12C02, Line 95)

Some remembered the exact dosage of their medication as far as 20 years prior and the exact months at which medications were switched or stopped. Many interviewees scrutinised what they ate to try to identify the cause of flares and paid attention to external stressors that might have precipitated the onset of the inflammation, recounting in precision to the month and year their first flare. Participants could say what specific symptoms applied to them: some reported bleeding but not having to rush to the loo; others said their symptoms never faded away completely, while others mentioned an all-or-nothing appearance of their IBD.

Similarly, during their first gestation – for 11 participants⁷, it was their only pregnancy – participants closely monitored their body's every movement, pain, and sensation. Some took pictures of their forming bump: this *close scrutiny* was irrespective of whether they had been previously or concurrently diagnosed with IBD. They had monthly, and sometimes weekly scans, to check progress, including the search for possible birth deformities. As with their first flare, many participants could recount the day of the week when they found out they were pregnant and had a strong and vivid awareness of the first changes in their body.

I woke up that morning and said 'I'm sure I'm pregnant!' [...] I kept getting little pain in my tummy that day and they were just different to usual and I just had this feeling (CDMumPi02C01, Line 176; 180)

⁷ I am including the twins in the count, as I am referring to the number of gestation and not number of children.

Participants further described keeping a close eye on their children's every movement, as many mums do: "you've got to keep an eye on where they are and that they're not putting anything in their mouth" (UCMum07C02, Line 101). However, they also tended to scrutinise their child's bowel movement with particular care. As mentioned in the subtheme *constant worry*, they had a specific concern that their children might develop IBD at a young age and monitoring their toilet habits was one way of coping with this fear.

As women went onto their second pregnancy, they started to 'know their body' and could anticipate when the disease was flaring up and when to ignore some minor pregnancy or illness-related symptoms. They become experts in their body whether with regards to IBD or motherhood.

Any pregnancy niggles that you might have (.) any random abdominal pains you get (.) any symptoms that you can get (.) there's just so many symptoms (.) the first time around that I probably would have paid more attention to (.) the second time around I didn't really think about at all (.) I didn't worry about anything as far as I'm aware (CDMum01C02, Line 102)

An exception to this lowering of guard in the second pregnancy applied to those mothers who had their IBD diagnosis between pregnancies or even during the course of their second pregnancy. Being novice at living with IBD, renewed experienced mothers' vigilance and they reported great scrutiny and monitoring of their symptoms during their second gestation and worried in a way similarly to that of first time mothers.

[She was diagnosed right after the birth of her first child and is currently pregnant with her second] but I stopped my Golimumab [immunosuppressant] a few weeks ago because the Consultant says I take it in the third trimester so obviously every day is a massive (.) I worry (.) I panic (.) is today the day I'm going to get sick and (.) like yesterday I had a bad day (.) I had a tough day and I was just (.) I'd been up since two this morning and I was just thinking 'Oh God (.) here we go' [...] And me husband had got up and me mother-in-law had got up and I'm thinking 'Everyone's getting up and everyone's got diarrhoea (.) I think it's food poisoning' (.) And I was lying in bed thinking 'Yes (.) yes ((laugh)) have we all eaten something it's food poisoning' (.) I was so happy (.) so happy (.) like saying a little prayer like 'Thank you for food poisoning' (UCMum11C01p, Line 245)

5.3.2 Weight changes

Weight changes were characteristic of IBD, given chronic diarrhoea and the effects of medications such as corticosteroids. *Weight changes* were also part and parcel of pregnancy. As detailed in the subtheme *Libido loss*, losing weight during a flare held the implication of losing one's womanly appearance and curves and a few participants who had the illness around their teenage years were thought to have "anorexia" or to have some kind of psychological eating disorder due to severe weight fluctuation.

I dropped Um (.) to about five stone and became very gaunt, very pale, very tired [...] my mum put it down to me growing and changing 'cos I was at that sort of puberty stage (UCMum17C01, Line 13)

As for the transition to motherhood, weight loss was also intrinsically perceived as a bad indicator given that pregnancy implicates weight gain in the course of gestation and weight maintenance whilst breastfeeding. Moreover, with regards to the baby, any drop of weight could be perceived as under-nutrition or illness. This led some medical professionals to push mothers into going for an emergency scan or supporting the nutrition of their newborn through (additionally) bottle feeding their child.

His sucking reflex wasn't fully developed (.) so um (.) we couldn't get him to breastfeed initially (.) and in fact we struggled with bottle feeding [...] when the midwife came round to see us (.) so she saw us the day after we were discharged and then the day after that (.) and his weight was really dropping [...] So he was about six pound two when he was born (.) which is quite a good weight considering he was sort of four weeks early (.) but he'd gone right down to five pound something by the time he was readmitted [to hospital for jaundice and low birth weight] um (.) and I just felt like (.) I wouldn't say a failure (.) because I don't think I felt that (.) but I don't know if I felt like I'd sort of let him down a little bit (UCMum14C01p, Line 355)

Conversely, a gain of weight was associated with good health, in IBD, motherhood, and in relation to the baby. In IBD weight gain reflected periods of remission during which food was ingested and contributed to nourishment. In pregnancy, weight gain indicated positive foetal development. However, there was an upper limit to which both plateau with regards to the positive perception of weight gain. Some participants noted the negative impact of being moonfaced due to steroids and having abdominal swelling due to IBD. I checked whether the use, or absence, of steroids had any implication in the report of change of weight, but it did not. Another participant expressed concern about her weight gain in relation to the practicalities of changing her external pouch as the gestation progressed and her belly expanded.

I'd got practical considerations (.) about how to change my bag and everything (.) how it might affect how the baby grows whether it presses on your bowel too much (.) How it (.) you know how you (.) Physically things that might be a problem that was more my worry how I would not mentally but physically how my body might change or how I might need to do things differently or things I might experience [...] [In the end] my tummy I didn't get enormous I didn't get a huge bump so it didn't affect my ileostomy too much I could still get to it I could still it wasn't a problem (CDMum09C02, Line 251)

Similarly, in motherhood, having a bump and gaining weight was accepted by participants as long as they did not totally lose their pre-pregnancy figure or became, as they put it, “fat” and not feeling “particularly attractive wearing these big pants” (CDMum16C01, Line 930).

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 (UCMum14C01p, Line 120)

5.3.3 Symptom confusion

Both gestation and IBD affect the abdominal and pelvic region of the body. This prevented some participants and some medical doctors from pinpointing whether the symptoms experienced were related to IBD or motherhood. My first pilot participant conveyed this

specific blurred line to me in an email exchange when she wrote, “How do you tell the difference between Crohn's pain and labour?” (CDMumPi02C01, Email communication, 14 October 2014). Hence, I added the following question to the interview schedule: “Can you compare IBD pain to pregnancy pain?” I found that, particularly, but not exclusively, for women who received a diagnosis of IBD during gestation, or shortly afterwards, the distinction between symptoms of their illness and symptoms of their pregnancy, and/or even labour, were hard to disentangle. The *symptom confusion* included abdominal and pelvic pains, diarrhoea and blood loss, *sleeplessness and fatigue*, *libido loss*⁸, as well as scar formation, which made the combined experiences – illness and motherhood – “ten times harder” (UCMum11C01p, Line 559).

I remember (.) thinking at the time I wasn't sure if I was having a flare-up or whether it was just the baby causing the impaction (.) whether it was just things getting squashed or whether I was actually having a flare-up (CDMum08C01, Line 178)

At 32 weeks (.) so whenever I had [Son's Name] I didn't realise I was in labour which was very scary (.) and the only way I can relate the labour pains to the Crohn's pains is that they are so similar and so intense [...] Whenever you are in a bad flare-up you're obviously doubled over in pain and (.) you know (.) you're breathing to get through the pain and that's exactly what happened to me whenever I was in labour (.) I laboured in the house for so many hours before I went to the hospital (.) and when I went to the hospital I was 10cm dilated [...] it goes to show you what (.) when people with Crohn's are in such a bad flare-up (.) just how bad they feel with the sickness and the stomach pains (.) the stomach cramps (.) the hot and cold flushes (.) the sweating (.) It is a bit like the stages of labour ((laughs)) (CDMum19C01p, Line 483)

There was distinction made, by some, in terms of the type and localisation of pain experienced during gestation (and later labour) and IBD. During gestation one participant said that she felt a dull period-like pain or stretching pain as opposed to IBD pain which she described as acute and caused by a stricture formed in her gut. That said, participants often experienced morning sickness during gestation, and diarrhoea and vomiting during their gestation and labour, making it very difficult to determine an IBD or pregnancy-related cause. Comparing pain, most participants rated IBD pain as bad and prolonged but less severe than labour pain which, while intense, was more short-lived.

The Crohn's pain I remember feeling very achy and having like a bad back with it as well which probably isn't that dissimilar to pregnancy pain in the sense that (.) you know (.) you've got that pain in your back quite often and (.) your tummy feels (.) tender and swollen as well I suppose (.) so there are comparisons that you could pull from Crohn's pain and pregnancy pain (.) The labour pains also made me feel sick and made me need to go to the toilet as well (.) so you know (.) there were things definitely that (.) you know (.) were similar (.) Um (.) I suppose what was different is the muscles involved in pregnancy (.) you know (.) were

⁸ The *Blurred Lines* between *sleeplessness and fatigue* as well as *libido loss* was addressed in the previous theme *Lifestyle Changes*, I will elaborate on the connections amongst the subthemes in the last section of this chapter: 5.4

really becoming tight and (.) you know (.) trying to squeeze out the baby and that was something that I'd never experienced before (.) it was quite different (CDMum05C02, Line 245)

In one instance, CDMum10C02 distanced herself from the pregnancy or child which was referred to as “it” to indicate the fear of gestation flaring IBD symptoms. And in another instance, CDMum08C01’s slip of the tongue – “from the Cro- from the baby” (Line, 163) – was a pertinent example of the blurred line, and sometime confusion, between the traumatic impact of IBD and of the child, however loved and wanted.

When I got pregnant I was slightly terrified ((laugh)) um (.) because I didn't know how it [Child/Pregnancy] was going to affect the Crohn's (CDMum10C02, Line 77)

Then towards the end [of the pregnancy] I found a (...) all of the pressure from the Cro- from the baby and the fact that I was getting impacted a lot towards the end (.) so obviously things were getting very squeezed with the baby (.) so my intestines (.) where they were already narrowed from the Crohn's were getting like majorly squished so I was constantly impacted (.) which was causing me a lot of discomfort and that caused a fistula (CDMum08C01, Line 163)

Other ways in which the lines were blurred between the symptoms of IBD and the experience of pregnancy were the swelling of the joints around the pelvic area (sacroiliitis) and anaemia. Both IBD and pregnancy were causing lower back pains whether due to the inflammation of the joints in the pelvic area or weight of the child that added pressure on the spine. Both conditions also led to a drop in ferritin levels (anaemia) as well as body stress from the additional weight of carrying a child and it was difficult to tell which was responsible.

I've got sacroiliitis so I've got arthritis associated with Crohn's as well (.) which affects my pelvis so I did get quite a bit of pain with that (.) but I guess that's to be expected with (laugh) suddenly carrying a baby and it (.) and a lot of women get problems with that anyway when they're pregnant (CDMumPi02C01, Line 198)

Moreover, having diarrhoea or losing blood in the stools was often attributed by participants to the pressure from the baby on the bowels “I just thought it's just because I'm pregnant (.) it's just because I'm pregnant and it's giving me a bit of a bad tummy” (CDMum22C02, Line 203). However, similar misattributions were done by their doctor thinking the blood was due to haemorrhoids which are typically reported in pregnant women: “my doctor said, ‘Oh it's piles, piles, you get it when your pregnant’” (UCMum13C02, Line 6). However, having the extra concern of IBD often led women to fear whether these symptoms were the prelude of an IBD flare rather than simple pregnancy symptoms.

I do bleed but it's not a flare and they [IBD consultants] think it's because when you're pregnant all the blood rushes to your blood vessels so there is still blood so I have to keep an eye on how much that is but it's (.) their assumption is probably there is some blood because I bleed quite easily versus some people's [individuals with IBD] symptoms is diarrhoea (.) having to run to the stool (.) whereas mine's just generally bled and they think that's just based on how my

blood vessels work so he's [main IBD consultant]not concerned (.) they wouldn't put a camera up there because it could risk a miscarriage and there's nothing to indicate there's a flare or that the baby's not getting nutrition (UCMum03C01p, Line 146)

Lastly, there was also an overlap in terms of scars: the incision made to deliver the child through a C-section (when necessary) and the incision made to operate on the bowel.

They [surgeons] actually was discussing with me already about whether they go through my bowel resection scar (.) which is straight the way down vertical on my stomach (.) or whether they would go underneath like a normal section 'cos we joked about whether it would be like noughts and crosses (laugh) on my stomach (CDMum02C02, Line 122)

5.3.4 Seeking respite

Participants kept a close eye on the impact of IBD on pregnancy and that of pregnancy on their illness. Women tried to make sense and understand what could exacerbate their illness and what could improve their health. For those who improved in their symptoms during pregnancy, they sought respite from the flares by timing their pregnancy and induce remission, and those who got worse whilst or a little after having children, sought respite from the flares by deciding not to have any more children.

One mother, who experienced remission during her pregnancies and whilst breastfeeding, requested investigation into the hormones that buffer IBD during those physiologically changing times. Other women, too, experienced remission during their gestation and used similar lexical terminology to draw analogies between being pregnant and being on IBD-related drugs.

When you're pregnancy your immune system goes down slightly so it doesn't reject the baby so it's like a natural immunosuppressant (.) I mean I don't know if that's true or not (.) but yeah um (.) (CDMum10C02, Line156)

I mean I don't know if this is true but somebody said that the placenta gives off natural steroids (UCMum07C02, Line 621)

Being in remission during pregnancy allowed participants to eat more fibrous foods without having to worry about being incontinent. Notably, CDMum10C02 described her pregnancies (or getting a baby/placenta bag) as giving her relief from IBD and the ability to eat healthily. She kept her two pregnancies closely successive to “avoid” having IBD as the gestation was keeping her symptoms at bay. In a similar way, CDMum06C02's description of having a portion of her bowel removed and using an external bag was expressed as a relief from her symptoms and one could draw a parallel between the naturally-forming of a placenta and the surgical formation an external pouch in providing symptom attenuation.

It was almost like a new lease of life because actually I wasn't in pain any more (.) I could eat things (.) um yes I had a stoma but at least I didn't have to be in that pain anymore and I go places and eat things and so (.) it was definitely (.) it became quite (.) it became positive (CDMum06C02, Line 121).

It is important to note that one participant who had achieved total remission prior to her pregnancy had two uneventful gestations and remained IBD free to the day of the interview (and hopefully continues to do so). However, even with this participant, the blurred line was noted with regards to breastfeeding where she wondered about a potential transfer of IBD “stuff” to the baby even though she was free of medication and had had an external pouch for over 10 years

I breastfed both my babies (.) I didn't (.) I didn't ever consider that I wouldn't breastfeed my babies (.) it wasn't ever something I (.) didn't even think about bottles (.) to be honest (.) I didn't even think about IBD and (.) I guess (.) maybe I should do because it's still stuff (.) you know (.) something that's being transferred from me to the baby (.) I don't know (.) but I didn't even (.) it didn't even enter my mind to think about IBD and feeding the baby (CDMum09C02, Line 375)

Conversely, a participant experiencing gestational diabetes at the time of her diagnosis, requested more research on the topic, making the explicit link between her experience of diabetes and the onset of IBD. In most cases, women experienced a surge of IBD symptoms within a year, if not sooner, of having a child. Whether or not they were warned by their medical doctor, having a flare was associated by some mothers with having a child and made some reticent to consider having more children through fear that they would not be able to cope being ill with a second or third baby. In fact, they felt exhausted and sought respite from the suffering imposed by the exacerbation of their illness whilst they transitioned to motherhood and cared for their baby.

When you give birth it's like coming off steroids right at the top (.) I think this was the Consultant that told me this actually (.) yeah (.) that it's like coming off steroids at the top as opposed to being weaned off (.) um so (.) it's almost a 100% of the time people have a flare-up after giving birth (.) how true that is I don't know (.) So for me (.) obviously it's just so hard that it's almost a given that you're gonna have a flare-up (.) so that's difficult really (.) because (.) you're sort of associating it with the fact that you're gonna have a flare-up so it's definitely put us off having any more I would say (UCMum07C02, Line 621)

For those having symptoms of IBD whilst pregnant, the delivery of the child was assumed to be associated with relief and immediate reduction of some of their symptoms. This was conveyed in phrases like “I just wanted the baby out thinking I can't cope anymore ((crying))” (UCMum13C02, Line 108), “If I hadn't have got pregnant would I ever have got this [UC]?” (UCMum12C02, Line 630) and some women even considered terminating the pregnancy to alleviate their intense suffering. And as just quoted, one participant described regretting ever getting pregnant as, for her, this was when her IBD was triggered. Pregnancy terminology was also noted when CDMum02C02 said “the Crohn's Disease was like starting to kick in again” (Line 506). I read this as analogous to the baby ‘kicking in the womb’ of the mother. Also, just like a child would, UCMum14C01p depicted how “the flare-up [...] kind of um (.) stimulated [her] uterus, which caused [her] to go into pre-term labour” (Line 73).

5.3.5 Identity change

As women transitioned into motherhood, or received a diagnosis of a chronic illness, their sense of self was altered. In relation to IBD, some expressed a felt sense of changing from being a ‘healthy person’ to becoming an ‘ill person’. IBD also shaped the person they had become and some participants described negative changes in their personality brought upon by the illness.

It's made me feel quite old (.) some days (.) and I've probably become quite insular as in not what I don't want to socialise because I don't want to I don't want to go out with the girls (UCMum12C02, Line 638)

Others adopted a more positive view of the impact of IBD on their personal development leading them to say they would not have changed the course of their life even if they could.

I've always been quite thankful for having Crohn's and that's a really strange thing for me to say and I've said that a lot to people and they've kind of thought (.) that's a really odd (.) outlook to have but having had it from a young age it sort of defined who I am (.) It sort of shaped how I approach things and my mind-set (.) and I think I'm a stronger person for having Crohn's and going through the things that I've been through because (.) (CDMum16C01, Line 255)

Changes in identity were also relevant to others around them, with some participants noticing their partner or mother becoming more protective, but also their children taking a more caring stance towards them due to the general debilitating effects of IBD. Specifically, children of ill mothers were perceived to be particularly empathetic towards others and would take on the role of carer and be well-behaved if their mother was feeling sick.

I think because I've got that experience of ill health and I mean it's what it's like to be in pain (.) And what it's like to be kind of different as well and feeling different (.) [Referring to external pouch] I think that's made me try and give that to my children [...] And I think particularly my older boy is very I mean even though he has a diagnosis of Autism he still is quite sympathetic towards people and he does think about people's feelings and that sometimes people might not be feeling well or and I try to instil that in him um (.) and I think that's a result of obviously having that experience and being unwell (CDMum06C02, Line 711)

In relation to motherhood, a good example of the experience of changed identity reported by participants was becoming known as their ‘child’s mummy’. Typically, participants experienced an initial lack of integration between their different identities, however, this developed for most over time.

In many ways you know women talk about losing part of your identity when you have a child and I do think that's the case (.) You can just become mummy and you go to all these (.) baby groups and you're always [daughter name]'s mummy (.) you're not [Participant surname] anymore and yeah ((laugh)) I mean that can be hard (CDMumPi02C01, Line 579)

All participants expressed experiencing motherhood as challenging, particularly in terms of personal changes and demands required to care for a child or children. However, some mothers followed by stating how rewarding it is: “having children is the hardest job I’ll ever have in my

life (...) but at the same time I wouldn't change it for the world" (CDMum01C02, Line 494). An increase in self-confidence and desire and capacity to speak up was noted by some participants. The change of identity was welcomed and they needed less re-assurance from others as they had their "little team" by their side.

A further implication in common between these changes of identity was the increasing responsibility each woman had to develop: increased responsibility for her own health in relation to managing the symptoms of IBD and increased responsibility in caring for others through becoming a mother. This could be very challenging and one participant, while ultimately optimistic, felt that motherhood had taken a toll on her identity and made her, not only more responsible, but brought a sense of mental and physical aging. I could sense she felt drained and exhausted from the effort she had to make to adjust to her new life stage as reflected in the following passage as well as the tone she had when she said:

It makes me feel old ((laughs)) yeah (.) I'm 30 and I still I can't believe it (.) I still think I'm 25 (.) It's definitely made me feel old but it's been the best thing (.) The best thing ever (UCMum11C01p, Line 587)

Moreover, motherhood and IBD led some women to develop a sense of purpose, creating a meaning for their experiences.

I mean it's made me feel (.) I mean especially in this community which I live in (.) I'm Jewish and I live in a Jewish community that's very much focused on (.) children (.) having children and family and all the festivals revolve around family time together and (.) that's really made me feel complete now that we have our family because it's very hard when you don't have that and everyone else is celebrating with family and you feel very left out so I feel that that's really made a massive difference (UCMum15C02, Line 558)

Participants took in the good with the bad and embraced their new sense of confidence as well as a new outlook on their 'ill' body. Indeed, motherhood had the added benefit for some of restoring to them positive aspects of their body which has now been responsible for the creation of "a beautiful little creature" (CDMumPi02C01, Line 543) and which has provided comforting nurture through breastfeeding.

5.4 Summary, Discussion, and Reflections

In this chapter, and as a result of the Thematic Analysis of the 22 interviews, I offer a novel frame for 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*. As explained below, these findings have implications for practice and may be transferable to other chronic conditions.

The first theme, *Need for Readiness*, captures how mothers with IBD cope with the news of their pregnancy and the resonances this has with their experience of being diagnosed

with IBD. The subtheme *shocks and secrets* portrays how some initially react by expressing their disbelief and desire to keep both the news of IBD and pregnancy hidden for fear of tempting fate or receiving others' judgements. In both instances mothers express an initial shock and state of denial underlying their lack of readiness to cope with the news. Moreover, women who feared for their pregnancy after a miscarriage expressed their anxiety as manifested by keeping the news quiet in their subsequent pregnancy. Participants in Gerber-Epstein, Leichtentritt, and Benyamini's (2009) study compared the burden of a miscarriage and their life afterwards "as living with chronic illness, a situation that grows problematic, extended, and needs to be coped with day after day" (p.21). Moreover, one woman in my study expressed keeping the news from work and the burden of the secrecy as she miscarried during her first pregnancy. This experience was echoed by Gatrell (2011) who reported how expectant mothers go to great lengths to silence and hide the news and appearance of their pregnancy in their workplace. Similarly, I had elaborated in Chapter 1 (see 2.1.1.2 Stigmatisation and concealment) on the hidden aspect of IBD making it more likely that patients will not share their diagnosis and suffering with others. This was depicted by Frohlich (2014) who spoke about patients keeping their loved ones in the dark with regards to their condition out of fear of their reaction.

Furthermore, the *Need for Readiness* captures how mothers with IBD considered both motherhood and IBD to involve a *need for maturity*. Participants understood maturity to come with age and to result from reaching certain 'life stages' – such as marriage or a stable relationship – which enable a woman to cope with the far-reaching changes that both IBD and motherhood can bring. This is somewhat surprising as, on average, participants had their first child at 31 years. This statistic is higher than the contemporaneous national average for first time mothers (29.8 years in 2012: ONS, 2013). However, this suggests to me that coping and readiness can be related to age but that experience plays a major role as well. 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 cognisant of, and realistic about, the challenges involved. For example, practical implications aside, having a baby, perhaps paradoxically, can be a profound reminder of the fragility of life (Taubman-Ben-Ari & Katz-Ben-Ami, 2008). And *fear of mortality* in the context of transition to motherhood may be magnified for mothers with chronic conditions who are already dealing with serious physical problems and may be anticipating further decline in health – and this despite of contrasting medically-reported IBD mortality (Card et al., 2003).

A diagnosis of IBD, or news that one is pregnant, can be accompanied by a need of *identifying blame*. In terms of IBD, a source of stress can be the suspicion that pregnancy triggered the illness, or at least a flare. Overlaps between the signs of pregnancy and symptoms of 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). As for

the pregnancy itself, even in the best circumstances, women can feel under intense scrutiny and vulnerable to being blamed for not doing the best for their babies (Sheehan, Schmied, & Barclay, 2010), which may include criticism for becoming a mother with a chronic illness. None of the participants were teenage mothers and although some pregnancies were not planned, most participants were not actively using contraceptives to prevent getting pregnant, so one could assume that if the child is actively not planned (i.e., use of contraceptives), and/or the mother is not an adult, blaming can be a fraught and damaging process involving extended families and even social services (Ellis-Sloan, 2014). Conversely, one participant CDMum22C02 was assumed to never want children and later blamed by her sister for being too old to have her children (she was respectively 29 and 31 during her first and second pregnancy). This example invokes the perception of the media representation of “motherhood on ice” captured by Shaw and Giles (2009), and alludes to the blame for selfishness and delay of motherhood in older mums. Hence, both experiences - of having chronic illness and of becoming a mother- place women in a position of accountability while they may, themselves, be in dire need of support, information and advice. In this regard, our 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), information-seeking and information-forwarding behaviours using cyber-based portal are positively associated with managing one’s chronic illness.

The theme *Need of Readiness* triangulates well with the qualitative meta-synthesis presented in Chapter 3 and the existing research on the experience of motherhood with IBD. First both analyses substantiate the secrecy and guilt experienced by mothers with IBD for its perceived negative impact on their family. Second, both look at maturation, however, the SRR mentions children’s ability to mature and develop strategies beyond their years to cope with the illness of their mothers, whereas the theme *Need for Readiness* documents maturity from the point of view of women about to embark on the journey of motherhood and dealing with the news of a chronic illness. Lastly, the need for support and communication and *seeking others’ experience* was equally present and mentioned. The added advantage of the Concept of *Blurred Lines* is with regards to the unique perspective and in-depth look at the existential *fear of mortality* and how the transition to a new stage of life, motherhood, in combination with IBD can place women in a particular state of vulnerability and concern regarding their youth and lifespan.

The second theme *Lifestyle Changes* reflects how both IBD and transition to motherhood implicate *regime alterations*, such as nutritional adjustment and the benefits of relaxation techniques such as yoga or reflexology during gestation or to manage IBD. For example, Langmead and Rampton’s (2006) review of the use of Complementary and Alternative Medicine (CAM, refer to section 1.9.3.4), placed people living with IBD amongst the most engaged users. Similarly, during pregnancy many women turn to CAM treatments for

relaxation but also in the hope of avoiding 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). In pregnancy, and when diagnosed with a health problem, it is likely that smokers are recommended to quit. However, interestingly, one participant – IBDuMum04C01 – in my study, described being protected from IBD symptoms whilst smoking before her pregnancy. Parkes et al. (2014) reported that smokers with UC tend to have a less severe disease course and that smoking may protect against the development of UC, while the reverse may apply in CD. Hence, while smoking would never be recommended, this example highlights the complex interactions between behaviours and health as women negotiate a pregnancy on top of chronic illness.

Other *Lifestyle Changes* relevant to IBD and transition to motherhood noted in the analysis were *libido loss*, and *sleeplessness and fatigue*. Disturbed sleep is a fact of early motherhood, having to feed and settle a small baby, but people 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, however, Timmer et al. (2008) pointed out that people with IBD report sexual dissatisfaction due to psychosocial factors rather than disease specific determinants. Timmer et al. (2008) mentioned depression, as the most predictive factor of sexual dissatisfaction.

Participants reported in the above analysis talked about emotional and practical *dependence*, as well as *financial and career implications*, especially during a flare and/or when children are young. Spiteri and Xuereb (2012) thematised the narrative of first-time mothers returning to work after their maternity and referred to a period when *lightning strikes* to depict the struggles of resuming their jobs followed by a period of *weathering the storm* when mothers attempt to balance their family and work life simultaneously. Sammut et al. (2015) also mentioned isolation in the work place as a burden for individuals living with UC and experiencing significant financial cuts as a result of reduced hours due to sick leaves. *Financial and career implications* included as well taking a break from or not attending university, however there were very few considerations given to the financial aspect of motherhood and/or IBD (it was the least populated subtheme of this analysis, refer to Appendix DD). I examined the demographics of women who talked about financial considerations. They, for the most part, reported having between GBP 30,000 to GBP 45,000 annual income, or preferred not to say their household income. Two of those who talked about the costs of IVF and IBD were from ethnic minorities: notably Ashkenazi Jew and Black Caribbean. They mentioned the role of their family, parents and individuals in their community in helping financially with the costs imposed by IVF or IBD medications. The information on the financial burden of IBD and

pregnancy is sparse, and I could not help but feel its absence due to my current status as a woman undertaking a PhD. I sometimes consider the idea of starting a family and wanting to have children, however the financial burden and career stub seem to weigh terribly in my balance. Hence, it is difficult to fathom how women, who also must take into consideration costs and expenses of a chronic illness, do not spontaneously convey more the burden of not having a full-time income/job and raising children. I was mindful to recruit women with full-time and part time jobs, as well as some from less wealthy backgrounds, but that did not change the limited reported impact of finances.

Moreover, Mitchell and Green (2002) found that first-time mums relied on family, particularly their mother, when adapting to their new role. This is depicted in the subtheme *relationship and network changes* experienced by individuals with IBD as well as mothers. For the most part the women felt closer to their partner due to the need of the couple to strongly bond together because of the illness. Both transition to motherhood and learning to live with a chronic illness involve *constant worry*, and *adapting to uncertainty* but it is worth noting that most *Lifestyle Changes*' subthemes documented in this chapter had some positive impacts on the participants. The *constant worry* was seen as part and parcel of motherhood and intrinsic to the unpredictable nature of the symptoms of IBD. Larsson, Loof, and Nordin (2017) mentioned the *need for toilet availability* as a disease-related stress IBD patients have to cope with, and the constant stress of diarrhoea, possible health deterioration and having surgery. The authors also mentioned, similarly to my study, adapting and *coping* behaviourally as well as emotionally by remaining positive. Some mothers in my study, mentioned how adjusting to a chronic illness, with all the challenges and uncertainties it entails, could be good preparation for the demands of motherhood such as developing a flexible schedule.

Once more this second theme echoes with the qualitative meta-synthesis with regards to the different ways women cope with the illness and motherhood through diet change, being housebound and needing support. Both the SRR and my study emphasize the concerns about adapting with the demands of pregnancy and young ones, as well as convey the emotional load and vulnerability of women to be financially, emotionally, and physically dependent on others at such times. However, the theme of *Lifestyle Changes* elaborated in this chapter also builds on the extant research specifically, highlighting the experience of *sleeplessness and fatigue*, and *libido loss* as particularly burdensome and challenging to mothers with IBD.

The third and last theme elaborated under the Concept of *Blurred Lines* is *Monitoring Personal and Physical Development*. It emphasises how mothers with IBD have parallel and sometimes blurred experiences with respect to the *close scrutiny* of their flare symptoms and how closely they monitor their body's every change during their pregnancy. Women with more than one child became experts on their body and learned to recognise the signs of true disease activity and to ignore small pregnancy niggles during subsequent pregnanc(ies). One other area of shared monitoring is *weight changes*. Appropriately increasing weight is usually a sign of

good health in both pregnancy and IBD (DeVader, Neeley, Myles, & Leet, 2007). Conversely having an active disease at the time of conception or during pregnancy could restrict diet, or compromise digestion which can lead to lower gestational weight associated with low baby birth weight and admission to neonatal intensive care (Oron et al., 2012). However, some women in my study feared excessive weight gain associated with steroid intake alongside the concern many women have of losing their pre-pregnancy figure. Boutros and Maron (2011) took a step further to show that an increase in body mass can be an issue for people with IBD whose weight increases for reasons other than pregnancy. High body mass index, and obesity, was initially a counter indication to perform surgical interventions on IBD patients, however, nowadays, these surgeries are performed and are relatively safer. Nonetheless, surgical complications and postsurgical infections were not uncommon when the patient had a high body mass index.

An additional complexity in this sample is the *symptom confusion* in that it could be difficult to attribute phenomena to normal, or problematic, aspects of one's pregnancy or to IBD. Pregnant women and people with chronic illness may be hyper-alert to potentially problematic physical changes while, for the same reason, vulnerable to having their concerns discounted. It can be particularly difficult to negotiate personal and professional knowledge within the context of pregnancy with chronic illness and one such woman in Tyer-Viola and Lopez's (2014) study explained how "(s)he had to balance that the attention she was getting was normal with the knowledge that she knew it was her treatment and not the pregnancy that was making her ill" (p.31). 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 can cause fatigue and looking after small children and breastfeeding can be exhausting. I was lucky enough that the comparison and concern about how IBD pain bares similarities with pregnancy pains was raised early on by the second pilot (CDMumPi02C01), which allowed me to make use of all the other interviews to capture whether mothers with IBD felt there was a comparable element between the illness pains and pregnancy/labour pains, but also the fatigue, sleeplessness, anaemia, loss of libido, and incontinences.

If in addition one has a chronic illness, particularly like IBD in which tiredness is a common symptom, or experiences IBD flares, shortly following the pregnancy and sometimes during gestation, it is unsurprising that *seeking respite* through delivery of their child becomes an important consideration. In this respect, my participants had to make, sometime hard, decisions about the number of children with which they could cope. However, some participants experienced symptom remission during gestation and breastfeeding and the transition to motherhood remitted and relieved them from IBD flares. Women thus tailored their pregnancies or stopped planning for another child depending on their experience of IBD throughout their transition to motherhood. That said, the literature shows that IBD follows the pregnancy 'rule of

thirds' where "one third of women will get better, one third will stay the same, and one third will worsen" (Beaulieu & Kane, 2011, p.2698). However, currently it is impossible to predict how any woman will respond and so pregnancy opens the door to additional unknowns for women with chronic illness.

Lastly, receiving a diagnosis of IBD and transitioning to motherhood can equally catalyse increased personal resilience through coping with vast changes to one's identity and activities. Participants described coping with *identity change* which incorporated loss, such as no-longer being a 'healthy person', but also the almost ubiquitous experience of losing some elements of individuality in becoming 'a mother'. They also touched upon the positive changes brought upon with IBD and motherhood, it made them stronger and more resilient to adversity, and were grateful for their child(ren). As Hoppe (2013) reported, individuals with a chronic illness not only find happiness in spite of their illness, but through the illness as well, for example in terms of closeness in relationships with friends and partner. As such, in my study, participants were grateful, proud and happy to have managed an illness and pregnancy, it brought meaning and a sense of purpose. Motherhood and pregnancy restores a sense of normalcy amongst chronically ill mothers they no longer felt like outsiders compared to other women (Tyer-Viola & Lopez, 2014).

These subthemes of *Monitoring Personal and Physical Development* also build on the existing research reported in our qualitative meta-synthesis. Mothers are vividly aware of the symptoms and triggers and highly vigilant of their children's physicality, which is captured in my study in terms of *close scrutiny* and *weight changes*. Both analyses also explore on the similarities in experiencing IBD and pregnancy leading experts to sometimes miss on the imposed challenges of having IBD whilst being pregnant. However, I substantiate this finding with a more in-depth list of *symptom confusion* between IBD and pregnancy, such as anaemia, joint pains, back pains, fatigue, scars to name a few. I further demonstrate the *identity change* experienced as women become mothers and live with the illness, which is not explored in the meta-synthesis. Mums may experience a complex constellation of *identity change*, often associated with loss; and this alongside the difficult decisions often required in the process of *seeking respite* from the challenges of motherhood with IBD represent the novel aspects of my study.

5.4.1 Implications of the analysis presented

The Concept of *Blurred Lines* has implications for clinical practice. First, as also identified in the qualitative meta-synthesis, my study confirms that there is a need for health professionals in general to have better training in order to provide better information and advice about IBD and pregnancy. As Toomey and Waldron (2013) mentioned, patients with less knowledge on IBD and pregnancy were more anxious about the potential impact of their illness and medication on gestation. Second, many women with IBD are childless merely due to lack of information where

they 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 substantiates that women with IBD are hungry for information about the impact of the illness on reproduction and I recommend that health professionals *initiate* this conversation, as *early* as possible, and provide an opening for discussions about maintaining sexual intimacy with their partner in the early years of motherhood (Borum, Igiehon, & Shafa, 2010). Third, I identify issues for health professionals to be alert to with regards to motherhood and IBD: these include a potentially increased (realistic) anxiety with regards to women's own health and that of their baby, use of self-prescribed diets and usage of CAM. Fourth, there is a need for a more holistic, multidisciplinary approach to pregnancy and IBD – and probably other chronic illness – which integrates better women's on-going treatments with their maternity care. Finally, mothers with IBD could benefit from official access to disabled toilets in order to avoid embarrassment and public censure.

5.4.2 Conclusion

Hence, although women with IBD are in some ways well prepared for the challenges of motherhood, and express positive changes as a result of being a mum, the transition can also constitute a double burden. The importance of this conclusion is substantiated by the growing evidence of the societal implication of identifying the needs and challenges of mothers with IBD, that seem to overlap in their lifestyle demands and changes, to enhance the reproductive choices women make.

The next chapter will address in detail the sequential narrative of the *Transitional Challenges* mothers with IBD faced as they progressed from a nulliparous life to their early years with young children.

Chapter 6

Transitional Challenges

This chapter offers a timeline which captures the concept of *Transitional Challenges*: a sequence of tasks that women with IBD negotiate in their journey to motherhood. There are four themes associated with the concept of *Transitional Challenges*: *Burden of Knowledge*, *Weighing Decision-Making*, *Blame and Guilt*, and *Ambivalence towards Healthcare Professionals*. I organised these four themes, with their respective subthemes, within five phases of transition to motherhood: *Nulliparous Life*, *Planning for Pregnancy*, *Conception and Gestation*, *Labour and Breastfeeding*, and the *Early Years of Motherhood with IBD* (see Table 15)

Table 15 Overview of the Themes, and Subthemes of the Concept *Transitional Challenges*, across the 5 Phases of the Transition to Motherhood

Concept	Transitional Challenges				Five Phases
<u>Themes</u>	Burden of Knowledge	Weighing Decision-Making	Blame and Guilt	Ambivalence towards HCP	
	<ul style="list-style-type: none"> • Making sense of IBD • Overwhelming (lack of) information 	<ul style="list-style-type: none"> • Acknowledging IBD • Trial and error • Restoring health 	<ul style="list-style-type: none"> • Justifying IBD • Partner acceptance 	<ul style="list-style-type: none"> • Mixed feelings 	Phase 1: Nulliparous Life
	<ul style="list-style-type: none"> • Assumption of IBD interference • Lack of information 	<ul style="list-style-type: none"> • Improving odds • Alternatives and acceptance 	<ul style="list-style-type: none"> • Selfish desire • Social pressures 	<ul style="list-style-type: none"> • Mixed support 	Phase 2: Planning for Pregnancy
<u>Subthemes</u>	<ul style="list-style-type: none"> • Haunting fears • Treatment conundrum • Lack of certainty 	<ul style="list-style-type: none"> • Shift of priority • Tailoring support 	<ul style="list-style-type: none"> • The good mum 	<ul style="list-style-type: none"> • Establishing trust • Power over birth plan • Liaising with specialists 	Phase 3: Conception & Gestation
	<ul style="list-style-type: none"> • Labour apprehensions • Mother earth 	<ul style="list-style-type: none"> • Unplanned labour events • Feeding choices 	<ul style="list-style-type: none"> • Easing guilt • Societal pressures 	<ul style="list-style-type: none"> • Speciality-focused 	Phase 4: Labour & Breastfeeding
	<ul style="list-style-type: none"> • Performing mother role 	<ul style="list-style-type: none"> • IBD management • Communicating need for help 	<ul style="list-style-type: none"> • The good mum • Invisible illness 	<ul style="list-style-type: none"> • Lack of integration 	Phase 5: Early Years of Motherhood with IBD

The timeline suggests challenges from the moment women are diagnosed with IBD to the early years of motherhood. However, the trajectory of the challenges of women diagnosed with IBD at a later stage in their transition to motherhood will also be addressed and combined into the timeline where appropriate and I will highlight the instances in which the timeline fails to

incorporate specific challenges of women diagnosed whilst pregnant or after their gestation. Analytical and interpretative points are supported throughout by quotes from the interviews.

This chapter presents a particular form of thematic analysis as outlined by Braun and Clarke (2006). First, this chapter provides a detailed account of an aspect of my wider initial analysis which has particular relevance to a sub-group of participants: the 15 women in my sample who received a diagnosis of IBD before becoming pregnant. The analysis, however, integrates the experiences of all participants as appropriate (See Table 16 for a description of participants who contributed to each phase). Second, this analysis has both theoretical ('top-down') and inductive ('bottom-up') elements: that is, the phases of transition to motherhood guiding the structure of the timeline and steps of the transition are imposed top-down as a logical timeline commensurate with the data, while themes and subthemes were derived inductively from the interviews. Third, the themes and sub-themes are a mixture of semantic (participants' own words) and latent (more interpretative) themes. The subthemes across the transitional phases differ and express nuanced challenges at each step of the transition to motherhood. Appendices FF to JJ visually capture whether a theme and subtheme was latent (L) or semantic (S) as well as the contribution of each participant across the themes and subthemes within each phase.

Table 16 *Description of Participants who Contributed to each Phase*

Phases	Description	N
1. Nulliparous Life	Participants were challenged by having a diagnosis prior to becoming mothers. They were 19 years old on average when they got IBD. 10 had CD 5 UC. And, they were on average 31 when they first got pregnant	15
2. Planning for Pregnancy	Participants who contributed to this phase include the 15 women who were diagnosed prior their pregnancies, but also 5 of the 7 women who got their diagnosis a little later (during or just after their pregnancy) who planned for a second child with IBD.	20
3. Conception and Gestation	All the participants contributed to this phase. 15 women got diagnosed prior to their pregnancies. UCMum11C01p, UCMum03C01p had some symptoms during first pregnancy but diagnosed between pregnancies. UCMum13C02, UCMum14C01p got diagnosed during their first pregnancy. And, CDMum22C02, UCMum12C02, IBDuMum04C01 had their first and/or second gestation with symptoms but no diagnosis until after birth of their child/ren. Overall 15 women went through 2 pregnancies (4 currently pregnant with their second) and 7 went through one pregnancy only.	22
4. Labour and Breastfeeding	All participants contributed to this phase	22
5. Early Years of Motherhood with IBD	All participants contributed to this phase	22

Phase 1: Nulliparous Life

The first phase of the timeline looks at the experience of women with IBD prior to becoming a mother. Although one might assume that this phase is tangential to the transition to motherhood, I felt that it was pivotal to acknowledge how the nulliparous life and experiences during this time influence the challenges, decisions and assumptions later made by women regarding reproduction. A total of 15 participants – those who had a diagnosis of IBD before becoming pregnant for the first time - contributed to the analysis of Phase 1 (see Table 16). These participants were burdened and overwhelmed with the diagnosis of IBD and its implication on their health. Forming a family or questions regarding their fertility and treatment became secondary to the decisions they had to weigh to alleviate their suffering. Furthermore, these women were challenged by feelings of guilt and blame, attempting to make sense of the illness and started dealing with a series of medical appointments, testing, and treatments to restore their health leaving them to feel ambivalent towards healthcare professionals. Their mixed feelings and ambivalent relationship with healthcare professionals as well as the battle against the illness meant that participants do not address the implications of certain medications and the idea of planning for the future and family with their healthcare professionals. The contribution of each participant to this phase and its themes and subthemes is depicted in Appendix FF.

6.1 Theme 1: Burden of Knowledge

During the years prior to their maternity, 15 women in the sample received a diagnosis of IBD. Their Nulliparous Life was challenged by the news of having a chronic illness. Women were dealing with their deteriorating health, and tried to make sense of their diagnosis and its implications. Their challenge was accentuated by the lack of information on living with IBD coupled sometimes with a plethora of medical jargon and worst-case scenario research available on the Internet.

6.1.1 Making sense of IBD

Before receiving a diagnosis, women recall struggling around making sense of their deteriorating health and ever spiralling down of their symptoms. Some mention having had a “sensitive stomach” most of their lives and others say “it” appeared ‘out of the blue’ (CDMum08C01, Line 21); but they all recall that first episode when they felt particularly physical unwell.

I was 21 and I went on holiday with my parents (.) Um (.) I thought I'd eaten something (.) 'cos I was abroad in Crete (.) I thought I'd eaten something that would upset my stomach (.) and we came back off holiday and I kind of just carried on and carried on and I was losing a lot more weight (CDMum02C02, Line 6)

Participants mentioned the distressing symptoms: constant trips to the toilet, seeing blood in their stools, as well as excruciating pain and tried to make sense of what could have caused their symptoms, the origin or triggers of their ailment.

I wasn't sure what it was (.) so I'd had quite a few weeks of not knowing whether I had piles or something like that (UCMum20C01, Line 6)

One participant who experienced symptoms at the age of 10 said “I just didn't really understand what was happening and I think neither did my family so it was a bit chaotic really (.) it was quite a chaotic time ((sighs, laughs))” (CDMum16C01, Line 57). The forming of understanding seemed to be a shared experience with the family for participants diagnosed around their adolescent years. They were often misunderstood by their school peers and family members and their condition was further challenged by their concerns.

Everyone in school would ask me 'Why do you look like this? (very thin) What's going on?' And you know teachers would come up to me and say 'Are you okay? What's happening?' (UCMum15C02, Line 37)

6.1.2 Overwhelming (lack of) information

Once diagnosed with IBD, participants are challenged by the lack of available information around the topic “back then (.) not that I'm really old¹ (.) but just the fact that it wasn't as heard of as it is today” (UCMum23C02, Line 22). Participants were diagnosed on average 13 years prior to the interview and online resources were not as predominant then as they are nowadays. Furthermore, coming to terms with the cyclical impact and life-long diagnosis was another challenge, and some participants were unaware that the illness would reoccur. They assumed it would be treated and controlled with the medication: “I didn't think that it was coming back (.) and I thought it was a disease not a condition that you have to have all the way through your life” (UCMum17C01, Line 45).

Some women had never heard the term “IBD” or “CD/UC” and attempted to research the new terminology to make sense of the implication and what their future would be like, but they faced a plethora of tangled information. UCMum07C02 typed “Ulcerative Colitis” in a search engine and “the first thing that came up was bowel cancer (.) and I thought ‘oh my God (.) I'm gonna die’” (Line 42). Others mentioned having read about the worse possible case scenarios of IBD progression in the first few hit searches they performed, or even within forums supporting individuals with IBD. Another participant said she could not understand the medical jargon which rendered the information quite obscure.

I was very worried (.) um (.) I think when you Google sometimes things about um (.) Ulcerative Colitis when it's mentioned to you (.) or Crohn's Disease (.) you (.) see the worst in the condition and um (.) maybe what is going to happen and your future (.) (CDMum19C01p, Line 126)

¹ She was 38 at the time of the interview.

Hence, participants struggled to find relevant information on their illness, but it was difficult to form an expectation of what it means to have IBD especially as very few of them knew someone else who had the illness. Some had a close relative, father or sister, even an uncle who had the disease. In those instances, making sense of the disease hence was not particularly challenging and their general practitioner was able to swiftly identify the illness due to family history.

6.2 Theme 2: Weighing Decision-Making

6.2.1 Acknowledging IBD

Participants struggled with the symptoms and their feelings oscillated between dismissing and being proactive in *acknowledging IBD*. Some of the initial reactions to the symptoms they experienced and later to the diagnosis included, shock, denial, over optimism, rejecting conventional medicine, and fear of death.

CDMumPi02C01, recounted what her GP had said “‘worst case scenario it’s going to be something like Crohn’s Disease’ and I [she] thought ‘oh well, it won’t be that’ because ((laugh)) I’m [she’s] a kind of ETERNAL OPTIMISTIC ((high pitch voice))” (Line 112). Another woman diagnosed at 15 years old went on to rebel and carried on her life as if nothing had changed. She went out, ate and drank, refusing to let the illness dictate her behaviour. A particularly extreme reaction was portrayed by CDMum16C01 who had her first symptoms at 10 years old and described her intense fear of seeing her health deteriorate:

I became so frightened of seeing bones protruding (.) from (.) my skin (.) I stopped washing (.) so (.) I would go (.) maybe (.) a week or two (.) without (.) even having a bath or a shower (.) because every time I took my clothes off (.) the reality of it was so frightening so my appearance wasn’t wasn’t good (.) you know (.) I had greasy hair (.) I had bad skin so it was a horrible time when I think about it (Line 52)

Others adopted a more stoic attitude and stayed positive. They had a fighting mind-set, opted to battle through with the illness, adhered to their medication, and hoped for the best saying “Crohn’s won’t beat me” (CDMum19C01p, Line 128).

6.2.2 Trial and error

Participants reported a continuous challenge of *trial and error* to get diagnosed, get the right medication, or alternative therapy to sustain their remission. They constantly went back to their GPs or consultant to attempt to resolve their symptoms and sometimes the process took months or even years.

The first kind of medication I remember getting put on was steroids (.) Prednisolone (.) [...] they [doctors] also tried (.) different tablets like Solazapidin and Pentasa (.) all these kind of things which I know since they don’t really use for Crohn’s as much now but they tried all of those (.) they tried (.) it was a big

cocktail of drugs I was on (.) I think about fifty or sixty tablets a day at one point and I had to put it all into little containers because I couldn't remember everything what I had to take (CDMum06C02, Line 22)

After a few weeks I went to the doctor's because it [symptoms]was (.) it wasn't settling and I had different tests and blood tests done and things and there wasn't anything that they really could put it down to (.) so for about a year I was unwell and had various tests until finally they did diagnose Crohn's Disease (CDMum05C02, Line 14)

One participant described severe side-effects from taking an immunosuppressant drug and although it had helped clear her inflammation she had to discontinue the treatment.

I was on Adalimumab at the time (.) and I'd started to get really severe neurological side-effects (.) I'd been on it for about a year and a half and it's actually probably the best treatment I'd ever had for my Crohn's and it's the first time I'd had a colonoscopy done and it was completely clear (.) and (.) so the Adalimumab was doing the job on the Crohn's but then I started getting very severe headaches and it was almost the first time I had it me and my husband thought I was having a stroke because all the one side of my face dropped [...] and I kept having repeated episodes of that and (.) then well obviously went to see a neurologist and they did some scans and in the end we kind of think that the Adalimumab was the culprit so I had to come off of that (CDMumPi02C01, Line 136)

Although there is no permanent solution, the chronicity of IBD pushed participants to try new treatments. Some tried different diets, such as wheat- or dairy-free, or cut down on alcohol, tried acupuncture, hypnotherapy, or Chinese medicine. However, participants had mixed reactions with regards to bowel surgery. Some opted for surgery to reduce the symptoms. Others were still trying their best (up to the day of the interview) to avoid having an operation. Some mentioned having recourse to surgery, as a last resource due to the rapid deterioration of their health. A unique complication arose as one participant, who had elected for surgery, had a sudden cardiac arrest on the operating table. She was induced into a coma for two weeks to avoid further damage. After this experience, she and her consultant refrained from choosing surgery to control her IBD.

6.2.3 Restoring health

Participants found temporary solace in steroids which seemed to put a halt to the inflammation. However, due to the severe side-effects (i.e. bone loss, weakening of immune system and cataract), none could remain for a prolonged period on this drug. Nevertheless, each woman seemed to have found her own unique way of gaining control over IBD, even if temporarily, in an attempt to restore a 'normal' life.

It did start gradually improving. um (.) And that was that (.) that was just with the steroids really and the different enemas and um (.) changing in the diet slightly so it was a very low residue diet um (.) so got back on track (CDMum10C02, Line 46)

Interestingly, one participant, who had an allergic reaction to a commonly used drug for IBD (*Pentasa*, a brand name for Aminosalicylates (5-ASAs) refer to section 1.9.1.1 Anti-inflammatory drugs), spoke about being referred by her father to a medicinal spa in France where they lived at the time². During her stay she recalled with ambivalence the treatment had “cured” her for over a decade until the illness surfaced again in her early thirties (more than a decade later).

You have to drink some water (.) like they [water] come come from volcanic thing (.) they come out of a they follow the journey (.) and when you see what it is in the water (.) you're really not quite sure whether you should drink it or not ((laughs)) but that's why it's medicalised (.) I think there's some cyanure [cyanide] in it (.) something like that (.) yeah (.) it's (.) you have to go very (.) you go up very gradually (.) and you go down very gradually as well (.) there's some- not very good things in it (.) it doesn't taste very nice either [...] I only drank water and um (.) just that (.) that cured me (.) I think the change of change of air as well (.) helped me with the appetite and (.) yeah (.) it just disappeared (UCMum17C01, Line 27)

Another participant, who had to have her bowel surgically removed at the age of 20, spoke about her “new lease” on life and how she has been in remission since then. As mentioned before, there is no cure for IBD and there was no one-fix-for-all, but every participant found their own way of restoring their health even if for a short while.

6.3 Theme 3: Blame and Guilt

6.3.1 Justifying IBD

Participants were challenged by the lack of specificity about the origin of IBD. To deepen their understanding of their illness, they attempted to attribute blame to a trigger that could have ignited the illness. Blame was at times placed on an external locus, hence out of their direct control, with some reporting a holiday abroad (outside the UK) as a catalyst. Others attributed it to an internal locus, and mentioned their student lifestyle (i.e., eating junk food, late-night parties), stressors such as moving house, job demands, having a low immune system, or having a family member affected by IBD (genetics of the family).

In my family it's between Crohn's Disease and Ulcerative Colitis (.) and my dad has rheumatoid arthritis and my brother we now (.) found out has (.) I think it's called sarcoidosis (.) so they all seem to be connected in some way (CDMum01C02, Line 9)

It was my interpretation that these causal attributions of the origin of their IBD were more of an attribution of blame. Trying to justify the origin and cause of an illness was not merely a rational cognitive process but served the purpose of relieving one from the burden of feeling

² She was 14 when she got diagnosed and her father opted for alternative treatment for her.

that one has suffered an injustice or unfairness in provision of some kind of an answer to “why me”.

My consultant said (.) it was like a three in a thousand ratio of young people getting colitis at such a young age and this was what (.) 19-whatever year it was when I was 13 (.) you know (.) '81 so (.) um (.) No (.) '91 (.) I just don't know (.) that ratio's really stuck with me because it's like (.) my gosh (.) why me and I guess for the next ten years I've still kept asking my question (.) why me (UCMum23C02, Line 49)

Participants diagnosed at an earlier age tended to blame others for their lack of awareness and misattribution of their symptoms given that they were often mistaken to suffer from an eating disorder by their friends and family, and even by medical specialists. They were probed about their food habits, monitored closely while they ate, and were thought to be purging on purpose in the bathroom to maintain their figure. One participant – CDMum16C01 – even recalled that “one girl thought I was contagious so when I told her [...] she never spoke to me again because she thought that she'd catch it from me and I guess (.) at the time it really destroyed me” (Line 112).

6.3.2 Partner acceptance

A few participants touched upon the implication of having IBD and finding a potential partner. They mentioned feeling lucky they had already met their partners when they were diagnosed because otherwise it would have been quite challenging to be on the dating scene, not drinking and discussing toilet habits to a romantically interested stranger. Hence, this was a hypothetically and latently expressed challenge that ultimately and fortunately did not affect the women who took part in the study.

I had it also after I'd met my husband (.) I didn't have that embarrassment of (.) like (.) people going (.) 'Why aren't you drinking?' 'Oh (.) because I've got bowel disease (.)' When you're dating (.) you don't really want to talk about that (.) to be honest (.) So (.) um (.) you know (.) I had it whilst I was with him so it wasn't an embarrassment (UCMum20C01, Line 713)

However, it is worth mentioning two instances where CDMum02C02 and UCMum23C02 alluded and blamed the illness and others for their lack of acceptance of IBD and its repercussion to their romantic life.

I had an ex-partner and I remember somebody saying to me (.) 'well at least he accepts you with your illness' (.) and I was like 'thanks for that' And I did actually think well a lot of people probably wouldn't accept (.) not accept you as such but (.) it kind of makes your confidence knocked if someone actually says that to you and you think (.) well are people just accepting you and you've got this illness that can't be accepted because of what it is [symptoms] and you know (.) how it affects your life (CDMum02C02, Line 759)

I was a lot bigger and I was a lot fatter than everybody else (.) [because of steroids] worse case I actually end up going to a private school which was all-girls school so there was pressure (.) peer pressure of looking good and having boyfriends and all of that and I didn't have any of that [...]before I got married I

was so ill that I ended up losing so much weight because I just had constant diarrhoea um(.) and my periods stopped (.) I was that underweight (.) for two years I had no periods and so at that point I was actually like (.) I don't know (.) I think I made myself numb to the fact that I might never have a family of my own you know um(.) and I just thought.. (.) Because at that point I wasn't married (.) I hadn't met anyone (.) I wasn't dating anyone and I just thought (.) this is my life (.) I might as well just accept it (.) it's just going to be this and in and out of hospital for the rest of my life (.) um(.) I think I was trying to protect myself from getting hurt (.) you know (.) and especially when my periods stopped and they were just like you know what (.) you're just so underweight (.) there's nothing we can do (UCMum23C02, Line 58; 270)

In the first instance CDMum02C02 resented and blamed those who made her feel 'grateful' for being accepted despite IBD, and in the second, UCMum23C02 pointed out how IBD and its treatment impact isolated her from having a romantic life and she thought she would never meet a partner and have children.

6.4 Theme 4: Ambivalence towards Healthcare Professionals

6.4.1 Mixed feelings

In their first contact with a GP about their symptoms, only a handful of women reported having a quick diagnosis, "My GP was quite on the ball with it" (CDMumPi02C01, Line 76). Some said they were 'lucky' to have been quickly diagnosed - whether it was due to their family history of IBD or due to the expertise of their GP. Unfortunately, the majority of participants struggled to get a diagnosis, and one did not receive a thorough investigation to identify her type of IBD.

[Referring to the local doctor in her hometown in France] I had my first colonoscopy then (2) [15 years later] because on the first time they actually didn't do any for so many (.) very strange reason (.) not quite sure why (.) though they did the second one (.) and I've been officially diagnosed with Ulcerative Colitis (.) and not Crohn's (.) so they could know (.) which one (UCMum17C01, Line 12)

They felt dismissed and 'fobbed off' going back and forth to the GP trying to have their symptoms validated over months and sometimes years. Participants attributed the lack of detection of their disease to the qualifications of their GP: "small doctor (.) gastroenterologue [gastroenterologist³] not very specialised in any of those [inflammatory diseases]" (UCMum17C01, Line 12). And, some were angered to have initially received the wrong diagnosis of Irritable Bowel Syndrome (IBS), or told they 'just' had haemorrhoids, or that they were "typical teenagers".

They suspected I had (.) for years I'd suspected irritable bowel and um (.) [...] Before I had been going to the doctors on and off um (.) saying I had bad pains in

³ The participant is French and it served me well to be native a French speaker to understand at times the interchangeable terms she used.

my stomach (.) you know (.) I either was going to the toilet or I wasn't and they kind of said (.) 'Oh you must have irritable bowel' (.) you know (.) and I would have been on tablets for irritable bowel (CDMum19C01p, Line 87)

UCMum23C02, added receiving “just top line information” from her consultant at diagnosis, leaving her with a huge knowledge gap.

I don't think the consultant was that good in terms of explaining (.) they're just like yeah (.) we see inflammation of the colon [...] it wasn't explained in a way that look (.) there is this disease and it's an auto-immune disease and it's our own body's response of attacking the organs and things like that (UCMum23C02, Line 95)

CDMum09C02 also expressed how she felt disempowered over the decision to have a proctocolectomy with a pouch (see section 1.9.2 Surgical interventions) as she had been too ill to give proper informed consent, as seen in the following quote:

I was so poorly (.) to be honest (.) that it wasn't really (.) I don't really remember too much (.) I think I was so ill it wasn't really a choice (.) it's (.) 'That's going to happen' (.) So (.) you know (.) I was upset at the time (.) but (.) actually (.) it's (.) you know (.) it's (.) I think you just do it because you have to do it (.) that you're so poorly that you don't really (3) you're not really aware (.) A lot of it sort of happens around you (.) if you like (.) you're not really sure of what's going on (.) So (.) yeah (.) upset at the time (.) Actually (.) once you have it done (.) it's more resigned to it (Line 71)

Despite often tenuous first encounters with healthcare professionals, at some point during the course of their treatments, all participants established a good partnership with a consultant or other member of the medical staff (e.g., IBD Nurse). For example, CDMum02C02 remembered being well informed and prepared for the outcome of her bowel surgery by the nurses who showed her what a pouch would look like and how to empty should she have one.

UCMum15C02 said she trusted her consultant would know what to do if the medication could not keep her well; and CDMum16C01 talked about the pros of being treated by leading experts in the field but paradoxically also briefly mentioned how intimidating it was for an adolescent to be in a room full of doctors in a teaching hospital.

6.5 Recommendations

Although this phase of the transition, being nulliparous with IBD does not apply to the entire sample, it does raise important considerations regarding the decisions and challenges made regarding reproduction. Two participants raised the issue that consultants do not usually address reproduction and forming a family during the time of diagnosis and while trying different treatments. Some medications however are counter indicated during conception and gestation and the course of the treatment can run for several months and maybe years. This can come in the way of family planning and it ought to be the healthcare professionals' duty to underline, early on, possible interactions of starting a treatment that can affect later decisions or desires.

Lastly finding a partner when one is already struggling with isolating symptoms and treatment can be a difficult experience. Tackling feelings of loneliness and empowering young women to feel accepted and have positive self-image and body image is at the crux of later reproductive and family planning.

Phase 2: Planning for Pregnancy

The next two phases were tricky to disentangle as women often talked about planning for and going through pregnancy conjunctly. However, they were notable singularities as elaborated below that represent unique challenges to planning for, and conceiving, a baby in the context of maternal IBD; which led me to separate the phases. That is not to say that when women were planning to conceive, they were not already anticipating and challenged by thoughts regarding pregnancy, labour, or coping with a young child. The distinction between the phases is an attempt to provide a guided step by step timeline faithful to the participants' experiences.

Participants who contributed to this phase include the 15 women who were diagnosed prior their pregnancies, but also 5 of the 7 women who got their diagnosis a little later (during or just after their pregnancy) who planned for a second child with IBD (N=20, see Appendix GG). The two remaining participants who were diagnosed after/during their second pregnancy never expressed the desire to plan for a third child and hence were not included in this section. I disentangle in this phase the planning of women who attempted to conceive their pregnancy(ies) with IBD, versus the planning of those who attempted to conceive with IBD in their second pregnancy (they were IBD free in their first gestation). I also underline the experience of those participants attempting to get pregnant at the time of the interview, or those who attempted prior to that, but were unsuccessful (so far).

6.6 Theme 1: Burden of Knowledge

6.6.1 Assumption of IBD interference

At times, participants wrongly assumed that IBD would limit their ability to conceive and give birth. They expected – more often than not – that conception would take a long time, and that IBD medications would delay their ability to have a child. CDMum10C02 said: “absolutely no issues [to conceive] which shocked me (.) bearing in mind my body had gone through so much previously I thought it'd be quite hard to get pregnant (.) but no (.) absolutely no problems” (Line 102). These concerns are, for the most part, assumptions and not necessarily based on factual information, which explains the “shock” also described in the previous chapter when conception occurred quickly. Furthermore, CDMum06C02 and CDMum09C02, both successfully carried two pregnancies to term with a colostomy bag. That is not to say that some women did not have to plan around their medications and flares, only that there was a general

overestimation of the impact of IBD on conception, gestation, and birth. Unfortunately, three women were attempting to get pregnant again; the first CDMum08C02 mentioned “not been able to fall pregnant again [...] due to complications of surgery after the pregnancy” (Line 72). A bowel resection post childbirth seemed to have obstructed her fallopian tubes, and she opted to reject IVF and accept to stop at one child. The other two, CDMum16C01 and IBDuMum04C01, were trying at the time of the interview but thought the illness, was getting in the way “I haven’t fell pregnant (.) is it for a reason umm (.) you know (.) could that [IBD] be part of a reason why (.) you know (.) in the back of my mind I’m thinking could I actually cope?”. They both considered resigning from their jobs to be able to cope and pursue having more children.

Other types of interferences that would add up to the *burden of knowledge* were the small window of opportunity to conceive and the age of participants, as well as having irregular or interrupted menstruation due to IBD. CDMum16C01’s husband worked abroad which delayed considerably conceiving a second child, as well as being tired from caring for a toddler and dealing with IBD flares. Two participants – IBDuMum04C01 and UCMum20C01 – were older mums and talked about the stress of trying to conceive their first and only child knowing that time was against them. One of the two women did not know she had IBD at the time she was planning for her first child but since she was planning for a second with a diagnosis she was included in this phase, the other knew she had UC, and the diagnosis acted as a double stressor.

That was quite a stressful time and (.) again (.) stress isn’t good for colitis ((laughs)) so (.) yeah (.) so it was quite stressful [...] It’s stressful because I think it’s probably less stressful if you’re in your early 30s and you’re like (.) ‘Oh (.) I’ll get pregnant one day’ and because the closer you are getting to getting older and also (.) I think (.) having colitis that you don’t want to be ill and have any affect to it that every month you’re not pregnant (UCMum20C01, Line 165)

6.6.2 Lack of information

A few women wanted their consultants to provide more information and wished they had discussed planning a pregnancy with their health providers much earlier. They felt there was not enough information on planning a pregnancy with IBD.

I think there’s not enough (.) I think there’s not enough (.) not that I thought I should be warned about it (.) but I definitely think I didn’t have much information about getting pregnant before (.) I did (.) you know (.) I wondered whether if I’d spoken to my consultant about wanting to become pregnant it might have been a different story (.) rather than actually saying ‘Oops (.) I already am’ (CDMum01C02, Line, 615)

UCMum15C02, feared switching medication whilst planning to improve her symptoms after reading about stillbirth in the recommended newline medication. In addition, a few participants felt a general sense of discouragement around having children with IBD and that was largely due to the inexperience and *lack of information* around pregnancy and IBD.

Women who have um (.) you know (.) the Crohn's should be allowed to have a family (.) you know (.) and I don't (.) I think (.) probably a lot of people fear pregnancy and Crohn's and that shouldn't be the case (CDMum19C01P, Line 445)

6.7 Theme 2: Weighing Decision-Making

6.7.1 Improving odds

Women attempted various changes including healthier diets, reducing lifestyle stressors (such as reduced work-time), and acupuncture to increase their chances of getting pregnant. I noticed the similarities between this subtheme and *regime alterations* elaborated in Chapter 5, however, in this section I am emphasising the challenges of *improving odds* whereas in the latter I was pointing out the similarities across IBD and motherhood in terms of *Lifestyle Changes*. All the participants in my study planned to get pregnant (some were not actively trying but had stopped using contraceptives in the hope of starting a little later than expected). To improve their odds, they actively planned around their ovulation days and checked for any fertility issues to improve the odds of getting pregnant when conception took longer than expected.

We did get referred to a fertility doctor um (.) and he was (.) he said 'well (.) I can't tell you there's definitely anything wrong or right or' he said (.) 'it might just be that you're taking longer to get pregnant' (CDMum06C02, Line 153)

UCMum03C01p received her diagnosis after her first pregnancy, it had delayed her a whole year to conceive her second child, which led her to wean herself off IBD drugs to get pregnant. Others usually planned around their IBD treatment, before attempting for a first or second child. And, one participant completely disregarded medical advice and went on to plan for a child saying whilst on a counter-indicated teratogenic medication:

Well I was told to not get pregnant for about 18 months ((I: How come?)) because I'd started the Golimumab trial (.) so they said 'Don't get pregnant' and I wasn't trying to get pregnant but we went to a wedding (.) and had a lot to drink and (.) you know ((laughs)) and then this one's ((pointing to her pregnant belly)) on its way now ((laugh)) [...] I didn't really care to be honest because I thought if (.) if (.) I'm going (.) you know postpone my plans then I've let the colitis win really and it's not going to dictate my life to me (UCMum11C01p, 177-195)

For those women who took longer to get pregnant (more than 2 years) they had to resort to IVFs (UCMum15C02) and one (CDMum08C01) used hormones treatments (e.g., Clomid), to increase their odds of conceiving. One participant (CDMumPi02C01), who suspected she was pregnant, refused to have an MRI scan previously planned in the off chance that she would be pregnant.

6.7.2 Alternatives and acceptance

Participants who faced difficulties getting pregnant, whether the first time and/or the second, considered alternatives such as adoption or fostering or “tried to accept that we [they, the

couple] weren't going to have children and that was how it was going to be" (CDMum06C02, Line 141). Three participants considered adopting or fostering but, in each case, there were several deterrents to these alternatives: their partner was less enthusiastic, they unexpectedly fell pregnant, or they assumed that their poor health would be a barrier to being selected to foster a child.

We did talk about fostering or do something like that (.) but with my condition, well, or what happened (.) and my husband had a pretty bad health as well (.) so there's no way nobody will (.) we're not on the list (.) we can't have (.) we can't foster because we healthfully (.) we don't have the health record for it (.) so the adoption would be exactly the same (UCMum17C01, Line 568)

UCMum17C01 had pre-empted in my opinion that she and her husband would not be suitable for adoption without checking the requirements for fostering or adopting in her living area (Oxford). I found it hard to believe that the two other women who had also thoroughly considered this option had not come across this potential health barrier whilst looking at the paperwork. However, these other two women: UCMum03C01p and CDMum06C02 lived in Barrow-and-Furness and Dumbarton (Scotland) respectively and it could be that the regional requirement for fostering and adoption vary from the one area to the next.

As for the fear of passing on the illness, CDMum05C02 was particularly anxious about the risk of transmitting IBD to her offspring and went for a genetic testing to decide whether to have her own children.

We were quite nervous you know (.) if they were to say (.) you know (.) yes there's a very high chance of having a child very young with Crohn's Disease then we would have had to carefully thought about (.) you know (.) whether to have children or not [...] but it was a relief afterwards because (.) you know (.) they said it was very unlikely to have a child really young with Crohn's (Line 57)

Four participants had planned/were planning for a second child at the time of the interview but had been unsuccessful for a prolonged period of time (a little over a year). IBDuMum04C01 was one of them and she mentioned that the decision to refrain from trying anymore for a second child was difficult as it meant leaving her first as an only child. However, participants who attempted or contemplated having a second had to weigh the impact of another pregnancy on their body and health, their ability to cope with young ones, and to be present for their family.

We [couple] talked about what the options might be (.) and I was pretty clear in my mind that actually I go through enough with my Crohn's that I didn't want to put myself through IVF [...] making a decision to not formally try for a second baby I think was quite a big point in the journey (.) because I'd decided not to put undue pressure on myself and acknowledge the fact that actually I've had it really tough (.) and to put myself through IVF and things like that would have felt just so much more invasive and emotionally draining (CDMum08C01, Line 659)

Due to the incredible demands of dealing with IBD, some participants chose to consider carefully whether or not to have a second child. This subtheme echoed with *selfish desire*

elaborated next, however, here, I am emphasizing, not the guilt aspect of having fewer children, but the formal decision regarding family size.

It's a balance of really (.) it's really really hard decision at the moment to think (.) do I need to (.) So you've got this kind of (.) ticking clock of that time and I've always (.) I never wanted to have only one (.) I always wanted to have two (.) but with all the implication (.) that might bring (.) I'm not quite sure if I (.) if I want to take the risk of having another one (UCMum17C01, Line 546)

Because the study involved a one-time interview with participants, I do not know how these women's plans developed. However, what seemed clear is that the decision about family size was weighed in light of their experiences of pregnancy and IBD.

6.8 Theme 3: Blame and Guilt

6.8.1 Selfish desire

Women reported feeling guilty for wanting a biological child when they could potentially pass on IBD. They considered their desire as potentially selfish and gave - as seen in the previous paragraphs - careful considerations to whether or not they should have children.

I think it would be an awful thing for me to do to bring someone into this world where they might actually get such a horrible disease (CDMum02C02, Line 683)

Nevertheless, as CDMum09C02 put it, they were “not concerned enough to not to have a baby” (Line 162). Conversely, even the decision to refrain from having any more children was sometimes equally perceived as selfish. It was selfish to put their own health ahead of providing a sibling for their child, or ahead of a partner's wish to have another child. UCMum07C02 expressed such an instance in the following excerpt:

I'd always wanted two girls (.) um so (.) I got my two girls ((laughs)) so I'm not that bothered (.) but had I had a girl and a boy I might have been a bit 'ooh (.) I wanted another one' because I did want three (.) my husband on the other side wanted a boy so he's a bit 'oh (.) it means we're never gonna have a boy' (Line 266)

6.8.2 Social pressures

Two participants from ethnic minorities - Ashkenazi Jew and South Asian - reported family pressure during their attempt to get pregnant. In the first instance, UCMum15C02 had undergone 11 rounds of IVFs and mentioned the lack of support of her mother saying:

'Right that's it (.) it's not good for you (.) you're obviously not (.) you can't cope with having a baby (.) that's why you're not getting pregnant (.) you should just adopt (.) you know (.) you shouldn't um (.) try anymore because it's taking its taking its toll on you (.) you're so stressed (.) it's so difficult and emotionally you're a wreck and it's (.) it's not good for you to carry on with these IVF treatments' (Line 287)

As for the other, UCMum13C02, she reported hiding her illness from her relatives in order to avoid misinterpretations as to her miscarriage or difficulties getting pregnant fearing speculation such as ““why she’s not having kids? Is something wrong with her? Do you think it’s affecting her ability to have children or (.)?”” (Line 984).

Although other participants from ethnic groups did not report similar challenges, these two women did experience pressure and, even though the story ends well for them both, it is important to note possible implications for women who fail to have children and consider how they navigate these additional stresses which may increase their feelings of *blame and guilt*.

I live in (.) I’m Jewish and I live in a Jewish community that’s very much focused on (.) children (.) having children and family and all the festivals revolve around family time together (UCMum15C02, Line 558)

6.9 Theme 4: Ambivalence towards Healthcare Professionals

6.9.1 Mixed support

Some women felt supported by their healthcare professionals when planning for a baby and reported encouraging conversation with their consultants. Getting pregnant was perceived as a positive experience that could help their illness.

I told him look (.) I’ve just got married and I really would like to start my own family and we plan to start soon so he was like (.) okay fine (.) (UCMum23C02, Line 269)

The doctors were all very positive and they’d always been saying to me ‘oh (.) you know (.) you never know (.) you could get pregnant (.) it could be the best thing that’s happened to you’ and yeah (.) they were very positive [...] the information they gave me about pregnancy and IBD (.) They were very reassuring and gave me lots of encouraging statistic (CDMumPi02C01, Line 210 and Email communication, 14 October 2014)

Unfortunately, some women had a very different experience. UCMum15C02 for example was told she was biologically incompatible with her husband and her only chance would be surrogacy or adoption. Two other notable cases were a woman based in Scotland – CDMum06C02 – who had her bowels removed at the age of 15 and an older mother – CDMum19C01p – based in Northern Ireland. In the first instance, the consultant mentioned her pouch as a barrier to her pregnancy and, in the latter, the participant expressed feeling a sense of overall discouragement by healthcare providers towards women who have IBD who wanted to have a family.

Women who have um (.) the Crohn’s should be allowed to have a family [...] a lot of people fear pregnancy and Crohn’s and that shouldn’t be the case” (CDMum19C01p, Line 445).

Moreover, UCMum17C01 had suffered from a stroke a few years after her first pregnancy and said her consultant did not “seem to be very (.) totally impressed with the decision of being pregnant again” (Line 558).

6.10 Recommendations

Participants in this phase expressed the need to get more information regarding the barriers and delays to conceive, in terms of treatment and illness interaction, as well as the risks to pass IBD to their children. They also welcomed a more encouraging attitude from their healthcare professionals as well as family and relative to their decisions to plan for a family.

Phase 3: Conception and Gestation

There were notable singularities and unique challenges to pregnancy with IBD. The entire sample contributed to this phase however, as seen in Table 16, some women experienced IBD with its implication in one or both pregnancies, or only its symptoms, and some even got diagnosed during their gestation. Women were challenged by the lack of certainty around the impact of their medication on the developing foetus, having to shift priorities from themselves to their children and battling guilt over the ideal of *the good mum*. During pregnancy, participants struggled to establish trust with the different medical specialists and regain *power over birth plan* and choices. They fought to liaise between the different specialities to enable a more integrated care. Although all participants contributed to this phase (see Appendix HH), I point out how the timeline failed to address some of the unique experiences of women diagnosed during and after their pregnancies.

6.11 Theme 1: Burden of Knowledge

6.11.1 Haunting fears

During gestation, participants feared experiencing an insurgence of their IBD symptoms, and its subsequent potential impact on the developing foetus: “I did have a concern that I would flare-up during pregnancy because I think sometimes that can happen” (CDMum05C02, Line 121). For the few participants who experienced bouts of diarrhoea during pregnancy, they were burdened by the thought that the foetus might not be absorbing all the necessary nutrients if they themselves were not able to eat properly or retain the food they ingested.

The fear of getting ill was linked to a fear for the child’s life, as elaborated in the previous chapter’s subtheme *fear of mortality*. Women were concerned about any potential anomalies or birth defects (e.g., Down syndrome), but also about miscarrying or not carrying the child to full term. Moreover, the *haunting fears* of a flare were also linked to the ability to

care for an existing child (given that the ages between first- and second-born were quite close in the sample – 3 years on average) and most of the sample had to manage a toddler whilst pregnant with their second.

My only concerns about wanting to check that I was really pregnant and the fact that I could potentially miscarry and the fact that it had taken so long to get pregnant (.) I was concerned that I wouldn't be able to carry the baby through of course (.) but (.) you know (.) that's always going to be in the back of your mind (.) whether you're ill or not I think (CDMum08C01, Line 144)

On the other hand, some women expressed the fear that their child's weight would "crush" their bowel and contribute to their symptoms. In my opinion, these concerns and fears were highly linked to the lack of knowledge around gestation and IBD and lack of communication of these concerns to their IBD consultant. It is worth mentioning that the *symptom confusion* elaborated in the previous chapter was of pivotal relevance in this phase and mothers' inability to attribute the gastric symptoms to IBD or to pregnancy added to their challenge.

6.11.2 Treatment conundrum

Women who were on medication during their gestations (N= 15, see Table 12 *Description of Sample Characteristics*) reported feeling uncertain and ambivalent about the impact of their drugs on their pregnancy. On the one hand, they trusted that the medication was keeping the disease at bay, however, they were perplexed as to the interaction of the drugs with the developing foetus.

I was worried about being on the tablets that I was on during the pregnancy um (.) because there has been a few things that I've read about Azathioprine um (.) and being pregnant and things like (.) and stillborn babies and things like that (.) so (.) that kind of scared me a little bit (UCMum07C02, Line 220)

As for women who were not on medication at the time of their pregnancy, they reported rejoicing about not being on treatment but, simultaneously, feared that the disease would flare and jeopardise their gestation. Medication and treatment gave a sense of control and safety from the illness, but *lack of information* around their chemical interaction with the foetus burdens women during this important time.

I was concerned because I wasn't on any medication to control it (.) but then at the same time I kind of thought 'well it's the best time for me to be pregnant because I'm not on any medication' (CDMumPi02C01, Line 207)

Two participants even feared that the accumulation of drugs over the year could yield noxious effects on the baby, although they were both medication-free during their pregnancy.

I've been on a lot of drugs (.) and because of the heart failure I'd had so much radiation and MRI scans and CT scans and I was really concerned about that level of radiation and things in my body (CDMum16C01, Line 239)

Changes in treatment plan were not welcomed by participants, whether they had to start taking drugs or switching medication during the course of gestation. And those who were flaring-up

felt uncertain about using steroids whilst pregnant. Exceptionally, a few women entering the third trimester were recommended to stop drugs that could potentially transmit to the baby through the placenta and upon delivery (i.e., Golimumab)⁴.

6.11.3 Lack of certainty

Mixed feelings around drugs and gestation were exacerbated by the lack of unanimous findings in the research literature. Forums and websites also contained conflicting messages regarding the safe use of certain drugs during gestation.

There was a few frustrating times where (.) for instance about the breastfeeding or about taking the Azathioprine throughout the pregnancy (.) the Crohn's specialist might say something that would contradict a little bit the specialist I was under for my pregnancy [gynaecologist] and that was quite hard then (.) quite confusing (CDMum05C02, Line 223)

Some participants mentioned finding no information whatsoever on drugs and pregnancy and, moreover, knowing no one who had IBD and gone through the transition to motherhood for support and advice.

Yeah (.) it was a real worry because I looked online (.) tried to find any answers to what anyone else had gone through and I couldn't find anything (UCMum20C01, Line 245)

The nuance presented in the subtheme *lack of certainty* versus the subtheme *lack of information* presented in the previous phase was that during pregnancy most women had discussed treatment impact on gestation but the research was not definite and some websites had mixed messages. In the latter phase, Planning for Pregnancy, participants wished there was more information communicated to them by healthcare professionals as well as more consistent information regarding which drug was safe to be and remain on whilst attempting to conceive.

6.12 Theme 2: Weighing Decision-Making

6.12.1 Shift of priority

Women who had previously acquired the knowledge that such things as stress, diet, and alcohol appeared to precipitate their IBD symptoms, attempted as much as possible to manage these

⁴ “Anti-TNF drugs including Infliximab, Adalimumab and Golimumab are very big molecules which resemble the chemicals of the human immune system in structure. They do not passively cross the placenta. Starting from week 21 they get however actively transported across the placenta alongside the other chemicals from the mother's immune system. These drugs are NOT contraindicated during the third trimester but exposure should be limited to the first 2 trimesters where possible. Most women will stop these drugs around week 24-26 and recommence after pregnancy. However, those where the disease is not 100% controlled are advised to continue throughout. At birth the drug concentration in the foetus exceeds that of the mother even when drug gets stopped around week 24” (Dr Christian Selinger, Gastroenterologist, Email communication, August, 8, 2017)

triggers particularly well during pregnancy. For example, some mentioned attending pregnancy yoga classes and meditation to learn how to better prepare for the birth.

You're looking after yourself constantly (.) I was (.) ate as healthy as I possibly could (.) I did everything by the book (.) I was (.) didn't drink (.) I didn't hardly ever have caffeine or anything like that (.) I really looked after myself ((laugh)) and that's probably why I got so big ((laugh)) towards the end of the pregnancy (CDMum02C02, Line 83)

This subtheme – *shift in priority* – echoed in many ways the subtheme *regime alterations* elaborated in section 5.2.1. Women opted to be healthy and altered their diets and activity level in the hope to remain well during their gestation. However, among the stressful tasks and decisions they had to make because of this huge life transition were: moving to a new house and acquiring money through selling their car and cancelling holidays.

The fancy cars had to go ((laughs)) and we didn't go on our holiday either because by that point I would have been (.) I think I was about thirty odd weeks pregnant by the time our holiday was meant to be coming (.) so we cancelled our holiday ((laugh)) and bought new furniture with the money that we were going to buy (.) so yeah (.) that was before the first pregnancy (CDMum06C02, Line 164)

Participants also had to make decisions regarding their choices of maternity care, whether to opt for a midwife-led unit, general care unit, or to be under high-risk care/specialised unit. That decision was influenced by the woman's health status at the time: if she felt well enough, and her consultant approved, she could choose the closest available care facility. However, for some, the choice was imposed when IBD symptoms appeared during gestation.

The reason why I stayed under general medicine at my local hospital (.) they did suggest to me I should go to one of the main hospitals but I said I couldn't at the time 'cos of my job (.) Umm I said 'I don't think they'd tolerate it' because obviously I had Crohn's Disease anyway (.) it was quite difficult with them (.) with my appointments and things (.) never mind if I had to travel another half an hour to go to an appointment and be an extra hour out of work and things like that (.) and it was obviously that time where people were made redundant and recession and things like that (CDMum02C02, Line 263)

Managing IBD meant adhering to the medication and balancing the benefits of being well with the uncertain impact of the drugs on the baby. As UCMum07C02 said: "I knew that to be (.) to have a healthy baby I needed to be healthy so I couldn't stop these tablets" (Line 223). The decision weighed heavily on their shoulders and participants mentioned needing to discuss their options with their partner and medical professionals. And, unfortunately, for one participant delaying treatment in order to discuss her options with other health professionals led to a premature labour. It is worth mentioning that participants who already had a young child felt less able balance their pregnancy, IBD treatment, and self-care. They found it difficult to take enough rest and to continue healthy habits because they had to prioritise their firstborn and deal with pressing IBD symptoms.

Perhaps wasn't quite as good with my organic food and you know, cooking everything from scratch because of course I'm looking after a baby at the same time so (.) [Daughter's Name] took priority over me maybe and probably felt more tired in my second pregnancy for that reason 'cos you're looking after a child already [...] I think any mother would tell you who's already got one or more young children while they're pregnant that you don't get to have the naps and the rest that you would maybe in your first pregnancy [...] it was hard, you know, in and out of the bathroom and looking after my daughter (CDMum05C02, Lines 139; 303; 308)

6.12.2 Tailoring support

Participants were challenged by the absence of a one-stop all-inclusive support that would provide answers regarding IBD and transitioning to motherhood. They had to tailor the help they received with whomever was available and supportive at the time of their pregnancy. The challenge resided in compartmentalising their support into practical, financial and sometimes emotional help. Most often interviewees answered that their husband was the most helpful person during their pregnancy (that question is found in interview schedule, Appendix AA).

My husband ((laugh)) he's always very supportive and wants to help out and look after me and cook for me um (.) and so (.) yeah, I mean I needed his support (.) you know (.) going to all the scans was very nerve racking and yeah (.) he was always there (.) whatever I needed (.) whatever I was stressed about I could always talk about with him because he understands where I'm coming from and what my stresses are (UCMum15C02, Line 371)

However, not all partners gave such dedicated support and the participant's mother sometimes added support on a day-to-day basis, answered queries regarding practicalities, and provided moral support.

When you're pregnant for the first time you don't know half these things exist (.) you know (.) you open a Mothercare catalogue and they're there (.) but you don't really know how they help you and I think from that (.) the advice side of it my mum was excellent and would advise (.) you know (.) get this pillow and 'cos I had such a lot of back pain (.) it was a great piece of equipment to help me through the last sort of four months (CDMum16C01, Line 434)

The most supportive people were also sometimes friends or even a close colleague when their family lived further away or their husband was not particularly present.

My husband (.) as I say (.) was not very involved in my [...] my manager (.) he's my best friend as well (.) but he (.) he (.) he lived my pregnancy with me (.) he wasn't my husband but he was the close enough (.) so he had a (.) the whole thing (.) 'Oh he's moving (.) oh he's duh duh duh' the whole the whole morning and everything (.) he had to deal with me (.) that my husband didn't ((laughs)) (UCMum17C01, Line 246)

Sometimes, participants had to turn to a charity, such as the Ileostomy Association or one focused on helping women with children who are at risk for Down Syndrome. However, it often felt like “one of those impossible things really [...] like it was just all a big question mark and it was a case of you've just got to wait and see” (CDMumPi02C01, Line 247). Participants could

not have definite answers from their established support network and had to live with the uncertainty regardless of to whom they spoke: “we didn’t know until he was born if he definitely did or didn’t have [Down Syndrome]” (CDMum06C02, Line 335). As it turned out, none of the participants in this study had children affected by a chromosomal anomaly or other such condition.

6.13 Theme 3: Blame and Guilt

6.13.1 The good mum

For participants who were on IBD medication during pregnancy, and sometimes even before their gestation, a sense of self-blame and guilt filled their choices regarding having so many treatments. For example, CDMumPi02C01 expressed her guilt over possibly “harming the baby” when she got the news that the child was high-risk for Down syndrome:

There’s always those doubts that maybe it’s (.) maybe there’s something about my body or the medication I’ve had over the years or has that impacted on her (Line 236)

Similarly, CDMum06C02 blamed herself for even ordering the trisomy test, as it only added stress and she would not have terminated her pregnancy whatever the outcome. I interpreted there to be a latent sense of ‘I should have known better’ emanating from her reflections. Guilt was not explicitly mentioned but resonated through the tone in which the participants related their stories. Furthermore, UCMum20C01 asked herself: “Am I a horrible person because I don’t want this now?” (Line 272). She was ambivalent about the pregnancy, despite trying for a child for over two years. In addition, CDMum05C02 reported that she was not “as good” in her second pregnancy, insinuating self-blame for not “cooking everything from scratch because of course [she was] looking after a baby [first child] at the same time” (Line 139).

Food and alcohol was a common topic, particularly when they had symptoms of IBD thinking “what have I done now to flare-up?” (UCMum20C01, Line 266) or “have I done something wrong because (.) I didn’t know I was pregnant so I’ve done all these things that they advise you not to do, I’ve taken this medication, I’ve done this that and the other [drinking alcohol]” (CDMum16C01, Line 319). In essence, the women attempted to rise to an ideal of the *good mum* and any perceived shortfall was a source of self-blame and reprimand.

6.14 Theme 4: Ambivalence towards Healthcare Professionals

6.14.1 Establishing trust

Experiences with healthcare professionals during the phase of *Conception and Gestation* seemed quite mixed. For some, *establishing trust* was a straightforward process but for others it

took some time to build a partnership with their healthcare providers. Those who felt supported by their consultants reported having an open-line of communication.

He [consultant] put my mind at ease [regarding drugs and pregnancy] and (.) as I said (.) you know (.) there's an IBD nurse connected to the [Hospital] and she would be my port of call (.) So if I ever have any questions I was always able to pick up the phone and just ask (.) which was great (CDMum19C01p, Line 447)

On the other hand, some participants felt uncared for as they approached motherhood: “nobody said (.) ‘Oh you’ve got this disease, we need to be extra careful” (CDMum01C02, Line 290). Others reported how they never got a clear answer and that there appeared to be a severe lack of knowledge about IBD and pregnancy, particularly amongst midwives and gynaecologists.

I sort of asked (.) I was asking people [consultants, medical staff] what can I expect [they said] ‘I don’t really know’ (.) nobody really knew (.) nobody could give me any information (CDMum06C01, Line 193)

This apparent lack of specialist knowledge, inculcated a mistrust of the recommendations provided by healthcare providers in relation to their pregnancy especially when this conflicted with what their gastroenterologist had advised.

I found the obstetricians and the midwives not particularly helpful because they didn’t really get the Crohn’s [...] But so I mean from a health professionals support the (.) antenatal guys were great in terms of monitoring my pregnancy (.) but they didn’t really get the complications that I was facing from a Crohn’s perspective I think (CDMum08C01, Line 436)

It is possible that participants who had been diagnosed prior to their pregnancy had a certain advantage in having already developed a relationship with their consultant and have established trust and good communication.

There was a point when the obstetrician wanted to put me on Prednisolone and they prescribed it [but] my gastro and I agreed that I wouldn’t start the Prednisolone (.) so we stayed on the Budesonide throughout (.) so I didn’t change my medication, he was quite wary about changing it (CDMum08C01, Line 180)

Such women felt that the decisions were made jointly and the consultants, for example, “took [her] lead in a [...] he always used to say you’re the expert in your care” (CDMum16C01, Line 389). This kind of partnership made participants feel heard and valued.

On the other hand, those whose IBD commenced during their pregnancy did not have a point of contact and, for one, “it took (.) three months into that pregnancy to actually speak to an expert of what was going” (UCMum03C01p, Line 148). Moreover, some felt unsure about commencing IBD treatment.

He [gastroenterologist](.) prescribed me Prednisolone, steroids, and I was really (.) really reluctant to start [...] I really wanted to see um (.) my consultant (.) my obstetrician about it before I started taking the med (.) steroids [...] and (.) actually (.) the day I had the appointment to go and see her was the day I went into labour (.) and now they think it was the flar- up that kind of um (.) stimulated

my uterus (.) which caused me to go into pre-term labour (UCMum14C01p, Line 72)

Sometimes the “honesty” of the consultant was not always welcomed and although those who were warned about the possibility of post-pregnancy flare could feel that this “was very good (.) he was very honest with me (.) very straight” (CDMum02C02, Line 502) others said “that wasn’t the best [...] ‘cos then you’re obviously more anxious waiting to flare afterwards” (CDMum10C02, Line 195).

Lastly, IBD nurses, seemed to be the main the port-of-call of women who needed more information and could not wait between one appointment and another to get a hold of their consultant. Unfortunately, not all women reported having access to an IBD nurse during their pregnancy. However, for those who did, IBD nurses helped provide reassurance with regards to such things such a dosage adjustment during pregnancy and calmed participants’ anxieties.

6.14.2 Power over birth plan

Five participants recounted their birth plan: their preferred choice of labour or the option suggested by their consultant, whether it was a natural vaginal delivery (V-delivery) or a caesarean (C-section). Some of the reasons for recommending a C-section were the presence of fistulae, heart condition, or having an external pouch. Although one woman was experiencing faecal discharges vaginally during her pregnancy and had requested to have a C-section, her gynaecologist seemed to have delayed giving her the final word on the choice of labour.

I remember asking quite early on to have a caesarean because of my fistula (.) I’ve got setons⁵ in situ (.) and when I discussed it with my gastro he advised that it wouldn’t be a good idea to give birth naturally (.) just because a) of the stress of it (.) but also that if I tore the impact on some of the fistulae and so on (.) so we agreed early on that I’d have a C-section, and (.) I remember discussing it with the obstetrician early on and he was like ‘Well we’ll discuss it nearer the time’ kind of thing (.) I didn’t feel like it was a given (.) I felt for me like it should just have been a given and that should have just been the end of the conversation (.) but I had to keep referring to it because (.) I didn’t get the reassurance from them that it was definitely going to happen (CDMum08C02, Line 331)

Two participants who had a traumatic first delivery, wanted an elective C-section for their second birth but were not allowed and felt disempowered by this lack of choice. Even though the consultant had reasoned with her about the risks and longer recovery time, UCMum23C02 said she was “worried and quite sad um (.) that I couldn’t make a decision on my own (.) from my own sake after knowing about my condition” (Line 636). Some participants had to go for an emergency C-section as complications arose such as liver failure, bowel stricture, or foetal distress and/or bleeding. They felt this was unfortunate as they would have wished to have a natural delivery. Most did not seem to mind, but one woman felt angry about the doctors taking

⁵ Suture material looped through the fistula.

over and inducing her labour leading to an emergency C-section. Hence, she challenged their decisions in relation to her second pregnancy and was more assertive about her preferences.

I was under consultant care um (.) and looking back it was probably I wish I hadn't been because they were a little bit more involved, um (.) [so the second time] they said 'No (.) we've got to book you for a C-section' um (.) so I said 'Well I have done quite a fair bit of research and I think it can be still migrate [placenta] so it could still go up a bit' um (.) the consultant was registrar that I saw (.) said 'No it's not going to happen' so he then spoke to the consultant (.) I asked him to speak to the consultant that then came in (.) she said 'Well we'll give you a scan at 38 weeks' I said 'I think we'll do that (.) and then we'll do another one at 40 weeks just in case' [...] unfortunately [Second Boy's Name] shot out which did cause a lot of damage (.) but it was just really unfortunate (.) but I still got my V back which is vaginal birth after C-section and it was brilliant it was really empowering and I wanted to tell them I proved them wrong ((laughs)) (CDMum10C02, Line 83)

6.14.3 Liaising with specialists

Unsurprisingly, pregnancy specialists seemed very focused on their area of expertise and rarely had knowledge around IBD. One participant even reported a lack of professionalism from midwives and nurses upon seeing her bowel surgery scars when attending a foetal monitoring scan. The general sense was that midwives, non-specialised nurses, and gynaecologists, were very baby/pregnancy-focused and lacked the qualifications necessary to guide women with regards to their IBD. Anti-natal classes were rigidly conducted and no advice on bottle feeding was given to mothers who could not breastfeed due to their medication.

There was one exception though where CDMum05C02 said she was impressed with some of the midwives, but “not all of them”. However, as seen in the quote below, it was more due to the form of advice given rather than the content being particularly IBD-informed.

I'd say I was really impressed with some of the midwives (.) not all of them (.) and I think some of that's just down to how well you get on with people maybe and personalities and things [they] really encouraged me throughout the pregnancy to do what I felt best for me (.) to you know (.) look after myself (CDMum05C02, Line 257)

A few participants benefited from having both of their consultants in the same hospital meaning that the two departments (gastro and obstetrics) could relay and share notes easily. This, ‘accidentally’ led to a centralised and holistic approach to care for IBD making it less likely to experience the kind of problems experienced by UCMum07C02.

I got missed quite a bit because the NHS had messed up my records and had (.) when I got married they'd given me a new NHS number instead of just changing my name (.) so I'd got missed a bit but I (.) so I should have seen her the first time (.) but I saw her [gynaecologists who knew about IBD] the second time (Line 304)

Importantly, participants who had both their IBD team and gynaecologist liaising notes in the same hospital felt taken care of in that “they worked really well together [...] they were looking at me from slightly different angles” (CDMum16C01, Line 459).

6.15 Reflections and Recommendations

The timeline as presented linearly in Table 15, failed to incorporate all the particularities faced by the two women UCMum14C01p and UCMum13C02 who were diagnosed during their pregnancy (see Table 16). On top of going through some of the challenges expressed as subthemes in Phase 3, UCMum14C01p and UCMum13C02 were also dealing with some of the challenges expressed by women in Phase 1, challenges relevant to receiving a diagnosis of IBD. I provide here below a visual presentation in Table 17 of the subthemes that applied to the unique case of these two participants as well as removed those who did not.

As for CDMum22C02, UCMum12C02, and IBDuMum04C01 they had fewer challenges with regards to the treatment of IBD and the fear of flares or even liaising between specialists as they had not yet been diagnosed. They were challenged by their symptoms and not knowing what was happening to them whilst going through their pregnancy(ies) but the timeline fails to incorporate again the specific intricacies when no diagnosis was provided.

As for the recommendations, participants wanted their files to be shared across specialists to be seen from different angles and get a unanimous course of treatment. They also felt they ought to have a say in the labour choice as well as get more information regarding the pros and cons on drug impact on gestation. They further suggest to other mums with IBD to drop any high expectations and ideal about being a good mother and be content to do the best they can to eat and remain healthy during their gestation.

Table 17 *Overview of Themes, Subthemes of Participants Diagnosed During Pregnancy*

Concept	Transitional Challenges			
Themes	Burden of Knowledge	Weighing Decision-Making	Blame and Guilt	Ambivalence towards HCP
Subthemes	<ul style="list-style-type: none"> • Making sense of IBD • Overwhelming (lack of) information • Haunting fears • Treatment conundrum • Lack of certainty 	<ul style="list-style-type: none"> • Acknowledging IBD • Trial and error • Shift of priority • Tailoring support 	<ul style="list-style-type: none"> • The good mum 	<ul style="list-style-type: none"> • Mixed feelings • Establishing trust • Power over birth plan • Liaising with specialists

Phase 4: Labour and Breastfeeding

During this fourth phase of the timeline, women gave birth and opted to breastfeed or bottle feed, they were hence faced with several challenges such as the fear of giving birth naturally, sudden unplanned labour complications and weighing the feeding choices in light of other life events such as medication and IBD flare. They mentioned the guilt of attempting to be a good mother and dealing with societal pressures around the ideal of motherhood. Lastly, they related the challenge of having speciality-focussed healthcare professionals and the particular challenge

to be seen as a woman, mother, and IBD sufferer at the same time. The entire sample contributed to this phase see Appendix II.

6.16 Theme 1: Burden of Knowledge

6.16.1 Labour apprehensions

The experience of having IBD and going through labour worried some of the participants who anticipated extra complications due to their illness.

I was under no illusion anyway (.) I don't know (.) whether it was 'cos I was just more realistic in general that I wasn't under any illusion it was going to be this beautiful experience that they feed you when you first get pregnant (.) 'cos I thought well I'm kind of up against it as I've got Crohn's Disease anyway (.) I've got scar tissue [...] and when you have the forms for an emergency section it does actually say (.) you know (.) they're not responsible if they accidentally nick your bowel or you know (.) or your bladder (.) you know (.) all these warnings that are obviously they're extreme but you do take it all in (CDMum02C02, Line 368)

For this participant, and others who opted/were required to have a C-section, fear of bowel damages, fear of the epidural, and anxiety about coping with the surgery pain afterwards came in the way of their hope for a smooth, enjoyable birthing moment. However, some women who knew they would have a C-section said this was calming because they could prepare for the day and “it felt like we were going shopping and we were going to go and buy come back with a baby” (IBDuMum04C01, Line 354). They were also relieved from the fear of labour pain.

For those who anticipated a vaginal delivery, most reported fearing the pain of giving birth especially when one was told the baby was going to be ‘big’ and recalled awaiting the event with panic and nervousness. In addition, because participants were already susceptible to diarrhoea they feared being incontinent during childbirth or having this exacerbated as a result of giving birth.

I've got an issue with because I already suffer from that with the colitis and I can't be doing with bladder incontinence as well um (.) and that would just make my life really really complicated [...] everyone says that you do a poo when you push out and stuff and I was really worried about that (.) I thought well that's fine for normal people but people with me (.) you know (.) what if I just have uncontrolled diarrhea coming out (UCMum23C02, Line 658)

Although most participants expressed worry about labour being “such an unknown entity”, they also expected to forget what happened and tempered their concerns: “people say (.) you know (.) it can be the worst pain and the worst feeling but (.) sure you get over it (.) why do women have babies?” (UCMum19C01p, Line 504). Indeed, some felt strong enough and with the help of yoga and pain management techniques they felt ready to go into labour. However, participants who anticipated a flare shortly after the delivery were burdened by the fear of being

parted from their baby and being unable to breastfeed them or care for their newborn or older children.

6.16.2 Mother earth

There was a general ‘*mother earth*’ attitude where women were making the claim that a “natural” approach to pregnancy and childbirth was best. A few requested in their birth plan to deliver in a pool, with music and scents, and some wanted to deliver at home although their partner was often concerned.

I wanted a very natural birth and you know (.) I'd (.) they encourage you to do a birth plan so I'd explained everything on my birth plan I wanted not to have any drugs if I could help it (.) maybe gas and air if really (.) you know (.) I was struggling I would have quite liked a water birth (.) I really would have liked a home birth but my husband wasn't keen on the idea so we compromised with a hospital birth (.) but as natural as possible (.) I wanted to stay as mobile as I could (CDMum05C02, Line 323)

This experience was contrasted by CDMum06C02's apprehension of pain saying “I didn't envision it [labour] without pain relief (.) and I just thought ‘I'll have whatever's going’” (Line 499).

Regarding breastfeeding, an underlying assumption that ‘breast is best’ – conveyed by midwives and society – ‘pushed’ some mothers to make the decision to breastfeed. One participant was told by a midwife that “giving your baby bottle (.) formula milk [is] introducing bacteria into their stomach that you would never introduce if you had breastfed them” (CDMum05C02, Line 185). Some received pamphlets and were assigned to prenatal classes on how to breastfeed, however the information was seldom clear on the dos and don'ts and risks of breastfeeding whilst taking IBD drugs.

The whole issue of the breastfeeding thing was probably one of the biggest things for a mum (.) so (.) being on the medication I take (.) that we're not supposed to breastfeed on it (.) we could choose to but (.) who's going to (CDMum01C02, Line 310)

Some seemed to assume that feeding one's child was the “most natural thing”, a privileged and bonding experience, for example that “nobody else can breastfeed (.) it was a special thing between her and I” (CDMum16C01, Line 660). However, this could be challenged by the reality that breastfeeding was a skill that has to be learned and could be difficult to master.

Lastly, regardless of what they ended-up doing, whether they decided to bottle feed or to breastfeed whilst taking medication, or even to interrupt medication in the third trimester of their pregnancy so that they could breastfeed their child, almost every woman said she would love to breastfeed with one exception – UCMum07C02 – who confided that “breastfeeding freaks me out a bit actually ((laugh))” and was relieved to be advised not to whilst on Azathioprine” (Line 599).

Some participants deliberately, or under instruction of their consultant, made the decision to bottle feed their child to prevent IBD medication being passed to him or her. Some women rationalised that breast milk ‘quality’ was affected by their health and having experienced flares during pregnancy and not holding nutrients in were signs they ought to refrain from breastfeeding. However, the decision to bottle feed was burdened by the knowledge that breast milk was better for their child.

It was quite disappointing umm ‘cos you get all this (.) especially when you go to all these clubs and you’re kind of sitting and they’re going ‘oh yes (.) I breastfed my baby for God knows how long and yes (.) it’s the best feeling (.) you know (.) it’s the best thing I can do for my child’ and you’re kind of sitting there a big sign on your head going ‘I’m not breastfeeding’ (CDMum02C02, Line 451)

6.17 Theme 2: Weighing Decision-Making

6.17.1 Unplanned labour events

As mentioned in the previous paragraph, some participants had a birthing plan, however most had to make compromises due to *unplanned labour events*. A few elected to attend a ‘high-risk’ facility and felt safe under the scrutiny of several doctors: gynaecologists, IBD consultants, and sometimes also other specialists. Others wanted to be ‘just like any other mum’ and be able to give birth in a homely environment. However, most of the time, labour did not pan out the way women intended. Three of the women wanted a home birth, but none did so; none of the women gave birth in the pool; some had to be induced; others had an emergency C-section due to foetal distress; sometimes labour took longer than expected; and some women needed a forceps delivery. As UCMum20C01 said about her birth plan: “there’s no point in doing that because no-one reads it” (Line 478). She had requested to be mobile but “felt like a lorry” stuck to a foetal heart monitor.

I was due on was um (.) one week late anyway from pregnancy so they actually had to induce me and then I ended up having a hormone drip and everything so the whole labour was just horrible (.) I mean forget the pain but everything else that went with it and then I ended up having an emergency C-section so everything was just like a lot worse because it was rushed (UCMum23C02, Line 641)

Ultimately, labour was highly medicalised and, as much as the women attempted to prepare for and be in control on the day, the birth never matched their expectations, the “body just takes over” (CDMum01C02, Line 295). However, more positively, IBD did not impact the birth directly for most women and, despite the widespread concern about having diarrhoea during labour, only two participants actually experienced a loss of bowel control.

In my second pregnancy (.) um (.) I (.) er (.) I had this urge to just poo ((laugh) I didn’t actually give birth (.) I just pooped everything out (.) and I just pooped (.) and I pooped (.) and I pooped and I know it happens but it happened quite a lot (.)

um (.) and until every little ounce of poo was out of me I didn't give birth (UCMum13C02, Line 631)

6.17.2 Feeding choices

The mode of delivery, and sometimes complications experienced during labour, impacted feeding choices as well as having 'skin-to-skin'. Other factors such as low or lack of breast milk supply or sleepy, tired babies who would not latch properly also played a role in the feeding choice. And some participants persevered through a great deal of suffering to maintain breastfeeding. One woman talked about delaying bowel surgery for a few months, and breastfeeding within hours after that bowel surgery, to keep at it; interestingly for one participant from Northern Ireland who had opted to bottle feed, she still wanted to provide her child with donor's milk.

She [Daughter] was so sleepy because I'd had a very long labour and then she was really tired and for a lot of the time she just slept and we couldn't wake her up to feed so it took a while (.) umm and I had to do a lot of hand expression into a tiny little syringe ((laugh), it took hours (.) Yeah (.) yes (.) umm (.) yea (.) It was very tough at the start [...] it would take about half an hour to get to get 1ml and then you'd have to be at it all over again about half an hour later (CDMumPi02C01, Line 425)

Some tried to inform themselves better on feeding choices and breastfeeding skills via YouTube, talked to experts outside the hospital, and endured through mastitis and exhaustion from waking up every couple of hours to feed their child. Some even reported breastfeeding over the toilet as they had to rush to the loo when their IBD symptoms resumed.

I have to say [Son's Name]'s been fed in the toilet quite a lot because um (.) obviously you're starting and there was sometime he wasn't very happy because I had to just drop off let him in the middle (.) when you start feeding them and stop in the middle (.) they're not happy ((laugh)) but (.) so you can take them to the toilet (.) so he's been in the toilet quite a lot with me ((laugh)) (UCMum17C01, Line 408)

It was clear that participants weighed the pros and cons of their choices. Amongst the benefits of breastfeeding, participants mentioned it was a bonding time, relaxing for the baby, easier on the digestion, and provides immunity. However, there was still an element of disillusionment: "One of the things that maybe I'd envisioned incorrectly was around breastfeeding [it was] quite upsetting when it wasn't what I wanted it to be" (CDMum05C02, Line 163). Those with an older child, needed not to "stretch themselves too thin" and opted for a balanced approach saying they would try to breastfeed the second time but "if my health isn't good enough to care for him [First child] because I'm breastfeeding then there's no point" (UCMum03C01p, Line 544).

As mentioned in the subtheme *mother earth*, participants who did not attempt, or who had to stop or interrupt breastfeeding, also discussed the benefits of bottle feeding. Some said their body was not retaining the right nutrients and "the formula milk nowadays with science

and (.) you know (.) all the research that goes into it is probably actually better [than breast milk] for children” (CDMum05C02, Line190). Furthermore, participants mentioned how bottle feeding had other benefits, it allowed the father and other family members to share the task of feeding, it was easier to get the child into a sleeping routine, less disruptive to the entire family if the mother had to be hospitalised or when she returned to work, and it allowed the mother to continue her full range of IBD medications.

6.18 Theme 3: Blame and Guilt

6.18.1 Easing guilt

In listening to participants’ deliberations regarding feeding choices, I interpreted this to often attenuation of the guilt they felt when “everybody says it’s [breastfeeding] the most natural thing in the world” (CDMum05C02, Line 158).

[Nurse said] ‘Your milk’s not coming um (.) so I think you should top-up’ so I was like ‘Oh I’m starving my baby (.) okay I’ll top-up’ so gave the baby a bottle (CDMum10C02, Line 316)

[At] about 10 weeks he used to feed at five o’clock in the morning (.) something like that [...] I woke up (.) it was time for feeding and I felt horrible (.) it’s just (.) I couldn’t do it anymore (.) and I felt very (.) not guilty (.) but a bit guilty about it (.) and I thought if I don’t stop (.) I’m going to go into depression (.) because I was that tired and that (.) so (.) um (.) I stopped (UCMum17C01, Line 440)

One participant said that her mastitis was “caused by his his [child’s] kind of feeding pattern” (CDMum01C02, Line 314) and, hence, that she had placed her fragile health on the line to breastfeed her child. Another articulated the link between mothering and health more strongly, stating that “maybe that’s selfish on my part but I think it’s more important for me to be healthy and strong for a new baby” (CDMum19C01p, Line 610). Some mothers discussed how their child developed perfectly well on bottle feeding, possibly in reply to an implicit assumption that babies who were breastfed do better. However, some mothers still carried a lot of guilt as CDMum05C02 showed:

She’s [Daughter] always been a hungry child and I think it’s always actually affected her appetite the fact that even in you know the first few days of her life she didn’t get the food that she needed even now makes her you know (.) hung (.) more hungry and eat more I think than probably she actually she needs⁶ (Line 212)

Some participants could be interpreted as using their illness, at least in some respects, as a way to ease their guilt with regards to labour and feeding choices. Fifteen out of 22 participants were

⁶ Although research from the Gemini twin study indicated that some appetite traits such as slowness in eating, and satiety responsiveness in the first three months of life of a newborn seemed to be highly genetically determined (Llewellyn, Jaarsveld, Johnson, Carnell & Wardle, 2010), the assumption that early days feeding patterns and satisfaction can taint and scar a child for life was still very present.

distraught by the restrictions imposed by their IBD (see Appendix II), whether it was for having a premature birth or being in surgery and hospitalised shortly after labour, meaning that they could not care and attend to their newborn at this time. For example, in the following, CDMum01C02 blamed IBD for interfering with her desire to breastfeed longer.

I remember just being in the dining room and just crying because I just thought I'd let my son down because my body had chosen to become ill (.) to flare-up again kind of to spite him (.) not to spite him (.) but (.) you know (.) this is I wanted to do that [breastfeed him for you [son] (.) but I can't because my body is not working properly [...]] And I remember feeling (.) at the time really cheated (.) and also because I'd fed my daughter till she was eight months (.) some element of well I wanted to feed my little boy till he was eight months and I felt like he was going to be disadvantaged because (.) I was cutting that short (Line 327)

6.18.2 Societal pressures

Participants were burdened by societal messages regarding the benefits of breastfeeding and most who chose, or were told, not to breastfeed mentioned how these *societal pressures* made them feel inadequate. Whether the message was labelled as general, or instigated by midwives' agenda to instil a culture of breastfeeding, women were angered by this ideal, which did not support their choice and what was, in the circumstances, best for them and their family.

They [midwives] just went and got a big medical dictionary and flicked it and read it and said (.) 'Oh no you can' (.) you know (.) 'You can (.) Come on' and I kind of felt (.) 'God (.) I'm being pressurised into breastfeeding' even though I had made the conscious decision beforehand not to breastfeed (CDMum19C01p, Line 605)

Others blamed midwives for pressurising them to breastfeed and handing them pro-breastfeeding pamphlets without consideration of the IBD medication they were on. One woman even reported being harassed at home by a non-profit organisation who seem to target women who chose bottle feeding.

The midwife was not happy because I didn't breastfeed (.) actual breastfeed (.) expressing breast milk was not good enough for them [...] they really made my life hell (.) they really did [...] They (.) they kept phoning (.) they kept coming out and (.) you know (.) I had family round and we were in a different house (.) it was a much smaller house than this and there was always people coming to see the baby and they were constantly knocking at the door and saying (.) you know 'Do you want to speak to someone about this?' and I'm like 'No (.) not really' within an hour someone would be there from Bosom Buddies 'um (.) I believe you're having trouble breastfeeding' (.) No (laugh) they're absolutely harassing (.) they really give me a hard time over it (UCMum11C01p, Line 474)

Conversely, there were instances where women felt unsupported in their choice to breastfeed and that there was not enough support from the post-natal care service, or others around them, to guide them through it.

I had so many people saying 'It's fine (.) it's not the end of the world (.) if you want to bottle feed you bottle feed' which actually was the worst thing they could

possibly have said to me (.) what I needed at the time was someone to say 'Look (.) we can get this back (.) you will do it (.) and I'll help you do it' because I just didn't know enough back then (CDMum10C02, Line 343)

6.19 Theme 4: Ambivalence towards Healthcare Professionals

6.19.1 Speciality-focused

Health professionals appeared to be highly *speciality-focussed* and did not take into consideration other aspects of the participant's life with regards to treatment, labour, and feeding choices. As in the previous phase, non-specialised nurses, health visitors and midwives often ignored the impact of maternal IBD, which left women feeling unsupported and devoid of integrated healthcare. For example, a health visitor did not take note of CDMum16C01 Crohn's condition and kept encouraging her to "feed her baby on demand". It turned out that a former bowel resection operation to treat IBD had stopped her from absorbing fat and, although some milk had formed, she was mainly expressing water for six weeks. Her child was constantly hungry and was diagnosed as "failure to thrive" and hospitalised soon after.

Only a couple of women reported receiving a poor quality of maternity service during their postnatal care: long wait, or swift discharge, and lack of follow-up on C-section stitches. This could be attributed to the management of specific hospitals rather than dissatisfaction with the expertise of medical staff.

Then this doctor came around to discharge me and she said to me 'Why did you have a C-section?' and I told her and then she said 'Well that won't stop you having a vaginal birth next time' and I went 'Did you actually just listen to me (.) they've advised me not to' and she obviously clearly didn't get it (.) it was a standard line that she said because I then had to go to the next woman and say exactly the same thing (.) she just wasn't listening (CDMum08C01, Line 432)

6.20 Recommendations

The recommendation in this phase was to accept the uncertainty of labour regardless of the birth plans made as it does not always go to plan, and if allowed to opt for what feels more comfortable whether it be gas and air or an epidural to manage the pain. There was also an overemphasis and added pressure on breastfeeding whereas mothers with IBD felt that if they needed to prioritise their wellbeing and resume medications they ought to be supported in their feeding choices whether that be breastfeeding or bottle feeding. They requested the information to be clearer on the safety of drugs and breastfeeding and for healthcare professionals to be more aware of the implications of IBD, particularly nurses, health visitors and midwives.

Phase 5: Early Years of Motherhood with IBD

The fifth and last phase of the timeline participants mentioned the challenge of performing their role as mothers, and weighing decisions regarding IBD management and communicating the need for help. Here again the ideal of a good mum and the challenge of the invisibility of IBD to others came into play. Participants seemed to suffer from the lack of integration of the different specialities of medicine focussed on treating IBD now that the gestation was over and did take into consideration the impact of the illness and its treatment on their role as mothers. All the participants contributed to this phase as seen in Appendix JJ. However, the timeline as presented linearly failed to show how women diagnosed after their pregnancy during their early years with a child or two were challenged, this limitation is discussed below in Summary, Discussion, and Reflections section.

6.21 Theme 1: Burden of Knowledge

6.21.1 Performing mother role

Women felt burdened by the knowledge that IBD might interfere with their ability to cope with and care for young ones, particularly when they had more than one child. They anticipated that “it was going to be hard, slightly harder” (CDMum02C02, Line 148) for them, due to the potential insurgence of stomach pains, excessive tiredness, and diarrhoea. They were also concerned with “how do you go to the loo if you’re on your own with a newborn – where do you put them (bearing in mind this can take a while with IBD)?!” (CDMumPi02C01, Email communication, 14 October 2014). These tasks were seen at the centre of their mother duties and role and it was anxiety-provoking to think they might not “cope physically (.) being able to do all the things you want to do (.) like going out (.) and take (.) because kids want to go out” (CDMum06C02, Line 621).

‘How the hell am I gonna cope with two little ones under five’ especially if you have a flare-up [...] I am actually like ‘what the hell am I gonna do’ [...] I think about going back to work (.) it’s like how the hell would I cope with the girls in the car (.) getting to a job (.) dropping them off at a child minder or a school or something (.) I just don’t think I would (.) cope (CDMum02C02, Line 335)

Furthermore, having active IBD could come in the way of daily tasks such as making breakfast and walking children to school. Mothers who did not have family nearby were particularly anxious if their symptoms returned, or just knowing that they could return, as they had to anticipate who would care for their child(ren) if they were to go to A&E or be hospitalised.

I had this (.) colicky pain came back and I was more worried about what am I going to do about the children because my daughter’s now in school but she wasn’t then and I haven’t got any family close-by and my husband works away (.) (.) if I get ill (CDMum01C01, Line 178)

6.22 Theme 2: Weighing Decision-Making

6.22.1 IBD management

Participants mentioned the endless number of decisions they had to weigh when their disease was active during the early years of motherhood. They talked about reducing working hours, getting - or sometimes postponing - surgery, resuming or changing treatments – even prophylactically – to stay at home with the kids. One participant even discharged herself to go back and care for her young one.

Cyclosporine you have to go into hospital [...] it can take ten days (.) well that's not particularly convenient with a family (.) whereas Infliximab is much more designed for a mum really because you go in for the day and you have the drip for say four hours and then you go home [...] if I'd had to have Cyclosporine again and have ten days in hospital with two children it's not very practical (UCMum07C02, Line 194)

Another made use of a radar key to access disability toilets whilst out and about with children and wore diapers to walk her children to and from school. Another decided to enrol her children in a closer school to manage walking there rather than having to travel longer distances. Some mothers restricted outdoor play, or soft play, and substituted these activities for those such as piano lessons in order to have easier access to toilets. Toilet urgency was challenging and women sometimes had to feed their baby on the toilet, or had to leave the loo although they were not “quite done” to attend to children’s needs and watch over them. When the disease was in remission they tried to do “as much as I can (.) especially for the boys and take them places and do things with them” (CDMum06C02, Line 431) to compensate the time spent at home.

When I took him and I really didn't feel well at all and people were having cups of tea and biscuits and things and I just thought if I have that I'm going to be in (.) I just knew it was going to cause me more pain because at that point as soon as I ate something (.) almost just after eating something it would cause me pain because it would make my gut start to work (.) so I would avoid having it (.) so by the end of it I was really hot (.) it was always a really hot hall, I was very thirsty and I just remember sitting thinking 'oh (.) I feel dreadful (.) but I'm here for him' (Line 644)

Participants had to weigh caring for themselves, on top of their mother role, to find some “me-time” away from the children to restore their energy and stay well. These moments of self-care were ways of managing IBD by keeping their stress level low in order to benefit the entire family.

I did try to have acupuncture as well (.) um (.) which didn't do that much (.) good (.) But acupuncture can go both ways (.) the only thing I liked about acupuncture was that she was my me-time so I didn't have any kids (.) I didn't have anything (.) it was just an hour which was just for me (.) which was a nice thing about it (UCMum17C01, Line 616)

There was a shift from career to carer which resonated with the subtheme *financial and career implications* elaborated in the previous chapter but also to care for themselves on top of their children.

6.22.2 Communicating need for help

Participants communicated their need for help in order to manage the challenges of motherhood from their partner, friends, family, and even their younger child. The resources they were able to tap into depended on the closeness – both geographically and relationally – they had with other people and, those who did not have family nearby anticipated that when the need arose they “would have had to have help somewhere” (CDMum10C02, Line 222). However, CDMum08C01 provided the insight that, although she was truly grateful for, and dependent on, the help she received from her friends and family, it was still a challenge to have others do the chores in her own house. This subtheme is closely linked to the subtheme of *dependence* discussed in Chapter 5.

I find it very difficult not to do things (.) I find it very difficult to sit on the couch and not do anything ((laughs)) so you know (.) not lifting and not doing washing and having to accept that [Husband's Name] might not hang the washing out the way I like (.) or people cooking meals for me that weren't necessarily my favourite but they're doing it out of the kindness of their hearts to help me (.) you know (.) silly things like that that you just have to just go with (.) I found quite difficult (Line 543)

Other suggestions included getting a cleaner, increasing nursery hours, having one's own mother to help with the morning routine, “tag team”-ing with their partner around children's nap and meal times, and sometimes having a friend over to “work alongside each other” and care for both their children together.

At the weekends (.) we share who gets up and then when it comes to a certain time (.) when it comes to her breakfast (.) the other person goes to bed so that we can both sort of get sleep otherwise you're both exhausted (UCMum20C01, Line 353)

However, as mentioned in the subtheme *tailoring support* in Phase 3 *Conception and Gestation* not every participant had a helpful partner, or understanding family members, and the challenges often involved to ask for help and convey the burden of dealing with an illness and young ones to a healthy person.

6.23 Theme 3: Blame and Guilt

6.23.1 The good mum

As CDMumPi02C01 nicely depicted, “being a mum comes [with] a lot of guilt” (Line, 493). Worrying that IBD might be impacting their ability to be a ‘good mum’ and that their family was also having to adapt to their illness, filled women with guilt. Mothers felt responsible and

blamed for most of the decisions described in the subtheme *IBD management*: “being a stay-at-home mum I’m a bit (.) you know (.) I feel a bit guilty generally for not being able to do those things with her” (CDMum02C02, Line 804). Here CDMum02C02, blamed herself for not going out more with her child. Other mothers also mentioned not being able to drive, get out of bed, or out of the house to increase social activities of children. Mothers’ guilt was exacerbated by the thought that their child was missing out on opportunities and was suffering from separations or interruptions in his or her routine caused by the illness. They also worried how unfair it was to constantly drag a child to the bathroom because they could not leave them unattended. As UCMum07C02 said, “actually (.) that’s not normal [laughs] to have toys in the downstairs loo to entertain your child while you’re on the loo” (.) and “mums are like buttons (.) they hold everything together (.) and that’s true (.) so I just thought ‘I have to be here (.) I can’t go into hospital’ (Line 405). This extract showed me the assumptions she had about mothers’ role, and the compromises she felt she was making from this ideal was causing her to burst into tears throughout the interview.

In one instance, CDMum06C02 recalled how she witnessed some speech development difference between her son and other toddlers of the same age and assumed it was due to her lack of good mothering. The reality may have been a little different, as seen in the extract below.

I thought I should be doing baby sign language with him and do you know what I mean (.) all these kind (.) all these things that I felt I should have been doing and wasn't [...] I thought 'why's he not doing this [naming objects] (.) it's because I'm not doing it [teaching him]' I'm not being a good enough mum to him (.) I'm not spending enough time with him (.) I'm not talking to him enough (.) I'm doing (.) not playing enough games with him (.) I'm not taking him out enough places' and that was really difficult (.) that was really hard to cope with [but] there was a lot of stuff going on that (.) my older boy's got Autism as well so developmentally (.) he had a developmental delay as well which I didn't really appreciate at the time (.) but I thought a lot of that was to do with the fact I wasn't interacting with him enough (Line 628)

Lastly, I inadvertently asked a leading question to CDMum10C02 who mentioned persevering to breastfeed her second child after receiving no encouragement to do so the first time. Her response could have been constructed on the spot, but I interpreted it as a latent guilt for the noticeable differences in health and attachment pattern she perceived between her two sons.

*I: do you see any (.) difference between the first child and the second child?
CDMum10C02: Health wise?*

I: Just (.) not necessarily (.) but do you see anything? ((I was already regretting using a leading question and tried to keep it open))

CDMum10C02: Yeah (.) I do actually (.) I think health wise [Second Boy's Name] if he had a cold he'd get over it a lot quicker than [First Boy's Name] would (.) um (.) I don't know if it's anything to do with it [breastfeeding] but [First Boy's Name]'s got (.) had to have grommets [Second Boy's Name] hasn't had any issues with that um (.) I don't know (.) I mean with [First Boy's Name] I

(.) I didn't follow quite an attachment style of parenting with him (.) he's quite an anxious child (.) whereas with [Second Boy's Name] he pretty much stayed in the sling till he was seven months (.) went off (.) walked and he co-slept and he's just so much more secure as a child really (.) but whether that's that (.) partly genetics you don't know (Line 351)

6.23.2 Invisible illness

Two participants expressed the need for mothers with IBD to have access to larger public toilets which could fit children, pushchair, changing bags, etc. so that they could avoid being incontinent in public. And the first participant to mention it, remembered being shamed by a lady in a wheelchair upon leaving the bathroom for the disabled facility.

There are times when I've gone into a disabled toilet with a pram (.) there's one time and I came out and the person who was waiting to get in was a person in a wheelchair and she had a major go at me (.) about saying that I should have used the other toilet for the baby change (.) and I was like 'Well actually it was for me' and 'Well it's got a toilet in there' and I remember saying back to her 'Just because I'm not in a wheelchair doesn't mean to say I've got a right not to use this toilet' (.) and then she just spent the whole time after that just cursing me around the shop (.) umm (.) that stuck in my mind quite (.) for quite a while actually (.) I was really embarrassed by that and I almost felt (.) well I was cross because just because you can't see (.) not that I consider myself to be disabled (.) but just because you can't see that somebody's got a condition doesn't mean to say it's not there (.) and just because it's not obvious (.) I'm not in a wheelchair or have a stick or something (.) doesn't mean to say that I didn't deserve to use that toilet (CDMum01C02, Line 355)⁷

In this quote, I could depict a lot of interesting information about the hidden aspect of IBD and the lack of understanding of others at face value that the participant would be entitled to use the disabled facility. Every participant has mentioned at some point in the interview a lack of understanding from others about IBD and what it entailed, but this became particularly challenging when they became mother and needed that extra consideration. There was a strong feeling of being shamed by others and participants felt an obligation on the public to recognise that need was not always visible.

She [Participant's 'boss' - using UCMum23C02's words] knows that I had colitis because I put it down on a form when I applied but she never once asked me about it (.) it was just get on with the job and do you have any concerns with the job and how's your health and health was how's your health regarding baby (.) is baby okay but not not me (.) you know (.) never and it would have been nice just to have even been asked that question (.) are you okay (.) how are dealing with everything you know um (.) and that makes a big difference (UCMum23C02, Line 984)

Another participant mentioned having to make her case at her local council to be given access to a radar key to open disabled toilets. In both instances the women blamed society for not

⁷Reflexive notes from diary: "This is not just about public perception of toilet use, it's more about general perception of her husband and others in her life that the condition isn't present just because it is not apparent 'all the time'" (November 19, 2014)

recognising and validating the legitimacy of how disabling IBD can be when having to go around with young dependent children.

I had to go to two of the council offices that I needed a radar key and they didn't understand why I should have one (.) so I said 'cos I can't fit a buggy into a normal toilet and I have Crohn's Disease' and they were like 'you shouldn't need a disabled (.) you're not actually disabled' (.) 'no (.) I'm not actually disabled but I do need to be able to use a disabled toilet to fit the buggy into the toilet so I can go to the toilet quick enough' and it took some convincing and I had to make a few phone calls and speak to two different council offices about having a disabled toilet key (.) even though you have to pay for it which is ridiculous (CDMum02C02, Line 886)

A few women talked about not wanting to complain and sounding like a 'broken-record', but they wished their partner was more mindful of their tiredness and the seriousness of the illness and tried to understand and help them more often.

6.24 Theme 4: Ambivalence towards Healthcare Professionals

6.24.1 Lack of integration

As seen in the contribution table in Appendix JJ., several participants complained about the *lack of integration* amongst the different disciplines around their care. One of those participants was UCMum07C02, she received her diagnosis before her pregnancies but still emphasised how the *lack of integration* of the different aspect of her life caused *ambivalence towards healthcare professionals*. However, in parallel, she and other participants were grateful to have a team in place, even though the specialities did not liaise well together. They at least had a port-of-call they could ring directly if need be, which was usually the IBD nurse or their consultant.

I was almost completely dismissed as to that that was a problem (.) it was almost like 'well (.) you know (.) you have to be better to be a good mum' [...] and I remember saying 'can't I be treated from home or you know something like that' and actually it was like 'well no, we haven't got time to deal with that' you know, and it was almost very dismissed that I was a mum that they were dealing with, it was just, I was just another patient [...] and I remember one of the doctors saying to me you know 'oh so many children (.) they're put in nurseries (.) you know (.) for eight (.) ten hours a day (.) you know (.) oh your daughter will be fine' [...] it was very much dismissed as to my childcare and (.) you know (.) it was almost like (.) well (.) you know (.) that's for everyone else to deal with, not you, because you're in here (.) but actually I'm still their mum and I still have to deal with that (.) so I think they should really put a bit more in place actually with dealing with a mum (UCMum07C02, Line 569)

However, three participants who were diagnosed with IBD during their early years of motherhood (between pregnancies or after they had their children), were still figuring out how to deal with the challenges elaborated in Phase 1 (i.e., Nulliparous Life) and attempting to establish a trusting partnership with a consultant, let alone discuss the challenges they were facing with IBD on top of being a mother. The overlap visually presented in the last column in

Table 18, portrayed how particularly challenging it was to form a trusting new relationship with a team of medical experts whilst dealing with the care of young ones.

As mentioned above, three participants had one or two children before they received a diagnosis of IBD. And, similarly to those women diagnosed during their gestation, they experienced some of the challenges expressed in the study in Phase 1 during Phase 5. Table 18 presents the merging challenges of these two phases across the four themes depicted in this analysis, hence the excess challenge that these participants had to face in dealing with young children and trying to get a diagnosis at the same time.

Table 18 *Overview of Themes, Subthemes of Participants Diagnosed During the Early Years of Motherhood with IBD*

Concept	Transitional Challenges			
Themes	Burden of Knowledge	Weighing Decision-Making	Blame and Guilt	Ambivalence towards HCP
Subthemes	<ul style="list-style-type: none"> • Making sense of IBD • Overwhelming (lack of) information • Performing mother role 	<ul style="list-style-type: none"> • Acknowledging IBD • Trial and error • Restoring health • IBD management • Communicating need for help 	<ul style="list-style-type: none"> • Justifying IBD • The good mum • Invisible illness 	<ul style="list-style-type: none"> • Mixed feelings • Lack of integration

6.25 Summary, Discussion, and Reflections

The concept of *Transitional Challenges* captures the assumptions and difficult feelings and decisions made by women with IBD throughout their transition to motherhood. The *Transitional Challenges* are expressed throughout five phases that I predefined as following a logical order from a nulliparous life to planning, conceiving, growing and delivering a baby. The four themes of this concept: *Burden of Knowledge*, *Weighing Decision-Making*, *Blame and Guilt*, and *Ambivalence towards Healthcare Professionals*, were present in each of the five phases. They intertwined and manifested themselves through various subthemes at each step of the transition to motherhood. In the following paragraphs, I provide a summary of the findings and discuss how the results relate to the literature on IBD. I also consider throughout implications of this timeline for clinical practice.

During Phase 1, *Nulliparous Life*, I elaborate on the themes *Burden of Knowledge*, and *Weighing Decision-Making*, particularly how participants attempted to understand their gastric symptoms and the decisions they had to make to manage their illness. They vividly described when their health began to deteriorate, recalled the distress and pain experienced including, sometimes, the assumption that they were about to die. This last point links to the previously mentioned *fear of mortality* elaborated in Chapter 5.

Woodward et al. (2016) identified five IBD-distress themes: *emotional distress*, *healthcare-related distress*, *interpersonal/social distress*, *treatment-related distress*, and *symptom-related distress*. These echoed with my findings. *Emotional distress and symptom-related distress* expressed, respectively, worrying about complications, feeling uncertain about the illness, and fear of incontinence and fatigue were similar in content to my subtheme *making sense of IBD*, as well as the subtheme *acknowledging IBD*. The *healthcare-related distress* (not being believed, lack of goals and clear plan), and *interpersonal/social distress* (feeling blamed by family members or others for not eating properly, lack of support at work), respectively substantiated the themes of *Ambivalence towards Healthcare Professionals* and *Blame and Guilt*. Participants in my study felt blamed and were *justifying IBD* to themselves and others and had *mixed feelings* towards healthcare professionals (HCPs) who demonstrated poor IBD knowledge and care. Participants were also faced with an *overwhelming (lack of) information* and sometimes tangled medical jargon leaving them in the dark with regards to what it means to have a diagnosis of IBD. The last disease specific distress reported in Woodward et al. (2016): *treatment-related distress* (treatments adherence or failure, and coping with side effects), was part of the challenges my participants faced when they had to resort to *trial and error* in managing their disease. However, my study added to Woodward et al.'s (2016) findings in underscoring the positive impact of gaining temporary relief through *restoring health*.

Loven Wickman et al. (2016) state that “being one step ahead facilitates living with IBD” (p.127) and individuals who had actively participated in making joint decisions with healthcare providers felt more in control and positive about their treatment. Participants in Loven Wickman et al.'s (2016) study also mentioned needing more information on using Complementary and Alternative Medicine (CAM) to control their symptoms. Furthermore, receiving a diagnosis of a life-long illness, having bowel-altering surgery, or feeling isolated due to repeated hospitalisation or chronic diarrhoea, could lead some women to feel anxious, depressed, and/or to have low self-esteem rendering it difficult to meet a romantic partner and establish intimacy (McDermott et al., 2015). Although one mum did report fearing when she was younger the possibility of not finding a partner, this ultimately was not the case for any of the mums in my study and all were in long-term relationships at the time of the interview. However, the potential for IBD to impact women's ability to form romantic relationships is very much present. Having a chronic illness can hinder women's self-esteem and body image and hospitalisations and constant diarrhoea can make it difficult to socialise and to meet a romantic partner. Moreover, having fistulas and abdominal pain caused by IBD could make it less likely to want to have sex which could, in turn, reduce the chances to conceive within the window of opportunity. This issue needs to be addressed by HCPs at the time of diagnosis, particularly for women nearing or within their reproductive age, in an attempt to enhance their reproductive choices when the time comes.

During Phase 2, *Planning for Pregnancy*, participants were plagued by *assumption of IBD interference* on fertility and family planning decisions and the *lack of information* around medication impact on conception. Mountifield et al. (2014) pointed out that the literature on fertility and IBD did not warrant those fears, as only women with active IBD at the time of conception, or those who have undergone surgery⁸, were at risk for reduced fertility compared to women in the general population (Hudson et al., 1997; Olsen, Joelsson, Laurberg, & Oresland, 1999; Olsen et al., 2003). The authors noted that fear of infertility was greater amongst IBD patients who had CD vs UC, and particularly higher in women with CD vs men with CD. However, despite the exaggerated fears, only a relatively small percentage (<20%) of the participants (N=217) had to refer to a consultant for fertility issues. Some participants decided to remain voluntarily childless and they shared some of the same concerns expressed by participants in my study: notably, passing on the illness, being advised by doctors not to get pregnant, and fearing IBD drug interaction with foetal development. Although many things will influence the decision about having children, it is interesting that, as mentioned in theme *Blame and Guilt*, some of my participants expressed the sense of having a “*selfish*” desire to have children and it seems important that, although they had concerns, these were not strong “enough” to stop them having children.

The findings of this second phase of the timeline also showed that mums-to-be with IBD attempted to *improve odds* to conceive and thought of alternatives such as adoption, or sometimes accepted to have fewer children than they desired. Lifestyle changes which might increase the chance of conceiving with IBD are discussed in the guidelines provided by Crohn’s and Colitis UK (CCUK, 2013). These guidelines, written by IBD experts, recommend taking-up exercise, having a nutritious diet, cutting alcohol and smoking, but also advise discussing with a specialist intent to start a family. For example, women who have IBD might be susceptible to having a folic acid deficiency due to their treatment and taking folic acid before conception and during pregnancy could be beneficial (Czeizel, Toth, & Rockenbauer, 1996).

A novel aspect of my findings was the experience and challenge of feeling blamed for having IBD and its impact on women’s perceived fertility. The associated subtheme - *social pressures* - was particularly relevant to two participants: an Ashkenazi Jew and a woman of South Asian ethnicity. Many religious celebrations in the Jewish community revolved around celebrating the family and this can be burdensome when struggling for over 10 years to conceive. Moreover, chronic illness, and particularly the nature of IBD symptoms, are often considered inappropriate topics of conversation within the South Asian community. Tavernier, Fumery, Peyrin-Biroulet, Colombel, and Gower-Rousseau (2013) conducted a systematic review of the literature on fertility and childlessness with IBD. The authors discovered 11

⁸ Although the authors only use the term “having previous surgery” without specifying which type, I have gathered from discussion with Dr Selinger that having an ileostomy can sometimes have an inadvertent complication infertility.

relevant articles and concluded that the drop in number of births from mothers with IBD was attributed to psychological factors. Hence, providing patient information and education about the impact of IBD on fertility and pregnancy, and in a format that can be shared with family and friends, could potentially reduce negative views around planning for a child in the context of maternal IBD (C. Selinger et al., 2013).

There were some overlaps between the theme of *Weighing-Decision Making* in Phase 2 and the *Lifestyle Changes* theme of the concept of *Blurred Lines* and the difference is nuanced. In the timeline, the process of weighing the pros and cons is in relation to altering one's lifestyle and continuing treatment throughout pregnancy. On the other hand, in *Lifestyle Changes*, I make the case that there are similarities between the changes a woman makes after receiving a diagnosis of IBD and when becoming pregnant. Hence, motherhood with IBD implies a double burden. However, my analysis also reveals the pre-established strategies and coping mechanisms some mothers could capitalise on in their adaptation to a new baby.

During Phase 3, *Conception and Gestation*, participants were burdened by a *lack of certainty* around the safety of IBD drugs, and even those who were not on medication shared the *haunting fears* of having a flare and not being able to carry a full-term pregnancy. Hence, the *treatment conundrum* was the potential for a negative impact on the developing foetus of IBD medication itself, or IBD symptoms, possibly triggered or exacerbated by staying medication-free. However, Willoughby and Truelove (1980), and later Van der Woude et al. (2015), demonstrate that pregnancy outcomes for mothers with IBD are no different than for the general population if the disease was quiescent and controlled at the time of conception and throughout the pregnancy. Specifically, the current best advice is that, "In general, the evidence suggests that active Crohn's or UC may do more harm to the growing baby than most IBD medicines. So most women will be advised to continue taking their IBD medication during pregnancy. [And, only] a small number of the drugs used for IBD are not recommended or should not be used at all by pregnant women" (CCUK, 2015, p. 2). Alstead (2002) recommends educating patients about the expected outcomes of pregnancy with IBD and informing them about the importance of keeping the illness at bay to insure the best chances of a normal pregnancy. Alstead (2002) insists that women should be encouraged to expect a normal pregnancy and healthy baby despite having IBD if the illness is in remission, for a flare could be more harmful than maintaining drug regimen. Moreover, participants in my study realised that they had to *shift priority* and do whatever was necessary to be – and remain – well during their pregnancy in terms of diet, exercise and maintaining drug regimen. However, my study also showed how women with IBD can be vulnerable to depleting *Guilt and Shame* despite the massive efforts they make to be a *good mum*.

The difficulty of *establishing trust* with HCPs was due to an over-attribution of symptoms to pregnancy rather than IBD by HCPs. These findings echo Cooper et al. (2011) case study of a mother with UC who was diagnosed with IBD during her pregnancy. She had to

struggle to have her symptoms validated and felt dismissed by healthcare professionals. As for women with chronic illnesses, Tyer-Viola and Lopez (2014) point to the balancing act between fantasising about having a normal pregnancy and the reality that something can go wrong at any point because of one's illness. Moreover, similar to my findings, these authors identify how pregnancy creates a new kind of worry with regards to one's chronic illness which can result in anxious collecting and hoarding of information on being pregnant with a condition. These similarities suggest the possibility of a more unified picture and maybe aspects of the proposed timeline apply, and provide insight into, the transition to motherhood with chronic illness.

Moreover, pregnancy has become a highly-medicalised process, and even more so in the context of chronic illness (Benyamini, Molcho, Dan, Gozlan, & Preis, 2017). My participants had ambivalent relationships with healthcare providers who seemed to have the *power over* (their) *birth plan*. Participants also suffered from poor *liaising with specialists* across departments (e.g., gastroenterology and gynaecology). Healthcare professionals could overlook the wishes and needs of individual woman, irrespective of whether they had IBD. For example, this UK-based sample felt disempowered in their choices for labour, their IBD seemingly providing them no additional consideration for a C-section, if this was their preferred mode of delivery. As a matter of fact, in my home country (Lebanon), women elect for a C-section or for a V-delivery so it was difficult to understand how, on top of their condition, this choice was not theirs to make. Hence, I researched a bit more what mothers could do legally if they wanted a C-section and I found out that the latest NICE guideline recommends the following:

“1.2.9.1. If When a woman requests a CS explore, discuss and record the specific reasons for the request. **[new 2011]**

1.2.9.2. If a woman requests a CS when there is no other indication, discuss the overall risks and benefits of CS compared with vaginal birth and record that this discussion has taken place (see box A). Include a discussion with other members of the obstetric team (including the obstetrician, midwife and anaesthetist) if necessary to explore the reasons for the request, and ensure the woman has accurate information. **[new 2011]**

1.2.9.3. When a woman requests a CS because she has anxiety about childbirth, offer referral to a healthcare professional with expertise in providing perinatal mental health support to help her address her anxiety in a supportive manner. **[new 2011]**

1.2.9.4. Ensure the healthcare professional providing perinatal mental health support has access to the planned place of birth during the antenatal period in order to provide care. **[new 2011]**

1.2.9.5. For women requesting a CS, if after discussion and offer of support (including perinatal mental health support for women with anxiety about childbirth), a vaginal birth is still not an acceptable option, offer a planned CS. **[new 2011]**

1.2.9.6. An obstetrician unwilling to perform a CS should refer the woman to an obstetrician who will carry out the CS. [new 2011]⁹ (NICE, 2012).

In terms of clinical implications, mothers with IBD ought to be informed of the best practice guidelines and HCP ought to take into consideration the demands of mothers who wish to be referred for a C-section after getting all the facts and counselling regarding their concerns of vaginal delivery. To clarify a little further, mums with IBD included in this research were not offered care that followed these guidelines and would have benefitted in some cases to get referred to a specialist who would conduct a C-section.

During Phase four, *Labour and Breastfeeding*, participants expressed their fear of giving birth, particularly that natural delivery would go wrong. The subtheme *labour apprehensions* is not specific to IBD as pregnant women have been noted to fear giving birth (Saisto & Halmesmaki, 2003). However, a unique aspect of having IBD was a particularly strong apprehension to being incontinent during the birth and the possibility of tearing, leading some to want a C-section. These apprehensions have been linked to elective C-section requests in the general population as well (Ryding et al., 2015). Interestingly, none of my participants expressed a fear of breastfeeding, although some mentioned trying but not persevering. The concerns mentioned were the possibility that their medication could be transmitted through the breast milk, that they would not have enough milk, or that they would not produce ‘good quality’ milk due to their illness. These barriers to breastfeeding constitute hurdles for many mums (U.S. Department of Health and Human Services, 2011), but issues regarding drug-transferal and illness-related milk quality are pertinent to mothers with an illness and requires medical staff to be more aware of providing information and reassurance.

As for the decisions made during *Labour and Breastfeeding*, participants in my study had to face *unplanned labour events* as well as resort to different than desired *feeding choices*. The idea that ‘breast is best’ prevailed in the sample and mums struggled to accept or feel accepted for choosing to bottle feed or for breastfeeding for a relatively short time. As described by Palloti (2016), some mothers in my sample who bottle fed wanted to share the task of feeding with their partner and other family members. This was particularly so for mothers who felt unwell after the birth of their child because the symptoms of IBD had returned. Moreover, the ability to settle a baby, make sure he or she is gaining appropriate weight, as well as getting back into a work routine, were offered as explanations and conceptualised as attempts at *easing guilt* of bottle feeding in a culture where the dominant ideal was to breastfeed. Despite the recognised benefit that breastfeeding reduces, amongst other things (Victora et al., 2016), the child’s risk of developing IBD (Xu et al., 2017) - which was of primary concern to my participants - women with IBD who chose to breastfeed had to navigate conflicting information regarding the safety of using IBD-related drugs whilst lactating (Ferguson,

⁹ These guidelines were taken verbatim from the NICE (2012) website, section 1.2.9 Maternal request for CS (Caesarean Section). It was not possible to reference the page of the quotation.

Mahsud-Dorman, & Patterson, 2008), when and if they can find any information at all on the topic. Hence, there is a clear need for pharmaceutical companies to provide consistent guidelines on medications and lactation in IBD to enhance *feeding choices*. Lastly, mothers in the study felt particularly unsupported by healthcare providers who were deemed highly *speciality-focused* and lacked the training and knowledge to integrate the various aspects of IBD and its impact on labour choices and breastfeeding. Habal and Kapila (2009), supported the claim that physicians and healthcare professionals need to appreciate the complex interaction and decision-making that women with IBD must undertake during pregnancy to better manage and guide them during their transition to motherhood.

In the fifth and last phase, during the *Early Years of Motherhood with IBD*, participants reported the difficulty *performing (their) mother role* particularly because IBD imposed so many restrictions. *IBD management* involved changing nutrition, adherence to treatment and locating nearest toilets. These findings echo with the ones described in the SRR detailed in Chapter 3. Moreover, the fact that IBD is often considered an *invisible illness* rendered the task of being a new mother more difficult and imposed *communicating need for help*. Their struggles pertained to accessing disability toilets that could fit the pram, bags, and child(ren) quickly enough to avoid being incontinent in public. Fortunately, ‘radar keys’ can be purchased now on the Internet from online retailers (i.e., Amazon). Furthermore, as of March 2017, the Tottenham Hotspur football club and some supermarkets in the UK are trialling new signs on the doors of disability toilets (Rackham, 2017) as seen in Figure 6, which draw attention to the fact that not all disabilities are visible. These advances benefit IBD but also other chronic illness which often have invisible symptoms, such as Multiple Sclerosis. Hence, some progress is being made on promoting the acceptance and recognition of invisible symptoms and this may limit some of the misunderstanding and blame levied at sufferers.



Figure 6. Invisible illness toilet label

The ‘IBD Standards’ is an initiative catalysed by the first IBD audit of care across England in 2006 (IBD Standards Group, 2013). Large variations of care were reported. ‘The Standards’ are an attempt to promote good services and care for all people with IBD and they have since formed the basis of the NICE quality guidelines for IBD patient care. The six standards are general to all people with IBD but they mesh well with the findings presented in

this chapter and represent the way forward in resolving the issues elaborated in my timeline. I provide a brief explanation of how the application of these standards (five out of six) can be interpreted to serve the clinical needs of mums with IBD. Specifically, the ‘IBD Standards’ promote: (a) high quality of clinical care, advocated by mums who felt healthcare professionals were not knowledgeable enough on their condition and pregnancy; (b) local delivery of care and efficient specialised services upon need, also mentioned by mums with IBD when feeling dismissed in relation to receiving a diagnosis or forced to travel between appointments whilst caring for young children; (c) patient-centred, offering choices and strategies to suit patient’s lifestyle when appropriate, including diet and newline of treatments; (d) education, empowering mothers with IBD to achieve IBD management and the best quality of life possible; (e) audit quality; and lastly, (f) provide latest evidence regarding drug interactions with breastfeeding and pregnancy to facilitate adherence to treatment, remission, and successful pregnancies.

As for helping mums with IBD, PhD and IBD Nurse Specialist Karen Kemp conveyed that IBD nurses often volunteer to go above and beyond their duty to administer IBD drugs (such as Infliximab) at home for patients who cannot attend the clinic or hospital (Presentation at IBD New Study day, Manchester 2016, see Appendix Q). This service is readily available for other drugs such as Humira (Abbviecare, 2017), and could be tailored to mums with IBD and avoid a *lack of integration* between their role as mothers and receiving care for IBD.

6.25.1 Conclusion

This chapter, and timeline of the *Transitional Challenges* of mothers with IBD, provides a novel approach looking at the phase-specific difficulties of having IBD and transitioning to motherhood. In the main, the timeline represents the experience of women diagnosed during their nulliparous years and incorporates four themes that intertwine and develop across the five logical phases of transition to motherhood. Although the timeline, as presented linearly, seems to miss explaining the unique challenges of women diagnosed during gestation or afterwards, it does provide a template of how some of the challenges relevant to women diagnosed in their nulliparous years might overlap with the challenges experienced by women diagnosed later in her trajectory. In other words, such participants seemed to experience similar challenges to the nulliparous women on top of those relevant to the phase in which they were diagnosed with IBD.

The next chapter details how mothers with IBD coped and managed their challenges through the extended metaphor of *Reflecting on Others*. This final concept of the thesis shows how children can act as shields against IBD, and how, sometimes, comparing oneself to others who appear to be worse off can shelter mothers with IBD from the adversities faced during their transition.

Chapter 7

Reflecting on Others

In this final chapter of analysis, I elaborate through an extended metaphor on how the participants coped with, and managed, the demands and challenges of IBD and motherhood. The metaphor is developed through the analytic concept *Reflecting on Others* which consists of three themes with their respective subthemes: *Shielding Child*, *Comparative Normality*, and *Two-Sided Mirror* (Table 19). The first theme *Shielding Child* discussed how children appeared to form – from the moment of their conception to their early years – a protective shield from IBD and its impact on their mother. In return, mothers attempted to shield their children from potential repercussion of their IBD. Second, the theme *Comparative Normality* showed how participants attempted to reconcile their experiences of IBD and motherhood by comparing themselves to various ‘groups’ of individuals to situate themselves in relation to others’ experiences and to assimilate their situation. The third theme, *Two-Sided Mirror*, however, is presented using a novel approach to Thematic Analysis. In this last theme, I analyse the ways in which participants position themselves in relation to the video-camera during the interview. I suggest that the camera served, in many ways, as a *two-sided mirror*, enabling participants to address a wider audience but also placing them in the position of being ‘overheard’ and ‘gazed upon’ by others, themselves unseen. The concept *Reflecting on Others*, is an extended metaphor which brings together these seemingly very different themes and I comment on the perceived usefulness of the strategies associated with each of the three themes to help mothers navigate the changes and uncertainties of their transition to motherhood with IBD. Appendix KK, Appendix LL, and Appendix MM show the respective contribution of each participant across the three themes and their subthemes. Analytical and interpretative points are supported throughout by quotes from the interviews.

A quick reminder of the type of Thematic Analysis presented in this chapter: I have taken a critical realist standpoint, provided a rich description of relevant material across my entire data corpus, derived the themes inductively, which are predominantly semantic with a smaller number of latent themes, as indicated respectively by the letters (S) and (L) in the Appendices KK, MM and LL.

Table 19 *Themes and Subthemes of Reflecting on Others*

Concept: Reflecting on Others	
Theme 1: Shielding Child	
<u>Subthemes</u>	Child as a shield Shielding child from IBD Reflecting IBD
Theme 2: Comparative Normality	
<u>Subthemes</u>	People and me Mothers and me Myself and me

Theme 3: Two-Sided Mirror	
<u>Subthemes</u>	Confiding platform
	Wallow window
	Staged performance

7.1 Theme 1: Shielding Child

In this theme, I elaborate on how the child served the mother as a shield from the negative impact of IBD by inducing remission in symptoms during pregnancy and by motivating mothers to remain well. The child was also used as a pretence to hide the illness from others. Moreover, the child was, in return, shielded from IBD by their mother, whether by the language used to talk about IBD or by the multitude of choices participants made throughout their transition to motherhood to reduce the impact of the illness on their offspring. Lastly, I examine how mothers perceive their children as reflecting back to them on IBD, they witness their young ones' understanding of the illness through the repetition of symptoms and comments on IBD. Refer to Appendix KK for the contribution of each participant to the theme *Shielding Child* and its subthemes.

7.1.1 Child as a shield

As discussed in Chapter 5 under the theme *Monitoring Personal and Physical Development* (subthemes *seeking respite* and *identity change*), the child played a role in protecting the mother from the illness. From the moment of conception and during gestation, some women experienced respite from flares and others “bloomed” and felt well enough to eat anything they wished. Moreover, participants talked about the positive impact of having a child on their morale and how they perceived themselves and their body. The child was buffering the mother from symptoms of IBD but also from thinking about the illness, as IBDuMum04C01 described:

The pregnancy and it just took over your life because I've waited for it for so long (.). And yeah (.). I think (.). I weren't really thinking about the IBD at all at that point [postbirth] (.). I were just more thinking about me and my baby and making sure that we were fine (.). so I actually just put up with the symptoms because you do (Line 76)

Having a child is perceived by some as an extra-incentive to remain well, for them and their family: “(it) forces you to get out and do things” (Line 610) said UCMum03C01p. Others shared that the lack of time to think about the illness, and preoccupation with the child(ren), made them less likely to feel down or negative regarding their illness. Their children helped manage how they felt about their illness.

I haven't got that choice now (.). yeah okay (.). it's a struggle but I have to get up and I have to get them ready and I have to take him [first born] to nursery and I have to pick him up in an hour (.). things like that (.). I'm so preoccupied by it which I love (.). that I haven't got any more time to sit and dwell on me and I think deep down that makes it better as well (.). that I'm not.. (.). I mean (.). I still feel

sorry for myself on certain days but just why me (.) why have I got colitis (.) why is everyone else okay (.) I used to have all those horrible negative thoughts and now I physically haven't got time to sit and dwell and I think me dwelling on it (.) made it probably about 20% worse in terms of feelings and emotions and then those negative emotions affecting my tummy so I'd get all the horrible (.) you know (.) grogginess and the pain and the cramps and stuff so I think potentially I could have been making myself better by thinking positive (.) feeling positive and not sitting and dwelling but because I didn't have anything else in my life at that time (.) (UCMum23C02, Line 911).

Some mothers actively and consciously used the respite they experienced during pregnancy to remain well and shielded themselves through the child. UCMum11C01p even said “if (.) I'm going (.) you know (to) postpone my plans then I've let the colitis win really and it's not going to dictate my life to me [...] if I hadn't (.) got pregnant (.) it would have done (.) I would not have been happy” (line 207). In addition, several mums mentioned using their child as an excuse to use the disability toilet, skip the cue, or cancel their plans: “[if] I need the loo I'll generally make the excuse that my little girl needs the toilet (.) and (.) people will always let little children use toilets” (CDMum01C02, Line 372). They preferred to say it was the child's need rather than tell people they had IBD. CDMum02C02 further related that if she were to have an accident in public, she would blame any odours or discomfort caused on her children: “It's a terror [being incontinent] you can just blame it on them [children] it's awful ((laughs))” (Line 252).

Although this was mentioned in Chapter 5, in *identity change*, mothers noticed a change in behaviour in their children reflecting their understanding and attempt to shelter their mother from the illness. This was interpreted to occur as early as in the womb, at birth, and in their early years, as outlined in the following excerpts:

The doctors actually said 'we don't have anything scientific for it' he said 'but sometimes if there is something else going on [an illness, IBD] like your liver function was off a wee bit (.) it's like the baby knows so the baby comes [labour starts] regardless of what we're doing' (CDMum06C02, Line 600)

She [daughter] literally slept all the time [post birth] and one of the nurses (.) midwives said to me 'I think when children know that mummy's not very well that they do seem to just behave well' [...] So I think it gave me a chance to kind of like feel better (CDMum22C02, Line 466)

[If I say] 'mummy's just going to have to lie down for a minute' (.) So if that does happen [Son Name] always shuts the door so doesn't let (.) just tries not to let [Daughter Name] (.) he'll usually shut the door and go 'come on [Daughter Name] (.) let's go and do something else' so (.) you know (.) the plan is watch a film on their tablet or something so that I can just have a lie down (CDMum22C02, Line 867)

Moreover, using humour, particularly with children, around the topic of IBD shielded the entire family. Mothers conveyed how they and their children could joke about poo, ‘mummy wearing one of her nappies’, or having to run to the bathroom: “We never have treated it [IBD] as a dark horrible thing (.) it's more [...] part of our life and part of our family” (CDMum02C02, Line

129). And children's lack of filtered speech and lack of awareness around social taboos often inadvertently rendered talking about IBD funnily embarrassing in front of the family and others.

My second child is quite loud in public toilets so he likes to give a running commentary to everybody 'what you're doing? what's that? what's that there? is that your special tummy?' at the top of his voice (.) that's kind of quite embarrassing ((laugh)) (CDMum06C02, Line 427)

She [Daughter Name] has to come in [the toilet] she's like 'I don't want to come in (.) you stink'! It's like 'I'm sorry [Daughter Name] (.) you just have to wait (.) hold your nose' ((laugh)) (CDMum22C02, Line 670)

7.1.2 Shielding child from IBD

When it came to talking about IBD to their child(ren), participants varied in their approach, content of the discussion, and breadth of the information shared. For some, honesty was the best policy, but others never had thought at the time of the interview how to open the subject: "I've never asked myself the question if I would (.) explain to him [son] what happened" (UCMum17C01, Line 493). Some said they would only discuss it upon need: "I wouldn't discuss it with her [Daughter] unless she needs to know about it (.)" (UCMum20C01, Line 692). There was a fear that "they [children] know [about IBD] they'll be more aware of it (.) and then they'll be worried that they're going to get it (.) um (.) so I'd rather not [tell them] what they don't know won't hurt them" (UCMum13C02, Line 902).

I think (.) that sometimes there's a tendency to try (.) and shield (.) children from things and protect them from it but I think that that doesn't necessarily help I think it might make it a bit more mysterious and therefore a bit more scary and I think (CDMumPi02C01, Line 564)

For those participants who did choose to openly discuss the topic of IBD with their child, they said they used simple terms such as "I've [Mum] got a poorly tummy' 'cos she would understand that (.) she's nearly five (.) she would understand that from herself (.) point of view from herself" (CDMum01C02, Line 417). However, it was important to distinguish between a tummy bug and an illness to avoid scaring the child.

'Cousins and the rest of the family and like daddy might have (.) you know 'oh daddy might have a stomach upset as well' (.) or 'I bet your cousins [Name] and [Name] have probably had this bug as well' [...] that's where we kind of divide it (.) as in mummy just gets (.) mummy gets her poorly tummies every now and then and you're just gonna have a bug every now and then but it's gonna be nothing to worry about and everybody else gets them as well (CDMum02C02, Line 674)

For the two participants with an external stoma, the visual aid – as well as the implication of emptying a bag rather than using the loo – raised the question of what is "mummy's special tummy". However, as these two participants explained, "it's just part of [them] and part of the family" (CDMum06C02, Line 426).

I just said that mummy was poorly and that mummy was poorly and her intestines stopped working properly (.) so I had to have a lot of my intestines taken out (.) I

had to have my bottom sewed up (.) um (.) and that's (.) you know (.) and that made me better [...] they don't want to know too much (.) they're too young (.) so in basic language they (.) we talk about why it happened and what happened (.) so they understand (CDMum09C02, Line 490)

There was a consensus that children under the age of two would not understand much about the illness but could start to form an understanding in child-friendly words. Mums were concerned not to overwhelm them: “I think it would depend on how old he [Son] was when I spoke to him about it (.) because I'd want to pitch it at sort of the right level (.) and as he got older I'd maybe explain it a little bit more (UCMum14C01p, Line 587).

Moreover, all participants mentioned shielding their children one way or another from the impact of the illness. As seen in Chapter 6, *Transitional Challenges*, participants weighed their decisions, and added pressure on themselves to stay well and/or to prioritise the welfare of their child, some even refusing amniocenteses and MRIs during pregnancy and, later, delaying surgery and scans to breastfeed and care for them: “I tried to make as easy on [daughter name] as possible [...] I don't like seeing that [IBD] impact on her (.) It's one thing it affecting me but it's another thing when it then affects her” (CDMumPi02C01, Line 506). In the following excerpt, UCMum23C02 recounted her motive to remain in remission as being hospitalised and the separation from her young children added undue pressure and burdened them.

Having my little one year old crying because he wanted Mummy [when she was in hospital] and obviously hubby then taking him away and every time they came to visit I was just in tears after they left because obviously he didn't want to (.) you know (.) and at one years old they don't really understand that much anyway (.) so he was like (.) 'Mummy-Mummy' and it was like just like (.) oh it was heart-breaking (.) um(.) So like now (.) part of the pressure (.) now at the back of my head is like I've got to keep well (.) I can't be in hospital (.) I just can't (.) not with two (.) it was bad with one but I just can't (.) you know (.) my boys need me and I think I'm trying not to put pressure on myself for that but I do feel like there's a little bit of pressure just to try and keep well (.) you know (.) (UCMum23C02, Line 346)

UCMum03C01p talked about maintaining a routine because “with a child you don't want to damage them by having them actually worry about you” (620). Others said they isolated themselves so their children would not see them in pain, but realised that “there will come a time when she'll [child] see me in hospital or after an operation or in pain [...] there will be times when she'll see things that she doesn't necessarily want to see (.) so it's just about being honest with her really” (CDMum16C01, Line 838). However, when the need arose, mums shielded their child by preparing them for an eventual separation:

It looks like I may have to have surgery (.) so (.) now we're already preparing her (.) that 'mummy will have to go back into hospital (.) hopefully I won't have to stay in like we did before (.) but I will tell you everything that you need to know' [...] She [Eldest daughter] analyses things and will bottle things up and think about it and think about it and think about it and then end up really upset (.) so we probably tell her really what she needs to know (UCMum12C02, Line 558).

Furthermore, when it came to feeding their child, some mothers said they made the conscious choice to breastfeed because they thought it decreased the chance their children would develop IBD, or any other illness (e.g., asthma). Others spoke about maintaining good eating habits during their children's first years:

I cook everything from scratch (.) she always has lots of vegetables and she only drinks water (.) I don't let her drink anything like fruit juice or anything (.) I think especially at this age [2 years old] just to keep everything clean and pure and wholesome (.) she doesn't eat a lot of chocolate (.) things like that [...] there will come a time when she eats food that isn't so good for her (.) but whilst I can I'm going to provide food that will make sure that her gut is working (CDMum16C01, Line 825)

7.1.3 Reflecting IBD

Participants perceived how their children formed an understanding of Ulcerative Colitis and Crohn's Disease and sometimes how they mimicked their speech, behaviours and even symptoms, to deal with their mother's illness. Interestingly, CDMumPi02C01 said her daughter knew "she can't go near them [IBD medication]" (Line 538); she inferred her fear that her daughter would mimic her as she witnesses her taking medication in the morning. Some participants understood their children's comprehension of the illness as a series of events: taking medication, eating different food, having a sore tummy, running to the toilet, going to the hospital etc. Nevertheless, CDMum01C02 noted that, even though her child tended to imitate her – "she's [daughter] quite likes going to the toilet to be honest herself (.) especially to visit (.) she has this thing about when we go into other people's houses always having to go to their toilet" (Line 435) – she is not sure whether her daughter made the link between the pain and the bathroom trips. This mother distinguished the mimicking behaviours from formal understanding and comprehension of the illness. CDMum22C02, on the other hand, made that link clear: "I said 'well mummy's got something wrong with her stomach (.) I've got Crohn's Disease' and I just explained to them 'that's why mummy goes to the toilet all the time' because they're aware of that" (Line 714). Participants also perceived children's understanding of the illness when they iterated their mother's speech on IBD, but also "there was a few times he's [son] pretended his tummy hurt (.) that he didn't want to go to preschool and he was just doing and he was laying down on the floor" (UCMum03C01p, Line 706).

She [Daughter] actually does love to (.) you know (.) she's like 'oh mummy's not very well (.) we've got to go into the toilet' and she's (.) she understands it in her own little way as well [...] and even when I've took her to appointments and things she tells everybody that mummy's not very well and if mummy needs to go to the toilet she needs to go to the toilet and things (CDMum02C02, Line 612)

Moreover, IBDuMum04C01 feared that her son had witnessed her in pain one too many times, and "I don't know whether some of that now has rubbed off on [him] because [he] now has problems going to the toilet and he will hold it in" (Line 541).

Nevertheless, there are some exceptions as some children are too young, according to their mums, to form an understanding and, even though they are witnessing the trips to the bathroom, for them “it’s the norm”.

I don't think they realise (.) they just think I need to go (.) like they need to go and that's it (.) I just happen to go before we leave and I don't think they really questioned it or put it down to anything [...] But I know when they're older (.) they might (.) they might question it (.) thinking (.) 'OK (.) why are you going again (.) you've just been?' or 'Why are you going an hour later?' because then they'll start to read the time and they'll be a bit more clued up on (.) um (.) you know (.) I mean (.) he can read the time now but I don't think he's quite sussed out that I just went an hour ago and I'm going again or something like that (UCMum13C02, Line 881)

Some mothers seemed to believe that by taking their children with them to hospital and explaining in simple terms that medics make them better, their children were more prepared to deal with hospital appointments: “she gets quite excited when I have hospital appointments because I take her on the train ((laugh)) and make it a day out for her rather than drag to the hospital and she loves it” (UCMum11C01p, Line 630). However, there was a latent fear of the illness in children’s understanding as depicted by two participants. First, CDMum06C02 indirectly related how her son might have assumed her illness was deadly:

My gran had cancer and then died and there's been quite a few people with different types of illnesses so it [IBD] kind of came into the language in that way that [...] Both my (.) well certainly my older child knows that I have Crohn's Disease (.) um he did ask quite a while ago if it was like cancer ((laugh)) which I said no (.) and he knows that I take tablets every day (Line 753)

And second, UCMum07C02 mentioned her daughter’s extreme reaction to her inoculation at school. She had assumed that through vicarious learning her child would learn to accept doctors and be amenable to injections. However, it seemed her child had picked-up and mimicked her mother’s anxiety and was mirroring his mother’s fear of needles:

Interestingly (.) my daughter is petrified of doctors (.) which is really strange because she's been to the doctors so many times with me (.) I thought it would be normal for her and that she wouldn't be worried about it because I go a lot (.) um (.) but actually I think it's made her the other way (.) that she is worried about going to the doctor's and doesn't like it so (.) it's interesting how it sort of (.) hinders their experience of it [...] I had to have an injection every day (.) of my pregnancy with [Second Daughter Name] with the second baby um (.) and for twelve weeks afterwards and I'm a bit scared of injections so I would always get my husband to do it for me (.) I was like 'if I'm gonna be pregnant and give birth you can do the injections' ((laughs)) so he did the injections for me and [First Daughter Name] would quite often watch me having them done and I thought it would make her quite OK with injections (.) but clearly by her performance with her pre-school boosters it doesn't ((laughs)) because she was absolutely horrific! She was really scared of her injections and didn't want them done (720)

Lastly, CDMum09C02’s eldest daughter even inquired regarding her mother’s external bag: “does she get to have one when she grows up (.) and you think (.) ‘No, hopefully not’ ((laugh))” (Line 427). Hence, the bag was seen as an accessory, almost like a product of adulthood that

women get to earn as they get older, and the child seemed to have normalised and integrated the bag into her world with no apparent link to feeling sick and having one's bowel removed.

7.2 Theme 2: Comparative Normality

To further cope with the demands and challenges of having an illness, participants compared themselves to several groups of individuals to situate themselves and reflect an image of their health as worse, better, or no better than others. Hence, in this second theme *Comparative Normality*, participants related themselves to: (a) all others (i.e., individuals who are not necessarily mothers, women, or ill, in other words to 'people' in general); (b) women and mothers, both healthy or who suffer from an illness; and (c) themselves: they assessed their own normality in relation to times where they had felt better, or worse in their transition to motherhood. The comparisons acted as mirrors and reflections of their own selves: a benchmark of ideal strength, times or even situations. The contribution of each participant to this theme and its respective subthemes is found in Appendix LL.

7.2.1 People and me

Some participants compared themselves to others without IBD (or any other illness) and communicated how difficult it must be for one not affected with an illness to relate to them and understand what it is they are going through.

I don't know (.) it's a bit frustrating I guess because we've been together so long (.) but I think it is difficult for somebody to understand exactly what it's like (.) unless it's them that's going through it personally (.) it's a very different (.) he's got no health issues at all (.) so you know (.) it's completely different (.) I think if it was a role reversal I'm sure I'd (.) think the same a lot of the time (CDMum01C02, Line 551)

Nevertheless, they deemed it unhelpful when others tried to relate to their illness by comparing it to a 'less' intensely debilitating disease, particularly, Irritable Bowel Syndrome (IBS)¹, “‘oh yeah I understand because I've got IBS’ (.) It's like ‘no you don't’ (.) you know (.) you don't really understand” (CDMum22C02, Line 510). CDMum22C02 felt particularly sceptical of people's desire to help, and conveyed in an irritated tone the following example of how little others seem to appreciate IBD.

People are very much (.) some people are (.) this is what you get a lot with things like this [like IBD] ‘oh yes (.) my brother's ex-wife's sister's cousin has that’ [...] ‘She tried’ ((hand gesture indicating ‘so and so’)) [...] It's like I have to take steroids to alleviate my symptoms (.) taking some kind of oil from Morocco isn't going to help (.) do you know what I mean? (Line 496)

¹ See section 1.3 in Chapter 1 for detailed explanation of the symptoms of IBS compared to IBD.

Also, relating to others, a few participants mentioned wanting to “act normal” and one refused to join a Crohn’s and Colitis UK support group because “in my family (.) it wasn’t one of those things (.) you don’t go and join the support group ((tough mocking tone))” (CDMum02C02, Line 235). Others said they preferred not to use the ‘can’t wait card’ as they did not want people to think about the implication and symptoms of IBD. There seems to be a desire to be seen as normal and to reflect an image of blending in, which is somewhat facilitated by the nature of the illness: “nobody knows (.) really (.) unless you choose to tell them” (CDMum09C02, Line 74).

I don’t want people envision me going to the toilet (.) I don’t really [...] I feel because there’s so much misinformation about it and then like people are always asking if you’re eating the right things and this and that and it’s very (.) people trying to show concern (.) I feel also I’m quite defensive (.) are they judging me or worrying about what I’m eating or thinking about me as a person who needs the toilet too much and I don’t like that so (UCMum03C01p, Line 894)

Comparing themselves to other people who suffered a temporary blip but are deemed otherwise healthy, was particularly distressing as it seemed to make participants feel even worse about others’ inability to empathise with a ‘real’ illness:

I remember being in hospital for one of my surgeries and there was a lady in the bed across who was getting a toenail removed and it was like the worst thing that had ever (.) ever happened to her and I couldn’t believe that she was so upset (.) and I realise now that everybody’s experiences are different and how they’re affected but (.) I just couldn’t believe that I was sitting there getting my abdomen opened again for the who many-eth time and she was really upset about getting her toenail removed (CDMum06C02, Line 75)

Comparing themselves to individuals in the general population placed participants in a vulnerable position. They felt on a lower par because they experienced a harsher reality with IBD and were seldom understood by others. This is portrayed by UCMum23C02 who mentioned feeling like “an outsider (.) I felt like I didn’t fit in (.) that’s it (.) I just thought (.) well I’m different to everybody” (UCMum23C02, Line 115). Other participants conveyed a similar sentiment:

You think (.) you know (.) it’s unfair like other people just go about their (.) lives normally and why do I have to deal with all these little things every day and always having to think where the nearest bathroom is and always stressing out what if (.) I’m going on a plane and I need the bathroom or what if I’m out in a park and I need the bathroom or (.) you know (.) there’s always so many different things that you have to think about and it’s very hard to control it (UCMum15C02, Line 678)

Even when comparing themselves to others with a chronic illness, or IBD, they mentioned the perceived (or medical)² degree of severity, the type of IBD, or even the individual expression of symptoms within the same type of IBD, to distinguish the presentation of their IBD in

² The Montreal classification categorises Ulcerative Colitis by the extent of the spread of the inflammation (i.e., left or right sided) and the severity of the relapse (i.e., mild, moderate, or severe) (Satsangi, Silverberg, Vermeire, & Colombel, 2006)

comparison to others with the same condition. Some said, “I am quite mild to moderate [UC]” (CDMumPi02C01, Line 95), or “I’m lucky” as they knew “other people [with IBD] who have had a far worse time than [them]” (CDMum01C02, Line 168), and even stated that “luckily [they] didn’t have to have a bag” (CDMum02C02, Line 35). Moreover, although most participants conveyed that it ‘takes one to know one’ to understand living with a chronic illness like IBD, they also insisted on how individual and unique each journey with IBD can be:

Even my family members ‘cos my sister’s got it as well but she’s got it slightly different to me (.) hers is the other side of the bowel and she has totally different treatment for it so (.) every individual person is different with Crohn’s anyway so people don’t understand it anyway and then you’ve got this total different end of the spectrum of it as well ((laugh)) (CDMum02C02, Line 220)

Hence, participants mentioned comparing themselves to others with IBD “to identify with all those people that had written in the NACC News saying, ‘I can’t work (.) I’ve got fatigue (.) I can’t drive (.) I’ve got fatigue’” (CDMum16C01, Line 646). This allowed them to feel better about themselves and reflect on the positive aspect of not having such a hard time as some other people: “I haven’t found it as painful as other people do (.) I know a lot of people complain about the pain but it’s not a huge issue for me” (UCMum03C01p, Line 335). Conversely, a participant who has had her bowel removed - CDMum09C02 - felt she was like anyone else, “normal”, apart from emptying the bag, and did not identify with others with IBD as she had been in remission for more than a decade.

7.2.2 Mothers and me

When it came to comparing themselves to other mothers, it was usually within the context of making decisions around the pregnancy and welfare of their child. Most participants mentioned how blessed they were to have had a child: “we have to just be grateful for what we have (.) and there are lots of people that can’t even have one” (CDMum16C01, Line 547), and having IBD made them appreciate having an easy pregnancy “just like anybody else”. A few compared their pregnancy as equal to, or better than, most mothers saying: “a lot of women get problems with that [back pains] anyway when they’re pregnant” (CDMumPi02C01, Line 192).

I had friends that were pregnant and they felt terrible and they had gone through that worrying first trimester and I didn’t have any of that and I was like ((laugh)) ‘oh I’m pregnant’ and (.) you know (.) ‘here’s my bump kind of thing’ ((laugh)) (CDMum16C01, Line 252)

Some participants, as described in *close monitoring* and *symptom confusion* in Chapter 5, talked about having more scans than healthy mothers during their pregnancy. The extra-scans were reassuring, but the similarities, and sometime confusion, in symptoms between IBD and pregnancy meant an extra burden compared to the healthy mothers.

So(.) it’s things like that that you think ‘this isn’t normal’(.) but they become normal to you because that’s how you’re dealing with it (.) but actually that’s not normal ((laughs)) to have toys in the downstairs loo to entertain your child while

you're on the loo 'cos most people [mothers]when they're on the loo are not there for long enough to need to entertain their children sort of thing [...] so that was quite difficult (UCMum07C02, Line 75)

Most participants alluded to the idea of an 'ideal mum' who "want[s] their children to have the best" (CDMum16C01, Line 823). However, when it came to breastfeeding – which was referred to as "one of the biggest things for a mum" (CDMumPi02C01, Line 565) – falling short of that ideal was a source of conflict and intense distress, as described in Chapter 6 section 6.18.1 *eEasing guilt*. Moreover, UCMum14C01p mentioned how she feared being perceived as an inept mother by health professionals as she, and her baby, were hospitalised a few weeks after delivery – her due to a flare and him due a failure to thrive.

It never occurred to me it would be like this (.) that (.) um (.) you know (.) [Son's Name] would have to go back into hospital after such a short time at home (.) And then I started to worry um (.) that the healthcare professionals were thinking that I couldn't cope (.) that I wasn't doing a good enough job [...] (.) because they're not going to discharge him unless they can see that I can (.) you know (.) I can get myself out of bed and be there for him (.) So I was like constantly worried about how they were viewing me as a mother (.) ((I: mm)) so that was (.) yeah (.) a really tricky time (.) (Line 395)

Hence, on the one hand, when comparing themselves to mums in the general population, participants oscillated between feeling luckier than some women and mothers who could not get pregnant or had difficult pregnancies, but also feeling worse as they sometimes did not meet perceived expectations of what a mother ought to be: "I just wanted to be like every other mum and I didn't want to be seen as different (.) and so that was a cause of concern for me when I was pregnant" (CDMum06C02, Line 242).

On the other hand, when comparing themselves to mothers with a chronic condition, or IBD, participants felt supported and gained perspective on their experience relative to others who were also suffering.

I've got a few friends that [...] they've got their own medical issues and things like that (laugh) so one friend did actually say to me (.) she's got a daughter the same age as me (.) she did actually say 'the worst thing that can happen is you will poo yourself' ((laugh)) And she said 'if that's the worst thing that can happen it's not the end of the world' and I was like 'yeah (.) if you put it in perspective ((laughs)) (CDMum02C02, Line 245)

Some also mentioned feeling lucky for having a supportive partner or family around to help them bear the burden of IBD and motherhood when others with this condition are not necessarily as lucky: "He [Husband] was really understanding but it's [IBD and motherhood] been really hard (.) emotionally hard and really testing on your relationship and thankfully (.) I think some people it may not have gone as well [...] he's stood by me" (IBDuMum04C01, Line 478). It is worth mentioning that, despite these comparisons, participants seldom knew at the time of their transition, another mother who had IBD: "I had no idea how many people have (.) sorry people (.) women ((laughs)) once they've had the baby (.) the amount of people [mothers]

that have a flare-up” (UCMum07C02, Line 589). Some could relate however, to a friend with a chronic illness different from IBD who faced similar difficult choices

I knew somebody else who had a chronic illness (.) not Inflammatory Bowel Disease (.) but had a chronic illness and (.) the drugs that she was on she wasn't allowed to keep taking and she had to change to a different type of medication because she was on quite new drugs which hadn't been tested during pregnancy so they couldn't (.) didn't have any evidence to show it was safe and as a result of changing her medication she became sick and I know it wasn't the same condition but it made me think if I stop this [medication] or if I change (.) if they put me on something else (.) I don't want to compromise myself and the baby (CDMum06C02, Line 627)

UCMum07C02 even advocated on behalf of all sick mothers, for healthcare professionals to take into consideration the impact of hospital stays on the family as a whole: “I think they [medics] should really put a bit more in place actually with dealing with a mum (.) not necessarily just with IBD (.) it's actually any mum [with a chronic illness] that goes into hospital for any length of time” (Line 589).

Two participants made no comparison to other mothers with an illness or IBD. Interestingly, they were amongst those mums that suffered from IBD symptoms during their pregnancy but got diagnosed shortly after. I interpreted this lack of reference to other mums with IBD as an indication of the latent awareness of the uniqueness of their experience. This was best illustrated by UCMum13C02 who got UC whilst pregnant with her first child:

The medical profession are saying that because you're pregnant you are less likely to have a flare-up (.) I'm not so sure if I believe that (.) I know my case could have been a one-off (.) and I'm sure they've got more people statistically to prove differently (.) so that's (.) but I don't think you should exclude (.) 'She's pregnant (.) therefore she can't have colitis or a flare-up.' um (.) I don't think that's a definite connection (.) I think there is still um (.) a percentage of people (.) I don't know how big or how small that won't (.) obviously (.) convey to that rule (Line 1063)

All these downwards and upwards comparisons allowed participants to imagine how their own experiences appeared through the eyes of other people and, hence, to appreciate better what was going well while, at times, commiserating with others in shared suffering.

7.2.3 Myself and me

Thirdly, to better understand themselves, participants self-reflecting and established a continuum of health as they progressed in their experiences with IBD and motherhood. They compared their state of health from a non-ill to an ill individual as also touched upon in *identity change* in Chapter 5. Participants rated how the illness was at times better or worse and established a new normality with IBD. For example, CDMumPi02C01 related how, although for any outside observer, having surgery and being unwell would be perceived as having a bad day, she interpreted her latest phase as ‘not too bad’ in light of how much worse the illness was:

So yeah (.) I have had to have surgery ((laugh) but it's not been (.) like really severe flares (.) I've not been hospitalised other than my surgery (.) I've not ended up in with flare-ups or anything which I have done in the past so (.) for me it's not (.) ((laugh)) it's not the worst if you see what I mean? My Crohn's has been worse (Line 466)

“You become a bit complacent” said CDMum02C02, and make do with what you are given: “you go through times (.) like for example today [interview day] I've had no issues today [...] and there will days when I do have you know more frequent trips to the loo” (Line 396). Most participants could recall the worst time they had with IBD, particularly for those diagnosed at a young age: “those were the worse years” (Line 25) said CDMum16C01; and others were able to describe a bad flare, as described by UCMum03C01p:

There was one job I worked (.) What year was it? I think it was 2008 (.) I ended up going off stressed for three months (.) when I was off sick then I did nothing (.) I didn't leave the house (.) I couldn't go out [...] that's the only time I've ever been off with anything like that but actually really got myself depressed and more worried about going outside but I think (.) again (.) feeling this sick and rubbish I could have easily just had Tesco deliver the groceries and never gone outside (Line 613)

Two participants, UCMum07C02 and UCMum20C01, rejoiced at the time of the interview that they were at their all-time best since their diagnoses. The former was a day-away from finishing a course of steroids and optimistically said “there might never be another one [flare] hopefully” (Line 337). She could clearly distinguish a notable difference between her current state and how she felt a few months back:

The other night (.) I said to [Husband Name] 'God (.) I just put my pyjama bottoms on' and he was like 'well (.) yea (.) what's significant about that' and I said 'well normally I can only put them up to my hips because my stomach (.) I'm always in so much pain in my stomach I can't bear to have it on my waist' and I said 'this is really weird that I've just put my pyjamas on and not thought about 'oh I can't put them there 'cos I'm in so much pain' and I said 'that's RIDICULOUS (.) I've been like for four months I'm positioning my trousers where I'm not in pain' and I said 'this is just ridiculous' and (.) but it's something you just put up with because that's your life and you just live with it (Line 764)

As for the latter, UCMum20C01, she shared her little victories over IBD such as being liberated from regular check-ups with her consultant for the foreseeable future.

I've not been unwell (.) So I've been keeping my medication on (.) I went to the consultant um (.) about two months ago and this is the first time he's said (.) 'I don't want to see you for' I think a year maybe (.) So I've not had it (.) to be allowed to go that long before (Line 605)

As for motherhood, some participants recalled the kind of mother they had aspired to be and limitations they had come to accept when it was realised that their ‘super mum ideal’ was actually a source of anxiety. They had to adjust to their new normality and admitted that “if you want to be a great mum (.) be a great wife (.) be a great friend you're going to muck it up

somewhere (.) sometimes and you can't be perfect" (CDMum08C01, Line 748). CDMum06C02 also shared in the excerpt below how she had to make adjustments to her new-found role as a mother, and how challenging it was at times to drop her idealistic view of what a mother should be:

The first time we went on a holiday [...] I found that a very strange experience because we'd just gone on holiday the two of us [couple] obviously because we didn't have a family then (.) and [...] I didn't know how to kind of act as a mum (.) with lots of other mums and lots of other families and it was very (.) very strange (.) it was just a very strange experience because I just felt on holiday I was a certain type of person but this was a holiday as a mum and with my family which was really and I was really quite anxious and it probably took to about day three or four before I relaxed and started to enjoy it (.) and I found that really difficult (.) and when I was back at work I still felt like I was there but I was somebody's mum (.) and I think it took me a long time to get my own sense of identity back and start to feel that I don't need to be a mum all the time (.) that I've other things if I'm at my work or with my friends or (.) but it just seemed kind of all-consuming at the time, (Line 766)

Moreover, as 15 participants had two pregnancies³, they could self-assess their health between the first and second pregnancy. They compared 'normality' relative to their own experience rather than the experience of other mothers: "At the twenty week point I sort of just suddenly bloomed and everything was absolutely fine [in the first pregnancy] [...] and got to twenty weeks pregnant again [second pregnancy] and I bloomed again ((laugh))" (CDMum02C02, Line 75; 313). Sometimes a bad experience in the first pregnancy led to particular apprehension approaching the second one. However, in general, most women found it easier and less worrisome to go through a second pregnancy as they were used to the little niggles and had learned a lot from the first. For example, the following extract depicts the comparison made by UCMum03C01p between her first and current pregnancy as well as the slight advantage she perceived in having had a diagnosis of IBD between her two pregnancies compared to having the diagnosis before her first gestation.

I mean there was nothing physically wrong with my health when I was pregnant with [Boy's Name] [...] I'm quite fortunate that I got the diagnosis in the second pregnancy because in the first pregnancy if I had to listen to all that and be worried about Crohn's Colitis I think (.) it would have been too much because I really found being pregnant the first time stressful and worrying that I wasn't getting the right information or doing the right things [...] I'm still a little traumatised from my last birth ((laugh)), I'm not really looking forward to it [this time] (UCMum03C01p, Line 136; 391)

³ I am differentiating between having two children and two pregnancies as UCMum15C02 fits in the former category with her twins but not the later. She cannot compare between pregnancies. I am also including the four that were pregnant for the second time during the interview.

7.3 Theme 3: Two-Sided Mirror

In theme three, I examine the participants' orientation to the 'visual' element of the study: the video-recording. As mentioned in Chapter 4 (Methodology), the study's context was simultaneously one of research and of gathering material for impact: that is, to utilise the participants' accounts as research data but also to create YouTube medleys (where consent was obtained) for public dissemination⁴. And, of the 22 women interviewed, 21⁵ agreed to be video-recorded (but not all who were video-recorded agreed to be re-contacted to request consent to use extracts in YouTube medleys).

Before presenting the analysis for this final theme, I will describe the particular method I used to identify relevant material and to analyse the data on which I based the theme *Two-Sided Mirror* and its subthemes. However, in order to do that, I need to situate the context of the interview and video-recording. During the interviews, which were for the most part at participants' homes, an iPad fixed on a tripod was used to film the session (see *Figure 7*).



Figure 7. iPad recorder fixed on tripod

The recording setting was always shape in triangulation with, the participant at the apex of a triangle facing me, and the lens (placed to my side) in between us (See *Figure 8*)

⁵ I included some comments made by women who were Skyped interviewed but who technically are not part of the "glance analysis". It is almost impossible to count glances during a Skype call as the person is looking at me and the camera through the same window. However, experiencing the recording and the use of the camera to capture their life with IBD pushed them to make some comments to the "audience". CDMum19C01p and UCMum13C02 (marked with*) were recorded on Skype but are not part of the count for this last theme. Nevertheless, they were at times empowered by the recording, and directed how they wanted to be perceived in the video (i.e., pushing to end the interview). I felt it was important to share those comments as it showed how they related to the visual element.

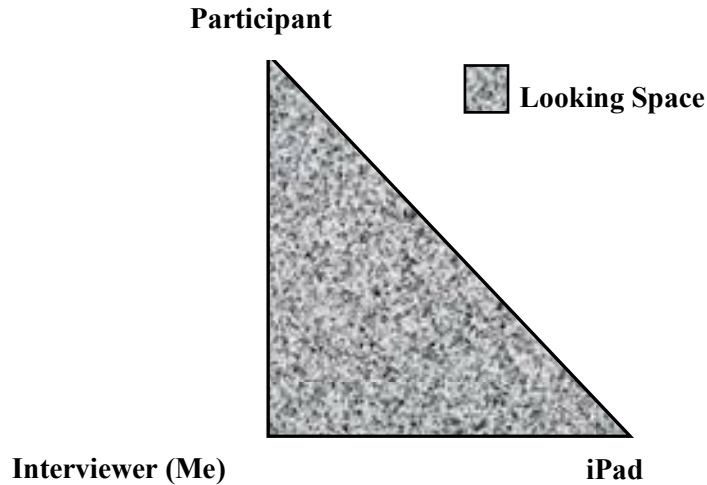


Figure 8. Interview triangulation

Within the “looking space” participants could either be looking at me or the camera. Image 2a and Image 2b shows, for visual comparison, a pilot participant looking at me during the interview and then looking at the camera. I noticed while looking at the interviews videoed for analysis, that participants often “glanced” at the camera and oriented themselves to it when discussing sensitive topics, such as bowel movements and losing blood. Hence, I was interested to explore further the context in which these glances occurred. To do so, I reviewed all videos, tabulating every instance when participants looked at the camera in terms of the time at which it occurred and the topic being addressed at the time (Appendix NN).



Figure 9. UCMumPi01C01
Glancing at the interviewer

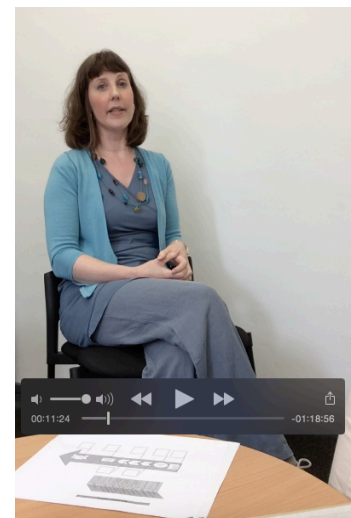


Figure 10. UCMumPi01C01 Glancing at the camera

This “glance” was systematically recorded across all 19 participants who were video recorded. Table 2 shows an example of how I coded instances when CDMum08C01 looked at the camera.

Table 20 *Video Glances Coding CDMum08C01*

Excerpts and Line Number	Comments	Glance Time	Codes/Theme
Um (.) I was 22 (.) in my last year at university 5		00:10	
what do you want me to tell you about, the symptoms or (.) just (.) 6	Asking the audience what do they want to hear	00:20	
the doctor said I had indigestion and gave me some indigestion tablets, and that didn't help 12-13	Inefficacy of GP	00:37	Complaining about Healthcare Professional
So yeah I was in end of my autumn term, in my last year at uni. 17		1:09	
so I puffed out and had all the insomnia (sigh) 23	Hand gesture to indicated full moon face	1:31	Confiding symptoms and difficult time
so I finished my degree and got a job and I was well 25-6	Things getting better	1:48	
So I've been on every drug going I think. 29	Nothing helped	02:08	Telling others she tried it ALL

I watched, read and familiarised myself with the videos even further and noted each instance participants looked at the camera. I coded the topics that were addressed at the time, and the codes were later clustered into three subthemes and an overarching theme entitled *Two-Sided Mirror*. The first subtheme, women oriented to the camera as a *confiding platform*, an intimate third 'person' in the room to whom they disclosed joys, fears, embarrassments and praise of others who have been helpful in their journey to motherhood. In the second subtheme, participants used the camera as *wallow window* through which they expressed their suffering. Hence, they oriented to the camera as an interested guest with whom they could share the injustices and wrong-doings they had experienced. Lastly, the camera was used as a stage through which to perform to a wider audience. Mothers glanced at the camera as they shared their advice and resiliencies, but they also directed their *staged performance* by indicating when they were ready to start or wanted to pause by turning away apologetically during particularly emotional moments of the interview.

7.3.1 Confiding platform

Participants confided to the camera and the lens in several ways. First, the interview and the camera became a sharing platform for difficult times. Participants revealed their moments of fears, doubts, shame and embarrassments. These included the fear of transmitting the illness to their child, or not being able to breastfeed, but also disclosing personal and intimate sexual details about their lives:

The vaginal ulcers because that in itself it doesn't just have an impact on me and [Boy's Name] it had an impact on my relationship with your husband because (.) you know (.) there were (.) it's obviously the intimacy side of things completely goes because umm you just can't (.) because you're in that much pain (.) you know (.) even down to having (.) to kissing somebody (.) you know (.) you couldn't kiss your husband properly because my mouth were that sore (IBDuMum04C01, Line 428)

CDMum02C02 also mentioned difficulties planning for toilet situations and looks directly at the camera. She speaks about the shame of having accidents when there was not enough time to push a pram into the nearest toilet. IBDuMum04C01 reported how people at work were understanding about her rush to the toilet when she was pregnant but were unaware of her condition. A short while after she broke down in tears and said, peeping at the camera, that now everybody was aware that she has IBD. Moreover, description of symptoms of IBD, and mentions of formed stools, bloody diarrhoeas, or painful colonoscopies are “not something that you really want to talk about” (UCMum20C01, Line 17). UCMum03C01p looked a bit embarrassed at the camera while lowering her voice, in a child-like manner, to say she is now taking all her medication rectally:

My understanding of it at least is when you take something orally your other part of your bowel absorbs the medicine (...) so they finally got me to the point where I take everything rectally and that seems to work (UCMum03C01p, Line 96)

These disclosures and uncomfortable topics were often accompanied by a glance at the camera. This led me to believe and form the understanding that participants had an awareness of the outside world listening in on the experience of an illness still hard to discuss publicly, and in front of a camera.

‘Have I finished?’ and you have to wait for ages until you’ve actually finished going to the loo (.) it’s such a bad subject (.) until you (.) you know (.) just to make sure that you actually have gone completely (.) (CDMum22C02, Line 672)

Second, the lens also became a confidante in relation to their joys and good times. Participants admitted their highs as well as proud moments. They addressed a compassionate friend to recount for example how pleased they were of their children:

If they do something at school that (.) or pre-school (.) that the other children haven’t got or have done something a bit more spectacular like getting themselves dressed ((laugh)) it’s only what every other mum would feel (.) it’s just that ‘wow(.) you’re a genius’ ((laughs)) So (.) and that’s what I think (.) she’s a genius with most things ((laugh)) (CDMum02C02, Line 618)

Some participants also shared positive news such as finishing a course of treatment or not having recourse to surgery. They even made jokes regarding their brooding desire to have children: “[we waited] five weeks after we got married (.) we didn’t wait ((laugh))” (UCMum11C01p, Line 159). And, ultimately mentioned with tears in their eyes how precious it was to find out they were pregnant: “so I felt just joy really, yeah, such a special time really ((laughs)) you’re going to make me cry in a minute ((we both laughed))” (CDMum16C01, Line 256).

Lastly, participants divulged their praises and tributes to whomever had contributed positively to their journey to motherhood with IBD. They made references to helpful healthcare professionals such as an IBD nurse or a re-assuring gastro consultant. Others mentioned supportive friends, colleagues, family members and partners saying, “it brings you closer

together as well because you've got that other thing [children] that you both share in to bring up together" (UCMum12C02, Line 638). One participant thanked her school: "my school were really good and I had lots of times off for colonoscopies and tests in [City Name] and I was really grateful to them for that" (CDMum16C01, Line 100).

7.3.2 Wallow window⁶

The interview platform was also one of criticisms and complaints addressed to various audiences, healthcare professionals, work and related establishments, as well as individuals in the participants' entourage.

Parts of the complaints included difficulties getting access to care or being validated for the symptoms. For example, UCMum03C01p scolded her local hospital saying: "The only way you can get any access into that department is complaining (.) which isn't great ((laugh)) so (.) because I don't want to come off as a complainer either so it's one of those" (Line 155). In my opinion, this participant was aware of the camera looking back in, and her desire to appear under a positive light, i.e., she did not want to sound like "a complainer", was a reflection of the potential risk of being recognised by her local care provider.

Other women stated the dilemmas facing mixed medical messages and personal stances on breastfeeding or going through gestation whilst taking IBD drugs. For example, in the quote below, the CDMum01C02 voiced a disclaimer regarding her stance on breastfeeding, possibly sending a message to other mums and indicating her awareness at the moment of the filming.

I would breastfeed again just because that was right for me (.) but (.) I have no(.) issues of people who don't do that (.) who want to formula feed (.) I think it's very personal and nobody should be told what to do (CDMum01C02, Line 591)

Interestingly, CDMum10C02 said, while gazing at the camera: "I wanted to tell them I proved them wrong ((laughs))" (Line 275). Hence, she appeared to use the opportunity of being filmed to tell a potential audience how angry she was to have been induced in her first pregnancy, and how hard she fought to succeed at having a natural delivery on her second, despite medics advising against it.

Similarly, some women reprimanded friends, acquaintances or even a sibling who had offended them, "She's not very good at being very supportive which is strange because you'd think her being my sister [she] would be" (UCMum07C02, Line 424). One participant was sharing her thoughts about screening people who would not accept her condition, she looked at

⁶ The name for this subtheme came from a landmark monument, a bridge in Venice, called the "Ponte dei Sospir" (The Bridge of Sigh). The bridge looks more like a tunnel with a narrow tiny window on one side. Prisoners were transported through it before their execution, and they would take one last glance at the outside world through this window. Although the picture depicted in this subtheme is not grim or fatalistic, it did feel like the participants were using this very small window of opportunity provided through the interview and camera to share their troubles

the camera sending a message to whomever she pushed away and sent a warning to those who might judge after seeing this video:

I literally just blurt it out [that I have CD] 'cos I have to see it's not (.) if it's gonna embarrass them I don't really want (.) you know (.) if they're going to be them sort of people that might be embarrassed by it or might judge it that's (.) you know (.) I don't need them people in my life which I think that's what's happened with a lot of people in my life (.) they've kind of just been (.) I've kind of blocked them out even though I'm (.) maybe they don't have such a big issue with it but I think if I've felt they've had an issue with it I've blocked them out because I thought 'well if you've got your opinion on that it's' (.) 'cos a lot of people are like 'oh yeah (.) it's just like IBS' and they don't want to know or have any more understanding of it (CDMum02C02, Line 826)

However, some felt the intrusion of the camera when telling-off someone close, “I don't think (.) he tried to understand (3) really (.) I mean I don't want to sit and criticise him but he's not a very sympathetic (.) person (3) he's just a man ((laugh)) he just worries about himself (.) his TV (laugh) and his beer” (UCMum11C01p, Line 114).

Almost half of the participants coded in this theme looked at the camera to report some distress and complain over the demands of having/keeping a job and those of IBD and motherhood: “I did go back to work three days a week” said CDMum02C02, “but that just wiped me out to be honest and I started getting ill again ((laugh)) so it was quite an effort” (Line 205). UCMum11C01p, protested that her former job was not very understanding of her chronic illness, “I was working as an agency social worker so I wasn't getting paid while I was off (Line 48). CDMum10C02 added that “we [stay-at-home mums] are putting everything (.) we've made a lot of sacrifices to do this and we are raising the next generation (.) so to me my first job is being a mum [...] I am raising the next generation (.) although the government don't realise that (Line 470). She criticised the UK government for not supporting mothers at home and doing more, in terms of benefits, to help them raise their children. Lastly, CDMum02C02 blamed the council office, as she had to convince them to sell her a radar key.

I went to two council offices and also had a phone call conversation with one lady about the reasons why I should have a radar key(.) disabled toilet key(.) 'cos of trying to get a pushchair into a toilet while you need the toilet so quickly as well(.) you really need access(.) and they didn't think it(.) 'cos it wasn't obviously on their list of why people need a disabled toilet key(.) which it doesn't seem to be(.) Umm but I generally think now it should be a standard issue thing for every mum who's got IBD [...] And it took some convincing and I had to make a few phone calls and speak to two different council offices about having a disabled toilet key(.) even though you have to pay for it which is ridiculous (Line 897)

7.3.3 Staged performance

The third way participants related to the visual element was to use this medium as a stage to tell the story of who they have become, their resiliencies, and gave their advice to other mums and mums-to-be with IBD. Interestingly, they also navigated through the interview and around the

camera by imposing a tempo, staging when they were ready to start the interview, scheduling interruptions and breaks, as well as concluding statements.

Some women looked at the camera and shared how they took in their stride and tried not to be too stressed about small stuff during their pregnancy. CDMumPi02C01, said she felt somewhat more adapted to other mums to the ever-changing schedule of her newborn as she was previously broken-in by IBD. Some share how their illness shaped them “as a mother it’s [IBD] just part of (.) I suppose it’s just part of me [...] like literally everybody I meet I will tell I’ve got Crohn’s Disease” (CDMum02C02, Line 824). However, some were mindful that although they enjoyed their pregnancies and being a mother “is the best thing ever” that “some people don’t feel like that or they struggle after they’ve had children or (.) you know (.) suffer from depression and things” (CDMum22C02, Line 911)

Participants also gave advice and tips to listeners, whether it pertained to pregnancy, dealing with IBD, or managing young kids. Amongst the recommendations were “know where the best toilets are situated”, “don’t read all the books” and “try and be easy going”. They were usually quite encouraging but realistic that “you wouldn’t want to have a child if you’re not feeling strong enough, you know, to cope with it” (UCMum15C02, Line 754).

And to all new mums (.) um (.) you know (.) you know it’s going to be hard because you listen to everybody else (.) however with IBD thrown into the mix it becomes a lot harder (.) extremely hard and it’s hard to cope with (IBDuMum04C01, Line 147)

Furthermore, I found participants sometimes addressing topics that had little relevance to their lived experience. It could be that they were broadcasting an awareness of other complications implicated with IBD such as postnatal depression and advocating for individuals with more severe forms of IBD. Moreover, they stated medically based assumptions or facts, but their uncertainty of these facts was betrayed by their wording and look to the camera. It was my belief that they did not want to be caught saying something wrong on film.

It felt sort of Crohn’s, it felt up here ((pointing at stomach)) [...] but (.) because everything got squeezed up anyway because of the pregnancy it probably felt higher [...] I don’t know, that’s my rubbish assessment ‘cos I’m not a medical person, but yeah ((laughs)) (CDMum08C01, Line 371)

No, it was more after really, I think I understand that you know, once all the hormones kind of leave your body and you kind of go back to normal, that seemed to be what triggered I think with my second, what triggered a flare again ... but while I was pregnant nothing (CDMum01C02, Line 122)

Although I can see how participants had an awareness of the lens when giving advice, I also felt that these comments were fuelled by the last set of questions of the interview schedule which open the floor to address any guidance and recommendation (Appendix AA).

Finally, most participants made eye-contact with the recording at the beginning of the interview. They familiarised themselves with the equipment and soon after I asked them if they

were ready we began the interview. I could not help but feel I was acting like a director with the initial clapperboard saying “take action” as the structured discussion unfolded.

I: [Beginning of interview] Hi UCMum15C02(.) can you tell me a little bit about when you discovered that you have IBD?

Yeah (.) I was 16 years old and I (.) sorry am I looking at you or I am looking at the camera?

I: Whichever you want (.) whatever’s comfortable

However, soon the roles reversed and the participants took hold of the stage asking “Can you see on that [video] I’m just thinking it’s going dark”. They were not passively subjected to the lens, UCMum03C01p, adjusted her cleavage, and CDMum19C01p* asked if I could “try and make me [her] look thin will you?” (Line 1012). They navigated the stage and decided whether they did or did not want to share some of the information as CDMum16C01 shyly giggled and revealed an uncomfortable incident precluding by saying “I don’t know if I want to say this on film”:

I had (.) I’ve always had really good control of my bowels (.) but there was one night, ‘cos I was on these iron tablets (.) my daughter was in bed with us because I was constantly feeding (.) and we didn’t agree with her being in the bed at all (.) we were really nervous about having her in the bed so she had a Moses basket beside the bed (.) but in the very long feedings (.) I’d fallen asleep with her crooked in my arm and my daughter her pooed the bed (.) really bad diarrhoea (.) So we’d got up in (.) you know (.) and I was like (.) all flustered ‘cos she was in the bed with us (.) and my husband cleaned the sheets (.) ‘cos I’d had a C-section (.) couldn’t bend (.) blah blah blah (.) and it had gone through the mattress (.) then we went back to bed (.) and then I pooed the bed in exactly the same way because I was so ill (.) and had the iron and everything like that and then he got up again and cleaned the sheets and he said to me ‘It was something that as a husband I don’t really want to clean up my daughter’s mess and my wife’s in the same night when I’ve got to go to work the next day’ (Line 801)

Participants almost unanimously requested pauses, whether to gather their emotions, take a bathroom break, check on their baby or take a phone call. They also sometimes decided when they had enough as demonstrated by UCMum13C02* who asked “are we not coming to an end? Have we covered everything?” (Line 1132), hence concluding shortly after our interview.

7.4 Discussion and Reflections

The first theme of this chapter *Shielding Child*, is noted in various instances when the child acted as a protective barrier against IBD. This could start during the pregnancy in that, according to Beaulieu and Kane (2011), one-third of women with IBD feel similar, one third worse, and one third better during their gestation. Moreover, the child was perceived as an extra-incentive and purpose to remain well and manage IBD symptoms. Similar results were gathered from accounts of mothers suffering from other chronic illnesses. For example, Vescovi, Pereira, and Levandowski (2014) interviewed three adolescents (14 to 17) who were diagnosed with HIV during pregnancy and reported that motherhood, having a baby, motivated

these adolescents to keep up with their healthcare checks and remain well for their child. These results were supported by a meta-synthesis of qualitative articles relating to motherhood with HIV (Sandelowski & Barroso, 2003). Having a child was a buffer for negative impact of HIV through providing a reason to live and fight the illness and, moreover, a source of self-esteem, strength, and sense of normality. The unique finding pertinent to the subtheme *child as shield* was that women with IBD suffer from incontinence and were able to pretend that their child needed the loo or blame any discomforting smell on them when in public.

In addition, mothers protected their child from IBD and made various choices regarding announcing IBD to their children. Some preferred transparency. Others opted for a child-friendly description of the illness. Participants also chose to tailor the details to the age of their children. Crohn's and Colitis UK (2017) prepared an information sheet guiding parents on how to break the news of their illness to young ones. They advise that information ought to be tailored to the age and maturity of the child and followed up with the opportunity to ask questions and to reassure in light of arising fears. Previous research documents the way in which parents with IBD witnessed the impact of IBD on their ability to cope with the demands of raising young children (Mukherjee et al., 2002). In my study, mums with IBD did their utmost best to maintain a routine and shield the child from IBD. For example, some decided to breastfeed to provide their newborn immunity and others opted for bottle feeding to avoid passing on IBD medication through breastmilk. Similarly, the three mums with positive HIV in Vescovi et al.'s (2014) study refrained from breastfeeding to prevent ART medication from harming their child.

Lastly, in the subtheme *reflecting IBD*, the reported reactions and explanations expressed by children to their parents is observed. Crohn's and Colitis UK (2017) warned parents to monitor their children's behaviour as their reaction to IBD's news might not be expressed verbally. In my study, mums reported what their children said about IBD which often involve comments made in the toilet as children of young age were kept in close proximity even when going to the loo.

Of the second theme *Comparative Normality*, the concept *Reflecting on Others*, gathers accounts of participants' comparison of times of illness and health in relation to other individuals, mothers, and themselves. In the first subtheme *people and me*, women interviewed in my study would situate themselves as affected by a "real" illness compared to healthy others in the general population. They would also feel particularly irritated when others related to them and their health through "less intense" experiences of an illness (such as having the flu or suffering from IBS). This finding was echoed in a qualitative study of women affected with another invisible chronic illness: fibromyalgia (FM, Armentor, 2017). On one hand, and contrary to participants in my study, the women in Armentor's (2017) study felt they could use people's common illnesses, such as the flu or headaches, to make them relate to how they feel daily. On the other hand, similarly to my study, some of women with FM felt misunderstood or

sensed disbelief around their illness, whether from medical staff or people in their surroundings, and preferred to recluse from social interaction and avoid legitimizing their seemingly contested disease. Ironically, when the “effects of FM [do] not allow [a participant] to “pass” as normal and [...] she contemplates avoiding contact” (p. 27). So, although at times the person’s health deteriorated unveiling the illness to others, they still preferred to isolate themselves. In my study, mothers with IBD mentioned pretending they were fine and avoided discussing their IBD with others who they thought “did/could not get it”. There seems to be a paradox here between wanting others to relate to their suffering and feeling validated about an illness that was invisible to others and attempting to mask the illness whenever possible in fear of being discovered and treated differently.

I cannot but notice the applicability of the Social Comparison Theory (Festinger, 1954) to the analysis of how women with illness often seem to compare themselves to others. When my participants expressed an upward comparison, mentioning individuals perceived as better off in their health status, they were left with feelings of inadequacy, increasing the gap and dichotomising their sense of illness as them being unwell and others being healthy. Also, when comparing themselves to others affected with IBD, they mostly reported a downward comparison, emphasizing that they could be doing much worse. This downward comparison, was associated with a positive feeling towards the status of their illness, putting in perspective how much worse it could be, and is, for others. Moreover, one participant compared herself horizontally to other individuals in the general population, stating that having an external pouch and her bowels removed allowed her to be like anybody else living a “normal life”. Hence, just like participants who used downward comparisons to cope with their health, horizontal comparison was also associated with a higher satisfaction about having a chronic illness.

In the two subsequent subthemes *mothers and me*, and *myself and me*, participants compared themselves in an upwards, downwards and horizontal manner to mothers in general and ill mothers or made comparison to times where they felt better or worse within their own illness trajectory. This phenomenon is reported in relation to other illness. For example, when pregnant, women with Type 1 Diabetes compared themselves to non-ill mothers, reporting that “Being pregnant without diabetes was nothing. Friends complaining about their simple pregnancy problems just don't understand what problems are” (Berg, 2005, p. 27). Berg (2005) stated that pregnancy in and of itself confirmed a feeling of normality, of being just like any other woman, however, the illness and checks and worry fortified a malaise and distanced women with diabetes from their healthy counterparts. Hence, once again in the literature and in my study, women used an upward comparison when relating to mothers without an illness. The transition to motherhood nonetheless was a normalising event, leading them to feel just like anyone else.

As for the self-comparison, it waxed and waned throughout their adaptation to a diagnosis of IBD and then to their transition to motherhood. Charmaz (1995) explained how

individuals adapt to chronic illness through three stages. Charmaz mentioned as a first stage the importance of experiencing the altered body and giving a definition to the illness. The second stage comprised an active assessment and comparison of one's current state of illness to one's former healthy physical state. The third stage involved "struggling with rather than struggling against [the] illness" (Charmaz, 1995, p.658). The second stage is particularly relevant to my study as mothers who suddenly become ill start to measure their new limits and assess which activities they can and cannot accomplish within their new bounded self. This self-comparison towards a previous state is, according to Charmaz (1995), a crucial step towards forming the distinction between the self and the body and enables one to cope by seeing the body as separate. Individuals attempt to be "normal" or go back to their normal self by exerting control over their body. This was depicted amongst the group of mums with IBD that I interviewed. Struggling against the illness and seeing it as the "enemy" was not conducive to the integration and acceptance of the illness. I argue, like Charmaz (1995), that the back and forth comparison is a way of coping but also a way of seeing oneself as more than an ill body. In order to cope with their illness mothers with IBD had to learn to struggle *with* the illness rather than against it.

An important point worth stressing is that these comparisons were not constrained by illness duration, severity, or type of surgery received. This means that a participant who had no surgeries, or very minor ones, could make use of upward comparison to cope with the changes in her illness and navigate the transition to motherhood with IBD; while a person with a complete bowel removal could make use of downward and horizontal comparison to cope with her life changes. Hence, I make the argument that these various comparisons along the health continuum are part and parcel of managing chronic illness alongside transition to motherhood. These mirrored experiences in relation to others helped participants cope with changes because they establish benchmarks, whether upwards, downwards or horizontal to deal with difficult times and to remain hopeful that good times will be experienced again.

In the third theme *Two-Sided Mirror* of this chapter, I observed how participants related to the camera lens in several ways. First, the interview and the camera became a *confiding platform*. Participants revealed their moments of weakness, doubts, shame and embarrassments. The camera became a confidante to whom participants admitted their lows but also their highs as if they were addressing a compassionate friend to recount how proud they were of their children, or praising those who had done right by them. However, this sharing was not perceived as a one-way street. In fact, it seemed at times that the participants were looking apologetically away from the camera while breaking into tears. They also, appeared to sense the camera as an intrusion when they were about to disclose leaking blood or often passing stools (Elmir, Schmied, Jackson, & Wilkes, 2011; Walls, Parahoo, Fleming, & McCaughan, 2010). In a study by Witty et al. (2014) titled *Engaging men with penile cancer in qualitative research*, the vast majority of participants agreed to share on video sensitive and intimate details of their experience of penile cancer. Similarly, in my study, I found that the majority of women, 19 out

of 22 women I interviewed, allowed me to video-record the interview and agreed to share passages of an intimate and sensitive nature regarding their experience of IBD on YouTube (See Chapter 8). I believe that, despite the risk of shame and embarrassment, through the camera participants were bravely transmitting information and wisdom acquired through their experience to others; particularly bits of information they wished someone had given them back when they were going through pregnancy. Through the lens of the camera they were able to warn others about potential difficulties, but also share and diffuse messages regarding IBD and motherhood.

Second, the subtheme *wallow window* is one that depicts how the camera can become a platform to air one's complaints. These complaints were mainly addressed to poor medical care or low level of awareness amongst medical staff regarding IBD. However, sometimes participants complained about others who have offended them.

Lastly, the camera provides a platform for a *staged performance*. Participants use this medium to send a message to their audience, for example giving them advice on how to deal with IBD and motherhood. In one instance IBDuMum04C01 said "I would like to say to all mums out there", sending a direct message to her listeners but did not look at the camera. I believe these advice-messages were invited by the last set of questions of the interview schedule which open the floor to giving recommendations or tips to mums-to-be. Nevertheless, I also believe that the presence of the camera, as well as the consent to release clips of the interview on YouTube, created this *staged performance* throughout the interview. This is further supported by those instances where participants addressed topics that had little relevance to their lived experience, such as complications such as postnatal depression or the placement of an external pouch when they had not experienced it themselves.

It seems from my interviews that the camera represented several different audiences. At times, it was an emblem of British citizens, their colleagues, employer, medical staff they dealt with, or ones from which they would like to receive answers. The camera also represented mothers in the general public, some with IBD and some without. It also was sometimes a person who had helped them: their husband, close circle friends, and family. This polymorphic embodiment is specific and only evident through video-camera and would have been missed had we only audio-recorded. Drawing upon Pauwels (2015) findings, some similarities between video-recording and participatory visual methods (i.e., photo-elicitation) can be noted. For example, the research is rendered more accessible and easily diffusible via media channels when using visual methods. Also, the use of visual methods allows redistributing the power through self-presentation and self-disclosure of information. Participants take an active role in directing and the scene. That said, one cannot ignore the influence of the interviewer in pacing and directing the scene.

7.4.1 Conclusion

Mothers with IBD may have an opportunity to navigate their illness by making use of their transition to motherhood as a shield from IBD. Mums with IBD were protected by their new role and bodily changes (pregnancy) from the symptoms of IBD and attempted, in return whenever feasible, to shield their children from experiencing anxiety around their mother's illness. Furthermore, to make sense of their illness and cope with the challenges of accepting the physical manifestation, participants compared themselves, at times, to how they were before the illness or to others who shared their experience of becoming a mother/having IBD, or both. These results are substantiated by the literature on chronic illness which shows that women with a chronic illness, perhaps paradoxically, often cope slightly better with their condition when they become mothers, due to the motivation to remain well for their children. Furthermore, the literature also supports the finding that people who compared themselves to others who are worse off, tend to feel better about their current health struggles. The last part of the chapter addressed how the use of visual method, video-recording, provided another means of coping with the illness. Making use of their participation in the research, mums with IBD were able to share their concerns, useful tips, and to a certain extent feel empowered by the visual method and the ability to convey information to "concerned others".

The next and final chapter of this thesis will summarize briefly the findings and conclusion of each chapter. Chapter 8 will also provide further details about the strengths and the limitations of the study as well as conclude with the production of YouTube medleys used to disseminate the results and provide impact via social media.

Chapter 8

Discussion

Discussion sections were provided for each analysis chapter. This final chapter will now offer a general discussion of the whole work presented in the thesis. First, I will summarize briefly the main findings of each analysis chapter. Second, this then offers a platform from which to stand back and assess what are the key findings from across the analyses conducted in this research and relate the theoretical and practical application of the findings. Third, I will consider the strengths and limitations of the research conducted. Fourth, I will review the impact generated by the creation and dissemination of the YouTube medleys in which I presented some of the main points of my research for a general audience. Finally, I will end by discussing the future research which could build on that presented here and articulate a succinct conclusion and implications of my work.

8.1 Summary of the Analyses

The aim of this research was to investigate the lived experience of mothers with IBD to inform women, their partners, and healthcare providers about the experience of planning and starting a family, and coping with young children within the context of maternal IBD. The three analysis chapters each posited a central concept: *Blurred Lines*, *Transitional Challenges*, and *Reflecting on Others*.

Chapter 5 tackled the first concept and emphasized some of the parallel experiences of receiving and coping with a diagnosis of IBD and transitioning into motherhood. Specifically, *Blurred Lines* were noted along three main themes: *Need for Readiness*, *Lifestyle Changes*, and *Monitoring Personal and Physical Development*.

Chapter 6 explored the second concept - *Transitional Challenges* - and proposed a timeline which captured and detailed a series of emotional states and decisions that mothers with IBD had to navigate in their transition to motherhood. These tasks are reflected by the four themes of this concept: *Burden of Knowledge*, *Weighing Decision-Making*, *Blame and Guilt*, and *Ambivalence towards Healthcare Professionals*. These themes, with their respective subthemes, are organised within five chronological phases of transition to motherhood: *Nulliparous Life*, *Planning for Pregnancy*, *Conception and Gestation*, *Labour and Breastfeeding*, and the *Early Years of Motherhood with IBD*. The timeline suggests that there are challenges from the moment women are diagnosed with IBD to the early years of motherhood and, most likely, beyond.

The final chapter of analysis – Chapter 7 - presented the third concept *Reflecting on Others*. This examines how mothers attempt to reconcile the experiences, challenges and demands of IBD and having children. The three themes elaborated are *Shielding Child*,

Comparative Normality, and *Two-Sided Mirror*. With regards to the first, the different ways children shield their mothers from the illness were noted as well as the attempts by the participants to protect their offspring from the repercussions of having a mother with IBD. Second, the mothers managed the burden of their illness through making upwards and/or downwards comparison to various groups of people and individuals –particularly other mothers - with or without IBD or other illnesses. Lastly, the theme *Two-Sided Mirror* highlighted how mothers made use of the camera during interview to confide to others their highs and lows as well as to convey their blaming of, and misadventures with, healthcare professionals. In fact, participants appeared to use the camera in interesting ways as a *staged performance* for others to better understand their illness and to gaze into their lived experience.

8.2 Key Findings Across this Research

Among the many results elaborated across this research, the following findings are particularly pertinent and cut across at least two of the three chapters of analysis. These key findings suggest novel ways to look at the experience of motherhood and IBD as a whole, taking into consideration the impact of experiences in the nulliparous life, relationships with medical professionals, friends and family, as well as coping processes described by these mums with IBD. In particular, although it might seem tangential to the central topic of research, it is important to understand the experience of nulliparous life of the women who took part because these appeared to shape how they tackled transition to motherhood with IBD. I gathered substantial information on the experience of IBD prior to pregnancy and then as a mother given that 15 of the 22 women in my sample received their diagnosis of IBD prior to their first successful conception. Understanding transition to motherhood with IBD in the context of longstanding prior illness is increasingly relevant given that, in developed countries already associated with growing prevalence of IBD (Molodecky et al., 2012), there is a trend for women to have their first child later in life (ISD, 2015; ONS, 2016).

The five key findings I identify from across this research are:

1. Prior to the transition of motherhood, and whilst receiving a diagnosis of IBD, there were difficulties establishing a relationship of trust between participants and healthcare providers. Knowledge about IBD, its chronicity, aetiology and potential treatment greatly impacted the formed understanding, management and acceptance of the illness. Some assumptions about interferences of IBD in forming new romantic relationship were present and needs to be addressed to facilitate later reproductive choices.
2. Dealing with, and experiencing IBD flares, as well as managing the lifestyle changes, helps to prepare women for their transition to motherhood. Nevertheless, participants often feared that pregnancy could worsen the symptoms IBD and that motherhood would always be more difficult than normal in the context of maternal IBD.

3. There is a severe misconception fuelled by societal “health messages” that taking IBD drugs during gestation and breastfeeding are detrimental to foetal development. Mothers had to balance their desire to be like mums who do not have a chronic illness with doing what is best for them to remain well and to take care of their young ones.
4. During gestation, women who suffer from IBD experienced a diagnosis shadowing whereby their IBD symptoms were often thought to be pregnancy symptoms. The lines were blurred leaving them and healthcare professionals unsure of the correct course of action. This was particularly relevant to mums diagnosed with IBD for the first time whilst pregnant.
5. Embarking on a journey to motherhood with IBD is facilitated by having an extensive network of support. Participants sought online forums, family members, partners, friends and neighbours to help them manage and cope with the ups and downs of motherhood with IBD. Moreover, children are helpful in their own way and learn to adapt to their mother’s illness.
6. Having a chronic illness and becoming a mother alters one’s sense of identity. Participants experienced quite a few losses of freedom, friendships and intimacy all the while trying to be the best mother they could be. These, and new demands, require effort and acceptance of the limits imposed by the illness in terms of outings and activities shared with their young ones.

The first key finding is that when participants first found out they had IBD they reported a feeling of shock (Chapter 5) that was exacerbated by lack of knowledge about IBD (Chapter 6). Their lack of knowledge, and sometimes lack of maturity and readiness due to their young age, left them unprepared to handle and manage this serious, often life-changing, chronic condition (Chapter 5). Diagnosis was often complicated and involved frequent visits to the GP with little or no validation or explanation of their ailments. Moreover, once referred to a gastroenterologist, many experienced another round of trial and error to find the appropriate treatment (Chapter 6). No wonder many of the participants felt ambivalent towards medical professionals and had some trepidation about the quality of care they would receive during pregnancy (Chapter 6). Making sense of IBD, and grasping that the aetiology is unknown and that they are not to blame for its onset, seemed pivotal in coming to terms with the diagnosis and avoiding making too many demoralising comparisons between oneself and others who do not have IBD (Chapter 7). IBD is an ‘embarrassing illness’ and participants mentioned the difficulty of disclosing their symptoms to a potential or new romantic partner (Chapter 6). Their partner’s understanding was central to establishing and maintaining an intimate relationship and, as a mother with IBD, the understanding or misunderstanding of the general public – for example when using a disabled toilet – could have a huge impact on everyday practicalities and, just as importantly, on the sense of personal dignity.

The second key finding pertains to the assumptions of interference of IBD with successful conception and pregnancy (Chapter 6). Many participants were shocked that they got pregnant so swiftly and that pregnancy was relatively uneventful (Chapter 5). Their biggest concern was of having a flare while pregnant and being in a flare at the time of birth. Fortunately, this was rarely the case for the women who took part and some even found respite from their illness during pregnancy and, for this reason, planned a second shortly after the first. This finding was echoed in Chapter 7 when discussing the many ways in which children could shield their mother from negative implications of IBD. Some women “bloomed” during pregnancy and felt well enough to eat anything they wished (Chapter 7). Existing research does suggest that most women with IBD feel the same or improve in their illness whilst pregnant (Beaulieu & Kane, 2011) and the current research contributes evidence optimistic about transition to motherhood with IBD, hence enhancing the reproductive choices of this population. In fact, in some ways, having IBD prepared mothers for life with a newborn. For example, dealing with the unpredictability of flares in IBD is good training for the ever-changing schedule of a new baby and attention to diet and making health lifestyle choices in order to deal with chronic illness are great skills to improve the odds of getting pregnant and sustaining a healthy gestation.

The third key finding relates to the assumed effect of taking IBD drugs during pregnancy and breastfeeding (Chapter 6). Societal messages seemed to promote a mother earth image suggesting that motherhood should be ‘natural’ and ‘unmediated’ and the mums with IBD were too often reticent to take medication while pregnant. However, the research does suggest that most IBD drugs are safe for gestation and that it would cause more harm to the baby to have a flare than to remain well on the medication (Van der Woude et al., 2015) but the lived experience is still haunted with concerns. At times of flare, if they did occur during the early years of motherhood, participants underlined the burden and challenge of feeling dependent and the importance to communicate the need for help (Chapters 5 and 6). Productive strategies included avoiding comparing oneself to an ideal of what a mother should be and, rather, comparing oneself to other mothers with IBD and feeling grateful that one has a child when others suffer from infertility (Chapter 7).

Similarly, with regards to breastfeeding the latent blame and messages imposed by societal messages and medical staff regarding the benefits of breastmilk weighed heavy on the decision-making process of some women (Chapter 6). The lack of information regarding the safety of certain IBD drugs and feeding rendered this decision heavy on most mothers. The conundrum lies between taking the medication to remain well and prevent future flares, and on the other hand depriving one’s child from breast milk or taking the risk to breastfeed him despite the lack of clear guidance on the matter. Mothers felt strongly about shielding child(ren) from the moment of conception to the early years from any negative impact of IBD such as separation due to hospitalisation or witnessing pain. Interestingly, having a child did buffer

some of the negative impacts of the illness, such as having a sense of purpose, reconciling with one's body and being able skip the queue to the loo for the baby (Chapter 7).

The fourth finding pertains to women who's IBD began during gestation and who unfortunately victims of "diagnosis shadowing"; where their IBD symptoms tend to be disregarded for normal pregnancy symptoms (Chapter 6). Moreover, even for women with earlier onset of IBD (prior to gestation) they tended to feel the double-burden of dealing with IBD symptoms of fatigue, libido loss, diarrhoea and sleeplessness on top of dealing with similar effects due to their pregnancy and/or caring for a young child (Chapter 5). Hence their lived experience is one of many challenges to distinguish between what is IBD and what is pregnancy, but also to convince the medical team overseeing her pregnancy of the validity of their concerns. Hence, compared to other mothers who did not suffer from IBD, they felt it was at times much harder to cope with a chronic condition and children (Chapter 7). Nevertheless, some noted that also compared to others who do not have the illness they were lucky to have the ability to conceive (Chapter 7) and that they had – for some – better pregnancies than women who weren't suffering from IBD. Hence, downward comparison to others who were less fortunate in their health of fertility made mothers take a different perspective on their challenges compared to upward comparison to an ideal of motherhood or health.

The fifth key finding tackles the need for, and benefit of, seeking support. Participants mentioned tailoring support from various sources because they found no one adequate source of information pertaining to IBD, or IBD and motherhood. They got in touch with their friends, charities, IBD nurses, and sometimes had an 'open-line' with their gastroenterologist to keep an eye on, and when necessary regulate, their medication. The good news was that, with the diagnosis of a chronic illness and the changes brought about by motherhood, the participants extended their circle and formed new ties. They attended forums and events about IBD and met new people with similar experiences, as well as signing up to mums groups to get support (Chapter 5). The children, themselves, could also be very supportive as they matured, for example being a little quieter when mum felt unwell and could help by watching their younger sibling (Chapter 7). However, some medical professionals were unsupportive of some of the women who took part in the study becoming pregnant (Chapter 6). Each woman with IBD is unique and realistic medical advice is essential. However, all the women in this study managed their transition to motherhood courageously and successfully; and this research provides evidence supporting this group of women's right to reproductive choice.

The sixth finding, identity change in the context of motherhood with IBD (Chapter 5), including how one is perceived by others, appears sporadically across all the three chapters of analysis. This included loss of friendships, freedom, intimacy and compromised body image during pregnancy and the first years with a young child. Interestingly, similar losses can be experienced when IBD is active. Being a parent brings new responsibilities and associated lifestyle changes, such as spending less time as a couple but more time as a family. And being a

parent with IBD means deciding how to talk about the illness to your child, while protecting them from developing anxiety about the condition (Chapter 7). Mothers adopted an “upon-need-to-know” strategy and used simple terms tailored to the age of the child (Chapter 6). Another important decision regarded the types of activities one could engage in with one’s children that can accommodate the symptoms of IBD (Chapter 6). Participants reported wanting to be “outdoorsy mums” and wanting to do fun activities and playtime with their children but had to limit their outings in and around the bathroom availability and illness activity.

8.3 Theoretical and Practical Application of the Findings

8.3.1 Altered self-concept

The findings of my thesis contribute to the available health theories on chronic illness and deepen understanding of the lived experience of motherhood with IBD. I had noted in Chapter 7: *Reflecting on Others* how the theme *Comparative Normality* and its three subsequent subthemes *people and me*, *mothers and me*, and *myself and me*, supported the claims of the Social Comparison Theory (Festinger, 1954). Participants who compared their experiences of IBD to that of others who were not suffering from a chronic illness felt intensely about their debilitating condition. Furthermore, when comparing their experience of being a mother vertically to an ideal mother – one who would for example be cooking her child’s meals from scratch and always be out and about with her child – they would often feel worse about themselves. Similarly, participants in my study reported feeling low when thinking about their former non-ill selves or times when the illness was less active.

These comparisons bring forward the altered sense of self-concept (“a personal set of beliefs about one’s personal qualities and attributes”, Taylor, 2018, p.222). Taylor (2018) related personal issues in chronic health disorders and emphasized that changes in self-concept are part of the experience of chronic health conditions (not specific to IBD). Taylor defines the self-concept as an evaluation of one’s achievement, social functioning, physical self (i.e., body-image, perceived health), and private self; all of which can be negatively impacted by a chronic illness such as IBD. The findings of Chapter 5 (*Blurred Lines*) highlighted the joint impact of motherhood and IBD on the altered sense of self. Particularly, in the subthemes financial and career implications and relationship and network changes of the theme *Lifestyle Changes*. Alterations and/or complete interruption of one’s work schedule due to IBD and motherhood were emphasized by participants and was underlined as burden by those who valued their work as an intrinsic component of their sense of self and achievement. Similarly, the subtheme *relationship and network changes* showed how social circles dramatically shifted as IBD and motherhood rendered participants more secluded and only oriented towards others who shared similar lifestyles.

Regarding the physical self, participants' views of their body were altered after experiencing a pregnancy and or IBD. This was particularly salient in the third theme of Chapter 5: *Monitoring Personal and Physical Development*. Participants experienced *weight changes* due to steroids and flares, as well as an inability to leave the house due to chronic diarrhoea. These experiences left them with a low body-image and poor sense of physical self. Taylor (2018) underlines the common experience of having IBD and across other chronic illnesses where having poor body-image could increase the risk of depression. However, this risk could be mitigated through exercise interventions. Moreover, self-rated health is also an aspect of the physical self that is altered whilst experiencing a chronic illness. According to the Health Belief Model (Rosenstock, 1974) a person's perceived vulnerability to a health threat, and perception of the severity of the threat or illness directly impacts one's response and health behaviour. Hence, self-rated health, or the perception of one's illness and vulnerability is a predictor of self-management. The direct implication of the Health Belief Model and self-concept alteration would be that to empower women with IBD and other chronic illness they could self-manage their symptoms and accurately assess their current state of illness or wellbeing. Unfortunately, as pointed out in the theme *Comparative Normality* (Chapter 7), participants waxed and waned in their perception of their health notably due to the nature of their chronic illness. Healthcare providers could promote the necessary coping strategies to support a more accurate self-representation of the illness and engage patients in self-management of their condition.

8.3.2 Avoidant, approach and attention-focussed coping styles

The literature mentions several coping styles and strategies in dealing with stressors, notably with the news and trajectory of a chronic illness. Coping is defined as the cognitive appraisals and actions taken in reaction to a stressor (Taylor & Stanton, 2007). The distinction between avoidant-oriented and approach-oriented coping styles is often denoted in face of adversity and the findings systematically underline how adopting avoidant-oriented coping style increases mortality rate and illness progression compared to adopting an approach-oriented strategy (Taylor & Stanton, 2007). Frank and Roesch's (2006) meta-analysis of individuals living with cancer showed that appraisal of cancer as highly threatening oriented individuals to adopt a problem-focussed and approach-oriented strategy. On the other hand, those individuals who perceived cancer to be the root of harm or loss (appraising cancer as the source of causing harm and loss already experienced by the patient) tended to adopt and engage in avoidance and minimizing coping strategies. Ultimately, having a more active coping style was conducive of better outcomes and perceived benefits post-cancer diagnosis. Similarly, in the theme *Weighing Decision-Making* elaborated in Chapter 6 (*Transitional Challenges*), the subtheme *acknowledging IBD* depicted some of the participants' dismissive attitude towards IBD and avoidance to follow upon medical advice which ultimately led to the worsening of their symptoms. These individuals soon after engaged in a more active approach-oriented attitude and

battled through the symptoms undertaking the necessary treatment to restore health. Moreover, in Chapter 5 (*Blurred Lines*), participants mentioned coping with the demands of a young child and cyclical flares of IBD by “just doing” the necessary steps day by day. Hence in the subtheme *adapting to uncertainty* participants who adopted an action-based coping style and active problem-focussed approach managed their worries and stressors better and even encouraged others women with IBD to do the same when undergoing their journey to motherhood. When it comes to long-term persistent stressors the literature consistently shows that an approach-oriented approach is more beneficial in dealing with the stress compared to an avoidant-oriented approach.

One coping strategy not mentioned in Taylor and Stanton’s (2007) review was attention-focussed process. According to Pennebaker (1982) and Schmidt and Trakowski (1999) individuals with a heightened sense of body-vigilance who focus on their visceral perceptions and physiological processes such as eating and drinking tend to do worse in terms of psychological adjustment. These findings echoed with the double burden underlined in *Blurred Lines* (Chapter 5) particularly in the close scrutiny subtheme. Participants monitored closely their pregnancy as well as their IBD symptoms. The excessive focus on the visceral abdominal area was a source of constant worry.

The application and practical derivative of these various coping strategies among individuals who have IBD or other chronic illness would be to encourage a more active-oriented approach and reduce the emphasis and bodily focus on the abdominal area. These guidelines could be incorporated in the standards of care and communicated via IBD nurses and other healthcare practitioners.

8.3.3 The Common-Sense Model: Illness representation as a dynamic process

In my opinion one theoretical framework that best captures the findings of the thesis is Leventhal’s Common-Sense Model (CSM) also sometimes referred to as the Illness Representations Model (Hale, Treharne, & Kitas, 2007). The CSM has been extensively used to provide insight into patients’ awareness, navigation and response to illness (Leventhal, Philips, & Burns, 2016).

Leventhal’s model has the added value to incorporate parallel cognitive representation of the illness. Hence, as one is faced with the news/sensation or perception of a health threat, he or she will develop a representation of the illness, a set of beliefs that match the person’s existing preconception of that illness allowing to form a coherent understanding of the experience. The five main components of the illness representation are: identity, cause, timeline, consequences and controllability (Diefenbach & Leventhal, 1996). The identity is the name of the illness, but could also be the label participants attributed to their initial symptoms (if one feels a lump on their body, one might think they have a tumour). The cause is the idea formed

around the various instigator of the illness. The cause does not have to be medically accurate and can be a representation of media portrayal of an illness, or opinions gathered from relatives and friends. The timeline is the belief of the chronicity of the illness, here again the accuracy is relative to the individual exposure to medical source (one could believe a sore throat to be acute and discover at another time that it is an underpinning for a chronic illness). The consequences gather the sets of beliefs about the anticipated impact of the illness both physically and psychological. Lastly, the controllability pertains to the belief that the cure is available and under one's control and reach.

The CSM has the advantage of being dynamic and multi-levelled which fits my data well. In Chapter 6 *Transitional Challenges* I presented a timeline of progression from nulliparous life to the early years of motherhood with IBD. In this timeline the themes intertwine and the subthemes evolve from one stage to another pointing to the cognitive and behavioural oscillation of dealing with a chronic illness and becoming a mother. The CSM reflects through its framework the changing processes of coping with an illness which is also depicted in my timeline. To begin with, when forming the identity of the illness it takes into consideration the dynamic process from the moment of depiction of the symptoms and its original comparison to pre-set prototypes of illness and the later relabelling post diagnosis. In the nulliparous stage of Chapter 6, I can illustrate the direct applicability and relevance to the CSM with respect to the three themes *Burden of Knowledge, Blame and Guilt* and *Weighing Decision-Making*. Participants who first experience symptoms of IBD (bloody stools, pain in their stomach and diarrhoea) form an identity and various set of beliefs (identity). Some believed they have cancer others thought it was gastroenteritis (see subtheme making sense of IBD). They further develop reasons (cause) coherent to their formed identity to explain the health threat (see subtheme justifying IBD) some say they had not been eating properly and others blame a trip abroad and viral/bacterial infection. In terms of outcome and durability (consequence and timeline), the subthemes: overwhelming lack of information and acknowledging IBD, depict the predicted outcome of trying treatment, the anticipated fears of taking steroids and sometimes lack of awareness that IBD is a chronic condition. Some assumed that it was a one-time occurrence and were shocked to see the illness return. The timeline directly impacted the treatment and self-efficacy (controllability) of participants to improve their health. Various treatments and remedies were attempted (subtheme trial and error) and each participant finds a way to, and restoring health.

Hence the dynamic and multi-levelled aspect renders CSM more pertinently linked and informed by my findings. The Health Belief Model, Taylor's description of the various facets of altered self-concept and other coping styles are indeed relevant however they are more static in their description and do not permit us to see the variability in cognitive processes and coping styles that are relevant to individuals who have a chronic illness.

IBD and motherhood follows the typical conceptual pathway that other chronic illness face. In a study by Ockleford, Shaw, Willars and Dixon-Woods (2008), 36 adult patients with Type II diabetes were randomized in a trial comparing the educational effect of enhancing patient's knowledge about their illness to improve their self-management skills. A total of 19 patients received educational sessions based on the CSM of self-regulation, and 17 received usual care. The techniques used in the education sessions was drawn from the theoretical CSM empowering patients to take ownership of their illness its management. The results gathered from semi-structured interviews showed various coping styles in forming an identity around type II diabetes. Some participants were "accepters", others "resisters". They either full endorsed their diagnosis and its implication or rejected both identity and consequences. Some participants also showed more acceptance around the identity of their illness but resisted the consequences and vice-versa. The use of the CSM model to form an understanding of the illness representation has a direct implication to identify areas that need to be addressed and improved on to promote independent self-management care. Also, the participants in the study mentioned preferring peer-led educational sessions targeting the components of their illness representation compared to more traditional doctor-patient top-down information transmission.

Pregnancy could potentially constitute a good teachable moment to promote positive behavioural changes in the lives of women (Atkinson, Shaw, & French, 2016). However, Atkinson et al. (2016) believed that for most women who do not experience any difficulties conceiving the changes are perceived to be more automatic. However, two women in their study who experienced fertility issues were changing their diets and lifestyle out of fear of impact on the course of the pregnancy. One can extrapolate to the findings of the thesis regarding the assumption IBD interference with pregnancy subtheme. Some participants who had a diagnosis of IBD had already made changes to their diets, targeting illness representations and changing sets of beliefs prior to pregnancy could be constructive as it is likely that the changes made during pregnancy will be related to the fear of miscarriage rather than a profound alteration in health behaviours.

8.4 Strengths and Limitations

This study has several strengths and limitations. I will use Elliott, Fischer, and Rennie (1999) evolving guidelines for publication of qualitative research studies in psychology to detail the fortes and shortfalls of my study. In their published paper, Elliott et al. (1999) mention 14 criteria, of which seven are pertinent to both qualitative and quantitative approaches and seven unique to qualitative research. I will start by considering those unique to qualitative research and then discuss the study in relation to the broader criteria.

Owning one's perspective. I have repeatedly posited my critical realist stance in the chapters of the thesis, particularly at the beginning of every analysis chapter. I have also laid out

my personal characteristics that I thought to be relevant and informative to the reader in understanding my unique perspective in this analysis. Moreover, dispersed throughout the analysis and their respective discussions I have made attempts to share my reflections and reflexive thoughts, notably when mentioning the unusual absence of financial consideration when talking about raising a family (Chapter 5).

Situating the sample. The sample of participants was composed of 11 women with Crohn's Disease (CD), 10 women with Ulcerative Colitis (UC) and 1 with Undetermined IBD. The women were sought from various ethnic background includes ethnic minorities such as Asian, Jewish, Guyanese, French, American British citizens. The participants were from various geographical locations and socio-economic status (SES) (ranging from less than 15,000 GBP to above 45,000 GBP annual income). All participants had undergone the transition to motherhood, most of them had one child, four were pregnant with their second at the time of the interview, and a smaller number had two children (including one mum who had twins). I am confident that the number of interviews conducted was sufficient to attain data saturation upon which it is likely that further data would add little to the results. I was able to demonstrate excellent contribution across the sample to each theme of the analysis via the use of the contribution tables detailed in the appendices. I have also been careful to describe where individuals had experience or opinions which were different or unique. It is however important to mention that throughout the analysis, it seemed that more often than not the findings encompassed the sample in its entirety. I had a sample of 22 women and not decoupled subsample contributing different elements and different parts of the analysis.

A drawback of data collection though, was that although I tried to recruit participants who could inform the study about diverse experiences of transition to motherhood with IBD, it is possible that I under-recruited women with very severe illness because they did not feel well enough to volunteer. I would have also liked to interview more single mothers but, despite the specific call, it was difficult to recruit this demographic. Similarly, I would have liked to have included women with more than two children and, although I did interview one with three children, heartbreakingly audio-recording failed (Chapter 4). Moreover, my sample was relatively well-educated, affluent, and White British and so may underrepresent the challenges faced by less apparently economically-privileged women. Finally, I considered it unethical to pursue women who stopped responding to my follow-ups so have no information on why individuals dropped-out after expressing initial interest.

Grounding in examples. The analysis chapters are parsed and filled with quotes from participants. Every subtheme is illustrated with a relevant quote to further support the analysis. I had noticed in analysing the transcripts that the coding was becoming redundant around the 18th interview (participant: UCMum17C01). Nonetheless, I kept the iterative process of coding for the rest of the participants and made every attempt to by systematic and carefully look at all the transcripts. However, I cannot completely say that I was able to avoid the bias to be inclined to

select quotes from participants who expressed themselves verbosely or were able to very clearly explain their thoughts and experiences. For that reason, I kept an excel sheet to record the number of times each participant was quoted in the analysis and tried as much as possible to balance it evenly across the sample.

Coherence. The chapters were presented in their chronological form, meaning that I presented the first concept I found *Blurred Lines* in my analysis first and moved on to the *Transitional Challenges*, then *Reflecting on Others*. The chapters have detailed tables and sometimes figures illustrating the structure of the analysis and were corroborated by the larger extant literature while adding a unique perspective. However, one cannot guarantee that it is the best possible presentation of the findings, even though I have had multiple supervision sessions with my supervisors to ensure the most coherent flow of presentation. In addition, coherence is also demonstrated through my ability to articulate and integrate key findings across the three chapters of analysis in the section above (Chapter 8) and found support across my results in the wider research literature while adding a unique perspective, rich details, and novel findings.

Providing credibility checks. One major possible limitation to this study is the absence of credibility checks as intended by Elliott et al. (1999). I did not have an informant check, nor compared multiple analytical approaches; and although my supervisors provided thorough guidance I have never shared any transcripts with them and co-analysed the results. That said, the data does seem to triangulate with the existing (but limited) literature on IBD and motherhood and more importantly it does echo with the literature on chronic illness as detailed in the previous discussions. As an example, looking at the SRR (Chapter 3) and the three chapters of analysis, I find that some of the subthemes were the same notably the maturity of children, the burden to maintain the role of being a mother and wanting to shield one's child. However, although Elliott et al. (1999) distinguishes between credibility checks and resonating with readers, I believe them to be related and that the audience does provide a source of rigorous check. These will be detailed in the next point.

Resonating with readers. Linked to providing credibility checks, in a more general way than might have been expected by Elliott et al., one strength of my study is its positive impact on, and the receptivity of, my audience at forums and conferences at which I shared the results. Quite a few individuals - both men and women - have approached me at the end of my presentations to express how relevant it was to them and how they felt it captured their lived experience or that of their family/partner. This appears confirmed by the pleasing number of views and shares of the YouTube Medleys created from this research (see next section for details). As described later, I wanted to convey the findings of my work in lay term and hence created short videos from the interviews for sharing with the general public. The number of views which is no less than 1K combined since the few months of its release date demonstrate excellent engagement with this resource.

Accomplishing general vs. specific research tasks. Most of the analysis chapters discussed concepts and themes that applied across the entire data set. These are ‘rich descriptions’ in Braun and Clarke’s terms or accomplished ‘general tasks’ in Elliott et al.’s (1999) terms. One of the chapters (Chapter 6) on the other hand, provides a more detailed ‘task specific’ account of the transition to motherhood. Hence one could say that the analyses cover the entire data corpus while taking into consideration uniqueness and specific research tasks. There was however a good amount of homogeneity in the sample.

Explicit scientific context and purpose. The aims and objectives of the research were to gather information on the lived experience of mothers with IBD to inform and enrich knowledge the knowledge of other mums with IBD, mums to be, friends, families, partners, as well as healthcare providers around the topic. The specified context adopted was a retrospective view on the journey of 22 mothers who informed through interviews on the challenges and demands of going through pregnancy and motherhood with IBD. Being able to specify this in detail, demonstrates that much thought was given to this prior to commencing the research and the key finding, as specified earlier in this chapter outlines how my stated purposes were met.

Appropriate methods and specification. I deemed it appropriate to conduct semi-structured interviews allowing participants to say as little or as much as they want about their lived experience. The various strategies of data collection were explicitly detailed and justified in their use. Moreover, the use of Thematic Analysis (Braun & Clarke, 2006) was detailed at length in the method section and at the beginning of each analysis chapter. As mentioned in the Method section, analysing exploratory data could have been done using either IPA instead of TA. However, I wanted to look at a relatively large sample, with little available research on the topic, did not anticipate that I would have a relatively homogeneous experience across the data set, and wanted flexibility to focus on issues in the data beyond the strictly experiential if this seemed important and relevant.

Respect for participants. Respect for participants was a central ethos of this work and is demonstrated in many features of the research. Aside from securing IRB approval, I have made iterative efforts to inform the participants about all the aspects of the study. Numerous sheets containing information about the study, guidelines to video recording as well as signing an informed consent insured safeguarding the rights of the participants. I anonymized the data while using the transcripts at conferences or in my thesis and publication, and have made every attempt to diversify the views and share the common and unique aspect of each participant. Furthermore, regarding the use of video clips (detailed in the next section) participants were consented twice and shown the exact passage that were to be used in the clips. Most consented a second time and some declined, which means that respect for participants right to privacy and confidentiality of records was achieved. As for the choice of interview, semi-structured: it was deemed that interviewing participants with a somewhat open-ended format gave them the freedom to choose what to say and how much to say. As for the location of the interview, if the

participant's home was their preferred choice, I respected that decision and adapted around their schedule to be considerate and amenable to their family life with young one(s). Interviewing at home also meant that participants were close to their own bathroom and did not have to worry about travelling and the possibility of having accidents and having to make additional arrangements to look after their children.

Appropriate discussion and clarity of presentation. Throughout the analysis chapters discussions were elaborated detailing links between the findings and the relevant literature. Furthermore, a final discussion was also drafted to capture the main findings of the thesis. There are however many topics and issues that were not addressed throughout this study, I will elaborate on them in the last section of this chapter. Moreover, *Blurred Lines* and the SRR literature have been published in *Qualitative Health Research*; these two chapters have gone through peer and editorial reviews and their publication provides evidence that at least these two chapters have been considered to meet the highest standards of quality by relevant research peers. With the tremendous help and guidance of my supervisors, I was able to learn from the experience of submitting an article for publication which raised my awareness and proficiency in presenting academic work with coherence and clarity and thorough discussion. I have made explicit links to extant research and considered the strengths and limitations of my work as well as its practical implication thoroughly.

Contribution to knowledge. This thesis provides invaluable information to young women, and couples, starting a family - or struggling through its early phases - within the context of maternal IBD. The findings help health providers and support services understand the concerns and needs of women with IBD who are considering starting a family, who are pregnant, or who are struggling to cope with young children. The research has proposed a novel and more integrated timeline of care to look at the challenges faced by mothers with IBD as they navigate from planning to pregnancy to the early days of motherhood. Recognising the various challenges as well as the difficulty to tease out symptoms experienced during pregnancy and in conjunction due to IBD are at the heart of providing better support to mums with IBD. The implications and future research ensuing from my work are discussed in the last section of this chapter.

Many talks and conferences have been held and the findings have also been conveyed informally when individuals in the audience approached me after a presentation. I have had one publication issued from this study and I anticipate to publish at least two more articles relevant to Chapters 6 and 7. Moreover, the study resulted in the creation of YouTube Medleys which, as described below, resulted in spreading and impacting the general population.

8.5 Creation of YouTube Medleys and Research Impact

As mentioned earlier, some of the key findings of my study have been communicated via YouTube medleys in an appropriate language to reach the general public and, in particular, to spearhead easy to digest, eye-catching, and inspiring health information with links to reports and publications of the research for those who would like to get more information about the study and its findings.

I had initially planned to create the YouTube medleys within the first three years of my PhD and funding, however the third year was coming to an end and I was about to run out of my grant stipend and I still had a lot of writing to do for my thesis. My primary supervisor and I decided to apply for the ESRC Impact Acceleration Account Grant (IAA, 2017). The IAA was successfully granted in February 2017 and it provided me with the necessary funding and resource to create more YouTube recordings and receive feedback from the local CCUK charity Leeds Network and Districts. Furthermore, as part of this collaboration between the local charity and the University of Leeds, CCUK's head office offered to put at our service their marketing department to help with professional editing and dissemination of the videos. This project is separate to the PhD outcome but is of great added value to the impact of the study.

The medleys created as a result of the IAA grant were short clips gathered from the 14 different interviews out of the 18 in which participants had initially agreed to be video recorded and included on YouTube. I worked with Crohn's & Colitis UK Leeds and District Network to draft three transcripts for the medleys based on key findings and contacted the participants for a second round of approval for the selected footage of their interview. When the medleys were first designed, all 18 women were evenly included in the clips, however one declined final consent after seeing the selected transcript from their interview and three did not answer my call or email to invite them to review the selected clips. I obviously immediately abided by their request (or lack of response) and removed the relevant clips and included only the 14 mothers who agreed upon the second round of consent. I consider this to be a successful application of the consent process and a guarantee that I have done my best to respect the participants wishes to decline, dropout, and/or take part in the videos two to three years after the initial intake of the interview.

8.5.1 Clips content

Three medleys were created, each roughly 4 minutes long, informing viewers on the challenges, highs and lows of: 1) planning for a baby in the context of maternal IBD; 2) pregnancy with IBD; and 3) the early years of motherhood with IBD.

The first medley: Planning for a Baby (see Appendix OO: Video 1 Transcript), conveys the challenges faced by women with IBD when first preparing to get pregnant. The stories end well for all the mums interviewed because they all went on to have successful pregnancies, but the message in the medley is also realistic about the challenges of planning for a baby in the

context of maternal IBD. Hence, the medley touches on the anxiety experienced by some women with IBD about establishing a romantic relationship and the isolation some feel due to their IBD symptoms, treatment and hospitalizations. However, the medley also addresses women's chance of conceiving and dismantles fears voiced by some of the participants that IBD would lower their ability to conceive. The clip further demonstrates how, in line with medical recommendations, the mums in my study often started trying for a baby while their IBD was in remission. Although the specific impact of the clips is discussed below, it is worth mentioning that this particular medley received the most attention from the public and gathered alone 1000 views. It was also posted on Facebook which makes difficult to assess the total number of likes and shares due to its propagation and individuals' privacy restrictions.

The second medley: Pregnancy with IBD (see Appendix PP: Video 2 Transcript), conveys key aspects of the experience of being pregnant with IBD: the physical challenges and worries, but also successes and achievements. For example, the medley illustrates how mums feared their IBD medication might impact the foetus. However, the positive, and medically-validated message, is the likelihood that mums with IBD will be equally well or improve in their health whilst pregnant. The mums interviewed offer also a realistic message about avoiding overly high expectation with regards to the ideals of pregnancy and that mums with IBD should prioritise their own health needs in order to have the best chance of sustaining a full-term pregnancy. This clip totalled 735 views and was the second most liked clip amongst the three.

The third and last medley: Motherhood with IBD (see Appendix QQ: Video 3 Transcript), conveys how women with IBD cope with young children in the early years of motherhood. It addresses the challenges of working around a new-born's routine and needs whilst coping also with the symptom of IBD. Some mums offered practical advice based on their personal experience, such as sometimes having to breastfeed while on the toilet and knowing ahead of time which toilets in the shopping mall could fit a baby, pram, and bags all at once. The medley concludes by encouraging women to not give up on having a family, if that is what they want, because IBD should not be a barrier to motherhood and, in fact, that by coping with IBD women have developed many transferable skills for managing well with small children. This clip was viewed on YouTube 474 times and most likely shared through other social media platforms. All three clips have a few likes on YouTube, no dislikes, and no comments.

8.5.2 Clips creation

8.5.2.1 Format

I used The Research and Impact Handbook's (Reed, 2016) recommendation to make the material on the clips Personal, Unexpected, Visual, and Visceral (PUVV). The findings were by default personal and relevant to the audience as they depict real-life stories, tapping into people's emotions, challenges, and needs (Visceral). To fulfil the 'unexpected' criteria I used

catchy phrases to engage the public to see and share the video. I tailored the video to represent the advice shared by the participants interviewed and, hence, to convey some tips and recommendations to mothers and mums-to-be with IBD. The three videos use tags relevant to IBD to insure the wider public can find them. The background music "Where I am From" by Topher Mohr and Alex Elena was taken from the free to use, copyright free, YouTube audio Library. All three clips contain links to my Facebook page, Twitter Account and the researcher's Academia webpage.

8.5.2.2 Feedback and checks

The clips went through several rounds of feedback and the format of the script, the background music, as well as the speed of delivery of the message and wording were all assessed and reviewed by a panel member of Crohn's & Colitis UK and District Network. The content of the clips was initially discussed at a Crohn's & Colitis Leeds and District Network group meeting held in Headingley, Leeds in June 2017. Then, based on the suggestions of the group, I designed the medleys first through selecting appropriate extracts from the interview transcripts for review. After this, medleys were created and uploaded with restricted view to YouTube. I then engaged in several rounds of emails in which I gathered feedback on the draft Medleys from members of the Crohn's & Colitis Leeds and District Network who volunteered to take part. The reviewers consisted of a total of 13 people from the charity who volunteered to take part in the review process. Although not all who volunteered provided feedback (only 4 replied with comments), YouTube permitted to estimate that, most likely, all the volunteers - or the majority of them - have looked at the Medleys (YouTube counted 23 views for video 1, 11 for video 2 and 10 for video 3). Hence, I interpret 'no feedback' as implying satisfaction with the medleys. Aside from the non-academic volunteers, my two thesis supervisors engaged actively in the process of reviewing and refining the medleys and three specialised reviewers affiliated with Crohn's and Colitis UK also provided review (1 Gastroenterologist⁷, Crohn's and Colitis UK Communications Manager, and Crohn's and Colitis UK Director of Marketing, Communications and Membership). As a final stage of feedback, Professor Madill presented the medleys at the Crohn's & Colitis Leeds and District Network general meeting which was held in October 2018. There was a larger audience at that group meeting and its members concurred that they were happy with the changes made based on their recommendation (See Table 21 for detailed for examples of constructive feedback received per video).

⁷ Dr. Christian Selinger insured that no misleading medical information was unintentional conveyed

Table 21 *Reviewers Comments on YouTube Medleys*

	General comments	Clip 1: Planning for a baby	Clip 2: Pregnancy with IBD	Clip 3: Motherhood with IBD
Reviewer 1	I found the information screens very succinct and useful (a lot of useful information and positive messages) but didn't like the way the text expanded before it moved on	I don't know whether the lady did go on to become pregnant and if so if that could be mentioned or could she be put after the second mum or could the message board 'Mums did face challenges but overall it was a positive experience' come first? Or a fuller introduction?		
Reviewer 2	I have watched the links and was really impressed, I liked the idea of title rather than an interviewer and felt it was enough info (not too long), it was clear and precise. The music was gentle and not in your face and the interviewees were clear and I engaged with them and felt it was very informative. I loved it! Didn't see any incorrect spellings			
Reviewer 3			I'd add dots after "Most mums feared having a flare during pregnancy – especially when....."	"so we asked mums what they could advise other mums-to-be" - I'd lose the "So" and think it should read "We asked mums what they would (or they'd) advise mums-to-be"
Reviewer 4	I think the length of the videos is perfect for all. For the description of the YouTube "Maybe a brief overview	The music/noise in the background of the first video isn't great but I imagine this is something that you are working on :-)		

<p>Gastroenterologist (Medical fact check)</p>	<p>of what the women are discussing?" The videos are informative and the women in the videos are very likeable and I'm sure many women will be able to relate to them :-)</p>	<p>Looks fine. Ends on a high note. Is there a link to education material i.e. Crohn's and colitis UK website at the end? What about a message to seek advice from IBD doctor or nurse at the end? Nothing needs correcting from medical point of view</p>	<p>Overall very good. Avoid term 'external pouch' very confusing. Stoma and stoma bag are the correct terms. 80% better during pregnancy is not a figure I recognise. Maybe add text there to reduce expectations</p>	<p>Video 3: looks great</p>
<p>Thesis supervisor's comments</p>	<p>P.B: the text and background – consistency is key and variation will in itself create confusion)</p>	<p>A.M: 'Planning for a child with IBD' is rather ambiguous because it can also be read as planning to have a child who has IBD. What about 'Planning for a baby'?</p>		
<p>Crohn's and Colitis UK Communications Manager</p>	<p>CCUK's logo ought to be added to the credits at the end I feel they address some good points about pregnancy and motherhood and its always very engaging to hear from someone who has the condition. Thank you for sharing with us</p>			

Although the feedback was highly constructive, it was challenging to negotiate between each reviewer's preferred style of presentation, the feasibility and restrictions imposed by the timeline to submit the clips, and the standards required for communications supported by Crohn's and Colitis UK. Hence, the clips are not all inclusive of the key findings of the PhD but summarize the gist of them.

8.5.2.3 YouTube impact

The clips were first released on my YouTube channel (detailed below) and received about 100 views within the first days of their release (September 16, 2017). To this date (October 25, 2018), their total views on my channel gathered is 2210. On a personal level, I have received a lot of praises from friends, family and co-workers who have eagerly shared these with a relative or family member who suffers from IBD. I was also contacted by a Lebanese charity to give a talk regarding the impact of IBD on pregnancy. The videos have been shared on the CCUK website (<https://companion.crohnsandcolitis.org.uk/long-term/i-need-information-on-fertility-and-pregnancy>) where within the first week of their release had 2500 views. It is safe to say that they have generated the intended impact and their viral distribution on the web can be attributed to the receptivity and approval of the content by the audience. I have received no negative feedback regarding the content of the videos and, although it is difficult to assess given the way in which information and links are shared on the internet, I truly believe that in the past year more than 10,000 people have been reached and that this resource has had the intended impact to inform the public about the challenges and joys of motherhood with IBD.

8.5.3 Other types of research impact

Impact is often associated with making a difference with regards to the widest possible audience in the 'real world' (Reed, 2016). Hence, impact is also often seen as a property of quantitative research rather than qualitative research. That is so because qualitative research is not intrinsically bound by concepts of generalisation, demonstrability, and replication (Braun & Clarke, 2006) but focuses more on the depth and exploratory intent of a topic of interest. However, that is not to say that impact cannot be tailored in ways appropriate to the research method at hand. Nowadays, it is more and more sought to consider the impact in qualitative research and, following the lines of this recent trend (i.e., EU Horizon 2020 research funding programme and UK's Research Excellence Framework), I took into consideration right from the start how to work impact into this research.

Engaging with mothers who have IBD and factoring in how others can benefit from and use these journeys was probably the most motivating and rewarding part of my PhD. I was not only researching the transition to motherhood within the context of maternal IBD for mothers with IBD. I learned to care deeply for my research topic and believe in the potential it had to make a difference to young women who in the future join this demographic, their future partners, and healthcare providers supporting and facilitating their reproductive decisions.

In order to make that difference I had to systematically go through these three steps: First, I had to make sense of the information received from mums with IBD and transfer the interpretation of this knowledge into a psychological and academic style writing as required for my PhD thesis. Second, I had to shift the academic and probably jargonistic writing style into an accessible, interesting and attractive content to the lay public to disseminate the results. Thirdly,

I had to actively engage and go at the forefront of events and gatherings with individuals who live and fight IBD everyday of their lives to connect and share my research findings with them. I will elaborate on the ways and practical considerations that I undertook to give my research the best chance of having an impact below.

8.5.3.1 Dissemination

Design. During the writing of the proposal for the grant application funding my PhD, my supervisors and I had taken the time to incorporate, plan and design ways of embedding impact into the research. We aimed to produce a novel, user-friendly resource: YouTube medleys, for women with IBD, their partners, and healthcare providers to share the experience of, and advice about, the transition to motherhood with IBD. The idea was to video record the interviews and to convey the main findings through thematised and carefully edited clips. This would translate as accomplishing principle one: Design of impact, which is the first of five evidence-based principles leading to efficient and fast-track impact (ref. figure3, Reed, 2016). The careful design and planning involved purchasing ahead of time an external microphone for a good quality sound recording, using a high definition recording equipment: the mini iPad and a tripod to best position the recording lens. We also crafted a high-quality recording guideline for women being interviewed to ensure clothing and visibility were not bland and maximise a visually pleasing result for the viewers (see Appendix V). Furthermore, I attended a workshop to learn about video clipping, recording as well as video editing for research. Had I not included the idea from the beginning it would have been impossible to plan and prepare in timely matter all the material required to launch the data collection on time.

Represent. Throughout the PhD programme, I developed my communication and dissemination skills by presenting my research topic and methodology to various audiences. Some audiences were either specialist or apprentice qualitative researchers interested to see the applicability of the method used – Thematic Analysis – in my study. They often had limited experience or knowledge with regards motherhood, IBD and chronic illness (see Appendix Q). For example, some audiences had a medical background and expertise (gastroenterologists or IBD nurses). They knew about IBD, however I added value by disseminating results regarding the lived experience of mothers with IBD in relation to their everyday routines and challenges (i.e., IBD Summit: IBD and Mums-To-Be: Transition to Motherhood with IBD in Birmingham, 29, 30 Jan. 2016; & New Nurse Study Day: IBD and Mums-To-Be: A 5-Stage Model in Manchester, 14 Apr. 2016). Lastly, some audiences were individuals affected with IBD, as well as their families and friends. They were interested to see how other people navigated the journey of motherhood and IBD. In these instances, I had to customise my talk to address this specific audience and use less medical and academic jargon, making the findings personal and relatable to them (Crohn’s and Colitis Forum Talk: IBD and Mums-To-Be: Blurred Lines in Leeds, 25 Apr. 2015; & Crohn’s and Colitis Forum Talk: Introducing IBD and Mums-To-Be Research Study in Leeds, 16 Apr. 2016).

It is worth noting that one way I found useful to promote my research was to have my credentials, websites and social media links at the bottom of my email signature. This straightforward trick allowed me to recruit participants or capture the curiosity of every person I exchanged email with by drawing them to colourful icon boxes representing YouTube, MyAcademia, Twitter, and Facebook accounts.

Challenges. Amongst the challenges met whilst trying to design and represent the widest possible audiences were some ethical considerations regarding sharing information in the early stages of the findings as well as reflecting on who was at disadvantage in this study. Several individuals approached me during the talks and presentations given and asked if I could share with them the slides, video recordings of the talks, or even the transcripts of some women whom I interviewed. Since I was only – at the time – in the early stages of the analysis I could respectfully decline and say that it might be worth holding off on sharing the recordings a little longer in the likely event that the outcome might change or evolve. Similarly, posting videos of the talks on YouTube was carefully thought through and a disclaimer was placed to specify that the findings were preliminary. During one presentation to the postgraduate students at the University of Leeds, I had to share how my personal biases of ‘how a good mother should be’ came to interfere with my analysis and opinion of a participant. I regrettably formed a negative first impression of my participant because her house was untidy and she subsequently appeared rather chaotic to me in her discourse. Only through reflection was I able to acknowledge how my personal views tainted the initial coding of the transcript. A couple of postgraduate students asked me if I could share with them the recordings of the talk, however, out of fear that the participant might recognise herself if the video gets shared on a public domain, my supervisors and I opted to decline and keep it private. Only anonymised slides were provided to the audience.

The second challenge was dealing effectively with ethical issues, particularly consent, when creating YouTube medleys to be uploaded to the Internet. I sought the consent of the participants when I first interviewed them to release their videos, knowing that they would have a second round of consent once the videos were drafted. I made sure to share the video’s content and the entire transcript with each participant so, not only did they know which words were used from their interview, but the overall context in which their story was embedded. I also clearly stated on the informed consent sheet (Appendix J) that if at any point in time a participant wishes to remove their input from the study they can do so (pertaining that the thesis was not submitted, with respect to the inclusion of quotes). Hence, conceivably, if at any point in time a participant wanted their contribution to a video removed from the Internet, I would have to comply immediately.

The third challenge, which can be considered a limitation to the design and engagement with the audience, was brought to my attention whilst attending a workshop by Mark Reed: Fast-Track Engagement and Impact of Research (2016). I realised that I had given very little

thought as to who might be disadvantaged by this study. I was so used to thinking about the benefits and probable minimal risks involved that I overlooked who might be harmed by, or excluded from, the findings. The individuals I can foresee as not benefiting from my study are those women who are suffering from multiple physical disorders in addition to IBD and who are going through the transition to motherhood. Within this category one can include those who have more severe and advanced CD or UC who were unable to take part in the study. Most of the women in our sample mentioned not knowing anyone who had undergone the same experience when they were pregnant and expressed how lonely it felt to have no support. In a way, not accounting for women with very severe conditions, I contributed to marginalise this subgroup even further. I can only expect that by reading about a study on mothers with IBD (who are relatively high functioning and stable in terms of their treatment and illness) can put at disadvantage and ostracised even more those women who had less support, more hospitalisation and are continuously suffering from IBD. This was far from intended and I can only hope that at least some of the findings I have produced with regards to the sample I was able to recruit will have currency more generally and, at the very least, catalyse better care for all women with IBD.

8.5.3.2 Active engagement

As part of my active engagement to promote impact, I have focussed on press releases, social events, and social media channels to gain attention and create momentum for the study. The earlier press releases and active engagement was sought to promote impact even when the results were not finalised.

Press release. A website other than Crohn's and Colitis UK (CCUK) was used to inform individuals about the progress and work carried out at the University of Leeds; the Jewish Digest is a UK based charity ran by volunteers discussing issues regarding food, diet, surgery and other treatments of IBD. The Jewish Digest website is a unique platform targeting the Jews community, presumably Ashkenazi Jews, who have been shown to have a higher prevalence of IBD and who might feel isolated by their chronic condition (<http://www.jewishdigest.org/about-us/>). However, the website is also a forum and medium for all individuals who suffer from IBD or for those who want to know more about this illness. The article published there had the aim to inform non-CCUK members who might also be interested in my work to get in touch with me and link them with our other social media channels. The article can be found through the following link and was released on Monday July 6th 2015 (<http://www.jewishdigest.org/doctors-digest/research-study-in-leeds-on-ibd-and-mums-to-be/>). Moreover, three press releases were issued to promote the first publication issued from the PhD (Appendix RR).

Social events. I continued to attend, whenever feasible CCUK support group meetings and local events in Leeds to continuously engage and promote the findings of the research informally with interested parties (i.e. morning coffees). At these meetings men and women

with IBD and sometimes their family would ask me questions in order to better understand what the study found or ask if their personal experiences matched in anyway with my participants' experiences. I found it to be a rewarding and good way to stimulate discussions and share informally my personal thoughts and encounters throughout the study. The feedback provided during those events promoted a good exchange on stakeholders' expectations and anticipations about the study outcomes.

Social media. My social media channels were continuously updated, even past the point of recruitment. They served the function of informing participants and all interested parties about the research developments, talks given, and papers published.

My Facebook page "IBD and Mums-To-Be" had an 'About' description section providing details about the study and links to other social platforms such as Twitter, YouTube and Academia.edu, where additional relevant materials were posted. Reflecting on this platform's usefulness, I found the Facebook group to be most useful to inform close networks of friend and colleagues about my latest updates. The group count to this day comprises 222 followers. It did not generate a lot of discussion, only encouragements and some likes from people I knew prior to commencing the PhD who supported my progress.

The Twitter account (@IBDandMumsToBe) on the other hand was particularly useful to reach a much wider audience. Twitter allowed me to disseminate my findings with the challenge to write catchy and interesting tweets using only 140 characters. I had to develop skills to identify the relevant "hash-tags (#)" that would increase my visibility and catch the eyes of other researchers interested in the same line of work and people more generally interested in IBD and pregnancy. It was challenging to increase the number of followers given that it was a purely research-based account. The account started by having a couple of followers in September 2014 and grew to more than 480 by June 2018. Twitter is unique in many ways. First, it allows you to follow leaders and other figures in fields of interests without the social barrier of having to have met them first. Second, Twitter facilitates connections with attendees and hosts of events and conferences. Tweeting about a specific talk given or attended with the relevant hash-tag engages other attendees and promotes constructive discussions and feedback about each person's work. Thirdly, Twitter being the most popular platform for my research, was subsequently linked to my Facebook account and Academia.edu website to raise awareness on these other platforms. Lastly, on a more personal level, Twitter allows you to broadcast your thoughts, concerns and even experiences. I used to tweet photos of the places which I travelled to interview participants but I also tweeted my joys and fears before and after each interview. I also shared my concerns about presenting an individual paper and a symposium in front of an unfamiliar audience and was quickly reassured by an attendee of the conference that these meetings are generally friendly and welcoming to new presenters and researchers. These simple exchanges with unknown fellow researchers are instantly reassuring ahead of attending an event.

Two other profiles were also created as part of creating research awareness and impact: Academia.edu and ResearchGate. The two platforms were more useful as one-way sharing medium rather than an exchange. For example, through Academia.edu I was able to share conferences abstracts, poster, talks, slides, documents relevant to the recruitments process as well as other papers published aside from the PhD. My Academia.edu profiles promoted 1,110 views and recruited 63 followers, it also allowed me to see that in the past four years over 332 individuals have seen the uploads and 90 individuals downloaded the documents posted, these statistics ran across a multitude of countries.

In parallel to all the above-mentioned media, a YouTube channel (@JIHANEGHORAYEB) was also created for the study and was used to add the video recording of the talks given at different points in time during the four years. It was important to keep the videos on a private setting to make sure they are not shared too soon with a wider audience, as the results were at the time only preliminary. However, the videos were shared with interested parties by adding them individually via email to the lists of allowed viewers. I also used the same channel to post the medleys that were detailed in the previous section.

Challenges. The timing and funding constraints also impact the social medias interfaces and events attended. Indeed, Twitter, Facebook as well as social events create unique opportunities to network further and receive invitations to promote your work. However, applying for conferences requires funding and sponsorships and similarly promoting one's website with advertisements to reach more viewers can be costly. For all these reasons, we had to limit the amount of conferences attended to allow enough time for writing and analysis and did not pay to promote the social media accounts. Instead I decided to opt to tweet at least once a week, making sure to convey meaningful and personalised information that could attract interested parties.

Another challenge faced was the delay in providing the audience with tangible and final results. The outcome of the qualitative analysis were only available in the final year of the study and most will be first disseminated through peer-reviewed papers a little after thesis submission. It was particularly challenging to manage others' – as well as my – expectations about what I could say about the results in the first two years. Participants interviewed in the study were fairly understanding about the limitations of divulging results too soon, however, the general public was a bit more sceptic as to why I did not have any tangible results after the first few years of work. I had to reassure them about the process and how analysis works as well as make sure I presented and worked on different aspect of the analysis simultaneously to always have something new to show for.

8.6 Future Research

There are several issues and challenges that were unfortunately not addressed in my study. They constitute the basis of future research remaining to be done. First, I do not target women who were voluntarily childless. Exploring qualitatively their experience could further our insight into the lived experience of women with IBD who considered motherhood and made the deliberate choice to remain childless. Among issues that may impact reproductive choice for women with IBD are body image, libido, social seclusion and all of these were mentioned within the data I collected for my study. I also do not address childhood onset of IBD, although a couple of participants were diagnosed between the ages of 10 and 15. Childhood onset (below the age of 8) is said to have a more severe course and worse prognosis and it would be very worthwhile to consider the impact of this form of IBD on women's later reproductive choice. It would be also interesting to include, as mentioned above, women with more than two children and have fathers' input as well. In some families both parents have IBD, and this dynamic of dealing with illness and having children is yet to be explored. Lastly, I would like to raise the question about the impact of video-recording in conducting qualitative health research on chronic illness. My study found that the use of camera was empowering, and even though not all women agreed to share their experience on YouTube, the recording allowed me to capture their awareness of an audience listening in.

8.7 Conclusion

In conclusion, this study addressed the research question: 'What is the lived experience of women who transition to motherhood within the context of maternal IBD?' My systematic research review demonstrated a paucity of research on the topic. Careful sampling and interviewing of 22 mothers with IBD, and analysis of this material using thematic analysis produced three central concepts. The first, *Blurred Lines* captured the sense of a conflated experience between that of becoming and being a mother and of coping with IBD. This could have serious medical implications if the symptoms of IBD and the progress of pregnancy and early motherhood are not disentangled. However, more positively, IBD can promote readiness for motherhood through the similarity of lifestyle adaptations required and the practice of self-monitoring in the support of self-care. Second concept, *Transitional Challenges*, revealed how the transitioning to motherhood with IBD was parsed with feelings of *Blame and Guilt*, *Burden of Knowledge* from having the illness and taking drugs, *Ambivalence towards Healthcare Professionals*, and *Weighing Decision-Making* to do what is best for the family. Third, *Reflecting on Others* explored how the mothers with IBD who took part in the study noted how the illness made them reflected on others and, in turn, how others mirrored the illness back to

them. Interestingly, they used the interview video-recording as a *staged performance* to let the world know the highs and the lows of having IBD and becoming a mother.

My findings shed light on a poorly researched issue in relation to women's health and reproductive choice. Importantly, it corrects assumptions that becoming a mother with IBD is overly difficult and preferably avoided. It also emphasises the necessity of providing support to such mums and for them to develop a strong network to cope with the challenges of their journey. It is a privilege to have conducted research that has the potential to empower women and their partners to make a truly informed decision about starting a family and to provide their family, friends and healthcare professionals with information to best support this decision-making. My hope is that more research is conducted to support women's reproductive choice within the context of chronic illness and that the user-friendly method I developed of 'YouTube medleys' makes a continued contribution to make academic research available, reachable, and understandable to the general public.

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Appendices

Appendix A Database Selection across Fields of Psychology, Healthcare, and Medicine

Field of Psychology Databases	Description	Inc./Exc.	Justification
British education index	Child development and education	Exc.	Irrelevant topics
The Cochrane Library	The Cochrane Library describes itself as a collection of databases that contain high-quality, independent evidence to inform healthcare decision-making. Cochrane reviews represent the highest level of evidence on which to base clinical treatment decisions. In addition to Cochrane reviews, The Cochrane Library provides other sources of reliable information, from other systematic review abstracts, technology assessments, economic evaluations and individual clinical trials	Inc.	
Counseling and psychotherapy transcripts, client narratives, and reference works	Counseling and Psychotherapy Transcripts, Client Narratives, and Reference Works is a searchable collection containing real transcripts of therapy and counseling sessions and first-person narratives illuminating the experience of mental illness and its treatment, as well as reference works to contextualize the primary material. New material is added on a biweekly basis.	Exc.	Irrelevant to peer-review
CSA neurosciences abstracts	This database allows you to search for journal articles in neuroscience and biomedicine, with the emphasis on basic research studies.	Exc.	Irrelevant topics
HINARI	HINARI Programme set up by WHO together with major publishers, enables low- and middle- income countries to gain access to one of the world's largest collections of biomedical and health literature. Up to 14,000 journals (in 30 different languages), up to 46,000 e-books, up to 100 other information resources are now available to health institutions in more than 100 countries, areas and territories benefiting many thousands of health workers and researchers, and in turn, contributing to improve world health	Exc.	Limited English articles and lack of translation available
Medline	This database allows you to search for journal articles and other reference types in medicine, dentistry and nursing. The database is updated frequently and can be searched back to 1946 until Week 4 of July 2015	Inc.	Ovid Search
Medline in process, other non-indexed citations	This database allows you to search for basic information about new medical journal articles before they are added to the full Medline database (Present)	Inc.	Ovid Search
Occupational health and safety information service	This database allows you to search for legislation, guidance, standards and best practice in all aspects of occupational health & safety, environmental health, fire safety, offshore safety, environmental management and food & drink safety, as well as a relevant set of British Standards	Exc.	Irrelevant to peer-review
ProQuest: Health and Medicine	This collection of databases allows you to search for journal articles and conference proceedings in a wide range of health and medical subjects	Inc.	
OldMedline	This database allows you to search for journal articles in medicine, dentistry and nursing between 1946-1965. The database is updated quarterly	Inc.	Ovid Search
PsycINFO	This database allows you to search for journal articles, books and dissertations and theses in core psychology disciplines and behavioural sciences and mental health. The database is updated weekly. It covers the years 1806 to Week 3 July 2015	Inc.	Ovid Search
PsycArticles	PsycArticles is a database of full-text articles from journals published by the American Psychological Association, the APA Educational Publishing Foundation, the Canadian Psychological Association, and Hogrefe & Huber. The database includes all material from the print journals since 1984	Inc.	Ovid Search
Science Direct	This database is a leading full-text scientific database offering journal articles and book chapters from nearly 2,500 journals and more than 30,000 books	Exc.	The software is not properly combining the terms and is likely to duplicate what is found through the aggregator database
Scopus	Scopus is a large abstract and citation database of peer-reviewed literature from more than 18,500 journals and quality web sources, with smart tools to track, analyze and visualize research	Exc.	Too many hits time management
Web of Science	Web of Science allows you to search for journal articles using three databases; Science Citation Index, Social Science Citation Index and Arts and Humanities Citation Index. Each database is updated weekly 01 Jan. 1898- current	Inc.	

Field of Healthcare Databases	Description	Inc./Exc.	Justification
AIDS and cancer research abstracts	This database allows you to search for journal articles, conference proceedings, books and websites on AIDS, immunology, virology and cancer genetics. The database is updated monthly and can be searched back to 1982	Exc.	Irrelevant topics
AMED	This database allows you to search for journal articles about allied and complementary medicine, and palliative care (1985 – July 2015)	Inc.	Ovid Search
Biosis previews online	Covers all areas of biological research, including biomedical sciences, agriculture, biochemistry, biotechnology, genetics, physiology, molecular biology, microbiology, botany, plants, taxonomy, fossils, zoology, biophysics, bioengineering, ecology and environment, and experimental, clinical and veterinary medicine.	Inc.	Web of Science Search
British Standards online	The full text of British Standards, covering: specifications for products, dimensions, and performance; methods; codes of practice; guides and glossaries. Also find BS equivalents to ISO and EN standards	Exc.	Irrelevant to peer-review
CINAHL	This database allows you to search for journal articles, books, dissertations and conference proceedings in nursing and allied health (1960-)	Inc.	
EMBASE	This database allows you to search for journal articles in biomedicine, psychiatry and pharmacology. The database is updated weekly and can be searched back to 1980. A current awareness service provides alerts for newly added content. Compared to Medline, EMBASE has a more European bias, and only about one third of the journals are covered in both databases (until Present)	Inc.	Ovid Search
EMBASE Classic	EMBASE Classic covers the period 1947-1979	Inc.	Ovid Search
ERIC	Education and related topics - journal articles, conferences, meetings, government documents, theses, dissertations, reports, audio-visual media, bibliographies, directories, books and monographs Subject Area(s): Social Sciences 1966	Inc.	ProQuest Health and Medicine Search
HMIC database	This database brings together the bibliographic databases of 2 UK health and social care management organisations: Dept. of Health (DH-Data); King's Fund. HMIC enables you to search for journal articles, books, Department of Health policy documents and unpublished material in the area of UK and international health and social care management and policy (1983 -)	Exc.	Irrelevant topics
Index to theses	Index to theses accepted for higher degrees by the universities of Great Britain and Ireland.	Exc.	Irrelevant to peer-review
International bibliography of the social sciences	Focuses mainly on the four core social science disciplines - anthropology, economics, politics and sociology - but also covers a range of interdisciplinary subjects. It contains over 2.5 million references to journal articles, books, reviews and selected chapters dating back to 1951 and is especially strong on international materials	Inc.	ProQuest Health and Medicine Search
International Pharmaceutical abstracts	This database allows you to search for journal articles in pharmaceutical science, with worldwide coverage.	Exc.	Irrelevant topics
Journal citation reports science edition.	This database is part of the Web of Knowledge service and allows you to search for journal impact factors and other rankings for journals in science, medicine and social sciences	Exc.	Irrelevant to peer-review
Maternity and infant care	The Maternity and infant care database has over 100,000 references relating to midwifery, pregnancy and childbirth. Each reference includes full bibliographic information, an author abstract or summary and is subject indexed with key words to enable easy searching of the database. The database also includes pre-prepared 'standard' searches (1971- June 2015)	Inc.	Ovid Search
Natural medicines comprehensive database	This database contains evidence-based information on herbal and non-herbal medicines. You can search by medicine name (common or scientific names) or by disease and condition. Medicines have been assessed for effectiveness and safety	Exc.	Irrelevant topics
PAIS International	Public affairs, public and social policies, international relations - journal articles, books, government documents, statistics, grey literature, research reports, conference papers, microfiche, Internet material, etc. (1914 - current) Subject Area(s):Social Sciences	Inc.	ProQuest Health and Medicine Search
PEDrO.	PEDrO is the Physiotherapy Evidence Databas	Exc.	Irrelevant topics
Popline: Population database	This database enables you to search for journal articles, reports, books and unpublished reports in the fields of reproductive health, population studies, family planning, HIV/AIDS and related health issues, particularly in a developing country context (1970-)	Inc.	
ProQuest dissertations and theses		Exc.	Irrelevant to peer-review

PubMed	A service of the US National Library of Medicine that includes over 16 million citations from the journals in the Medline database as well as biomedical articles from further life-science journals. This version of Medline also includes PreMedline, references to articles that have been published but not yet included in the full version of Medlin	Inc.	
RDInfo (Health Research Funding)	RDInfo is divided into two databases. RDLearning provides information about postqualification training courses for health and social care researchers and RDFunding gives information on health-related funding opportunities	Exc.	Irrelevant to peer-review
Science Citation Index	Covers 1900 to the present. Available through Web of Science	Inc.	Web of Science Search
Social care online	The UK's largest database of information and research on all aspects of social care and social work. Updated daily resources include legislation, government documents, practice and guidance, systematic reviews, research briefings, reports, journal articles and websites (2005-)	Exc.	The software is not properly combining the terms and is likely to duplicate what is found through the aggregator database
Social Sciences Citation Index	The Social Sciences Citation Index is a multidisciplinary database, with searchable author abstracts, covering the journal literature of the social sciences. It indexes more than 1700 journals covering 50 disciplines. Access is provided via the ISI Web of Science service (1956-)	Inc.	Web of Science Search
Social services abstracts	Social Services Abstracts (via CSA) provides bibliographic coverage of current research focused on social work, poverty, homelessness and human services, including social welfare, social policy, and community development (1979-)	Inc.	ProQuest Health and Medicine Search
Social work abstracts	Social Work Abstracts provides indexing and abstracts for over 450 journals dealing with all aspects of social work and services (1977-)	Inc.	CINAHL Search
Sociological abstracts	Covers international literature in sociology and related disciplines in the social and behavioural sciences. Provides abstracts of journal articles and citations, books, book chapters, dissertations, and conference papers. Social Services Abstracts (via CSA) (1952-)	Inc.	ProQuest Health and Medicine Search
Sport discus	Covers sport, fitness and related disciplines, including sport medicine, physical education, coaching and training, arts and history of sport, engineering and health and safety for sport	Exc.	Irrelevant topics
Transplant library	The Transplant library is the bibliographic database of the Centre for Evidence in Transplantation (CET), the Royal College of Surgeons of England (RCS), and the London School of Hygiene & Tropical Medicine (LSHTM)	Exc.	Irrelevant topics
TRIP database	The TRIP (Turning Research Into Practice) database is the Internet's leading resource for evidence-based medicine. It allows users to easily and rapidly identify the highest quality clinical evidence from a wide range of sources.	Exc.	Clinical reports and practices within therapeutic settings
UKOP Online	This database allows you to search for British official publications (1980-)	Exc.	Irrelevant topics
Web of Science proceedings science and technology.	This database is part of the Web of Knowledge service and allows you to search for journal articles and conference proceedings in science and technology	Exc.	Irrelevant topics
WHO reproductive health library online	The WHO RHL includes the full text of systematic reviews produced by the Cochrane Collaboration, with commentaries on implications for practice, as well as the Lancet epidemiology series on randomised controlled trials, videos on implementation, and other resources to help improve reproductive health in a developing country context.	Covered	Covered in Cochrane Library
11 repeated databases not inserted			

Field of Medicine Databases	Description	Inc./Exc.	Justification
ASSIA	An indexing and abstracting tool covering health, social services, psychology, sociology, economics, politics, and education. It is a comprehensive source of social science and health information from over 500 journals. It can be searched as a single database or within the CSA Social Sciences collection if your subject is multidisciplinary	Inc.	ProQuest Health and Medicine Search
Biological sciences	This interdisciplinary database offers abstracts and citations to a wide range of research in biomedicine, biotechnology, zoology and ecology, and some aspects of agriculture and veterinary science.	Exc.	Irrelevant topics
Biotechnology research abstracts	Part of Proquest: CSA	Exc.	Irrelevant topics
CAB Abstracts Online	Covers research and development literature in agriculture, forestry, biofuels, biotechnology, microbiology, entomology, genetics, virology, applied economics, food science, aspects of human health, human nutrition, animal health, and the management and conservation of natural resources (1910- Week 30 of 2015)	Inc.	Ovid Search
CSA neurosciences abstracts	This database allows you to search for journal articles in neuroscience and biomedicine, with the emphasis on basic research studies. The database is updated monthly. It covers the years 1982 to the present day. A current awareness service provides alerts for newly added content.	Exc.	Irrelevant topics
Database of uncertainties about the effects of treatments	Since (2011-)	Exc.	Irrelevant to peer-review
Genetics abstracts	One of 23 Biological Sciences sub files available via Cambridge Scientific Abstracts, Genetics Abstracts' unique blend of articles gives readers the widest possible perspective of genetics as a whole, from microbes to plants to humans. The burgeoning field of molecular genetics is emphasized, with important information on all aspects of DNA, differentiation and development, RNA, protein synthesis, ribosomes, nuclear proteins and chromatin, enzymes, and gene regulation. An essential resource for scientists across the life sciences, Genetics Abstracts will prove particularly useful to researchers and institutions directly and indirectly involved in the Human Genome Project. (CSA) Major areas of coverage include: Molecular Genetics; Chromosomes; Extrachromosomal Genetics; Cell Cycle; Chemical Mutagenesis; Radiation Genetics; Immunogenetics; Developmental Genetics; Evolutionary Genetics; Ecological Genetics; Behavioral Genetics; Theoretical and Population Genetics; Viral Genetics; Bacterial Genetics; Fungal Genetics; Algal Genetics; Plant Genetics; Invertebrate Genetics; Vertebrate Genetics; Human Genetics; Medical Genetics	Exc.	Irrelevant topics
Global Health	As well as the usual academic sources such as journal articles, books etc., Global Health enables you to search for less traditional publications from more than 125 countries. In addition to comprehensive coverage of the international public health literature, the database includes significant unique content particularly in the areas of tropical medicine and communicable diseases, vector control, food safety and epidemiology	Exc.	Irrelevant topics
Health and safety science abstracts	this database allows you to search for journal articles, technical reports and conference proceedings on the subject of aviation and aerospace safety, environmental safety, nuclear safety, medical safety occupational safety, and ergonomics. Health and safety related aspects of pollution, waste disposal, radiation, pesticides, epidemics are also covered	Exc.	Irrelevant topics
Henry Stewart Talks		Exc.	Irrelevant topic
Human genome abstracts		Exc.	Irrelevant topics
Immunology abstracts	One of 23 Biological Sciences subfiles available via Cambridge Scientific Abstracts, Immunology ranks as one of the most rapidly expanding areas of biomedical science, covering topics from cancer and vaccine research to immune deficiencies and autoimmunity. Immunology Abstracts performs a vital function for scientists in this field by monitoring significant advances and bringing together diverse research results in one succinct journal. Studies relating to all aspects of immune systems in man and animals, in normal functions and disorders, are summarized.	Exc.	Irrelevant topics
International Pharmaceutical abstracts	This database allows you to search for journal articles in pharmaceutical science, with worldwide coverage	Exc.	Irrelevant topics
Journal citation reports science edition.	This database is part of the Web of Knowledge service and allows you to search for journal impact factors and other rankings for journals in science, medicine and social sciences.	Exc.	Irrelevant topics
LILACS Database	This database enables you to search for literature related to the health sciences published since 1982 in countries of South and Central America and the Caribbean. It contains articles from about 670 of the most well-known journals in the medical field and other documents, such as: theses, chapters of theses, books, chapters of books, congress and conference proceedings, technical and scientific reports and governmental publications. Some articles are available free in full text.	Exc.	Most articles are in Spanish or Portuguese - Limited English articles and lack of

			translation available
Microbiology abstracts. Section A: Industrial and applied microbiology abstracts.		Exc.	Irrelevant topics
Microbiology abstracts. Section B: Bacteriology.	One of 12 databases available through Environmental Sciences and Pollution Management. This database contains information from 1982 onwards about bacterial immunology and vaccinations, diseases of man and animals, all aspects of pure bacteriology, biochemistry, and genetics.	Exc.	Irrelevant topics
Microbiology abstracts Section C: Algology, mycology & protozoology		Exc.	Irrelevant topics
Natural medicines comprehensive database	This database contains evidence-based information on herbal and non-herbal medicines. You can search by medicine name (common or scientific names) or by disease and condition. Medicines have been assessed for effectiveness and safety. The pharmacological mechanism and active ingredients for each are given. Information is also included on known adverse reactions, side effects and possible interactions with other drugs. Links are provided to the bibliographic details of relevant research papers and other sources.	Exc.	Irrelevant topics
NHS Economic Evaluation Database (NHS EED)	NHS EED is produced by the Centre for Reviews and Dissemination, University of York and enables you to search for structured abstracts and bibliographic details of economic evaluations of healthcare interventions published since 1995.	Exc.	Irrelevant topics
NIHR CRN Portfolio		Exc.	Irrelevant
Nucleic acids abstracts		Exc.	Irrelevant topics
Oncogenes and growth factors abstracts	One of 23 Biological Sciences subfiles available via Cambridge Scientific Abstracts, Oncogenes and Growth Factors Abstracts covers every aspect of oncogene research into the molecular basis of malignant transformations. This will prove indispensable in suggesting new directions for research and helping scientists avoid dead ends or costly duplication of work. A necessity for molecular biologists researching cell growth and oncogenesis, Oncogenes and Growth Factors Abstracts will also be valuable to researchers in immunology, virology, bacteriology, genetics, and other related fields. (CSA) Major areas of coverage include: Oncogenes; Viral Oncogenes; Growth Factors; Tyrosine Kinase Activity; Serine-Threonine Kinase Activity; Serine; Threonine Kinases	Exc.	Irrelevant topics
OpenGrey: system for information on grey literature in Europe.	OpenSIGLE - System for information on grey literature in Europe	Exc.	Irrelevant to peer-review
PathCAL	PathCAL is a series of online tutorials covering a wide range of pathology and pathophysiology subjects produced and published by the College of Medicine and Veterinary Medicine at the University of Edinburgh	Exc.	Irrelevant topics
Physical Education Index	This database allows all researchers and professionals in the field to acquire accurate and scholarly information. These abstracts feature a wide variety of content, ranging from physical education curricula, to sports medicine, to dance. Health education and physical therapy are also covered as they continue to become more prevalent in our society	Inc.	Covered in ProQuest Health and Medicine
PILOTS database	The aim of the PILOTS database is to 'include citations to all literature on post-traumatic stress disorder (PTSD) and other mental-health sequelae of traumatic events, without disciplinary, linguistic, or geographical limitations, and to offer both current and retrospective coverage.	Inc.	Covered in ProQuest Health and Medicine
Toxicology abstracts	Specifically focused to meet the needs of toxicologists, Toxicology Abstracts covers issues from social poisons and substance abuse to natural toxins, from legislation and recommended standards to environmental issues. Topics of current concern such as the effects of alcohol and smoking, drug abuse, hydrocarbon studies, nitrosamines, radiation and radioactive materials, and much more are extensively examined. Toxicity testing methodology and analytical procedures for toxic substances are also covered. Through many years of delivering crucial information on the tough, far-reaching issues of toxicology, Toxicology Abstracts has become the single most widely-used journal in this field. Major areas of coverage include: Pharmaceuticals; Food, Additives, and Contaminants; Agrochemicals; Cosmetics, Toiletries, and Household Products; Industrial Chemicals; Metals; Toxins and Other Natural Substances; Social Poisons and Drug Abuse; Polycyclic Hydrocarbons; Nitrosamines and Related Compounds; Radiation and Radioactive Materials; Methodology; Legislation and Recommended Standard	Exc.	Irrelevant topics

Toxline	This database allows you to search for journal articles and other reference types on all areas of toxicology, including chemicals and pharmaceuticals, pesticides, environmental pollutants, and mutagens and teratogens. The database is updated monthly and can be searched back to 1996	Exc.	Irrelevant topics
UpToDate	UpToDate is a comprehensive, point of care clinical decision support system designed to give doctors practical and reliable answers to questions that arise during clinical practice. The physician authors synthesize current medical information and provide diagnosis and treatment recommendations based on both the available evidence and their clinical experience	Exc.	Irrelevant topics
Virology and AIDS abstracts	Virology research has become more important than ever, as scientists around the globe race to overcome the deadly challenge of Acquired Immune Deficiency Syndrome - while ongoing projects continue the quest for answers in other crucial areas of virology. Comprehensive coverage of the world literature on every aspect of virology in humans, animals, and plants is featured, with topics ranging from replication cycles to oncology. The same comprehensive treatment is devoted to such topics as hepatitis B virus vaccination, viral genetics, interferon, and more - demonstrating the breadth of coverage that has long helped researchers meet the challenges of this field. (CSA) Major areas of coverage include: Acquired Immune Deficiency Syndrome; Virus Taxonomy and Classification; Methodology and Tissue Culture Studies; Physico- Chemical Properties, Structure, and Morphology; Replication Cycle; Viral Genetics Including Virus Reactivation; Phage-Host Interactions Including Lysogeny and Transduction; Immunology; Antiviral Agents; Oncology; Viral Infections of Man; Diseases Associated with Slow Viruses; Viral Infections of Animals; Animal Models and Experimentally-Induced Viral Infections; Viral Infections of Invertebrates; Viral Infections of Fungi and Lower Plants; Viral Infections of Higher Plants	Exc.	Irrelevant topics
WHO Regional Databases	These WHO health and medical databases have been compiled to give access to the important body of health and medical literature from developing countries which is not available in databases such as Medline. The WHO regions covered are: Africa, Eastern Mediterranean, Latin America and the Caribbean and South-East Asia. The databases are free (2011- onward)	Exc.	The software is not properly combining the terms and is likely to duplicate what is found through the aggregator database
29 repeated databases not inserted (repeated from previous fields)			

Appendix B Search Hit Results per Database

Databases	Cochrane Library	Ovid	ProQuest Health & Medicine	CINAHL	Web of Science	PubMed	PopLine	Scopus
Keywords ¹	1995 – 4 Aug 2015 (Week 1) ²	1946 - 6 Aug 2015 (Week 1)	1872 – 14 Aug 2015 (Week 2)	1960 - 09 Sep 2015 (Week 2)	1898 - 17 Aug 2015 (Week 3)	1996- 15 Sep 2015 (Week 3)	1970- 16 Sep 2015 (Week 3)	1823 - 26 Aug 2015 (Week 4)
1. Bowel* Surger* (ADJ6)	603	8492	467	419	14,246	41410	361	18,576
2. Colitis*	2,537	170806	4675	2,962	228,218	59998	68	189,634
3. Colon* Disease*(ADJ6)	2,682	78494	4195	1,100	198,165	113498	344	215,887
4. Crohn*	2,081	121509	4079	2,908	171,370	43903	86	127,778
5. Digest* Disease* (ADJ6)	3,385	34806	5083	668	1,717,946	72556	256	305,949
6. Digest* Surger* (ADJ6)	772	3951	1637	1,226	178,430	37473	64	76,343
7. Gastrointestinal* Disease* (ADJ6)	4,314	150781	1912	3,901	168632	128328	28	221,350
8. Gastrointestinal* Surger* (ADJ6)	2,020	15565	1647	889	16267	65293	4	131,903
9. IBD OR IBDs	4,101	45339	2400	980	62413	15135	17	33,193
10. Ileo-Anal* Pouch*	34	1606	58	42	1,160	921	0	3,416
11. Inflammatory Bowel Disease* (ADJ6)	1,470	90676	3459	2,983	159,046	37187	72	133,540
12. Pouch*	602	50854	3371	782	71,202	18805	162	89,915
13. Stoma OR Stomas	436	25679	2309	1,410	53,690	8269	4	34,646
14. Ulcerat*	4,274	214249	7141	5,157	259,308	76849	108	208,224
15.1-14 (Or)	19,728	678200	29517	18,569	<u>2,402,909</u>	228907	1421	1,073,624
16. Adult* Female*	290,663	67137	46868	2,968	5,244,416	3354532	1225	5,139,862
17. Human Female*	135,358	80164	42824	304	9,728,439	1418	1566	7,494,458
18. Matern*	12,765	757798	58820	53,318	806,564	284001	44690	814,743
19. Mother*	9,108	662540	124457	70,438	593,915	186876	34653	610,268
20. Mum OR Mums OR Mom or Moms	1,121	419479	2802	2,564	379,017	78747	75	43,200
21. Wom?n	82,671	2603806	513807	182,570	2,880,884	892305	139236	2,622,392
22. 16-21 (Or)	368,336	3951467	671747	263,411	<u>12,661,512</u>	4078720	165974	9,153,692
23. Trimester*	3,579	160499	4733	6,981	168,131	59798	721	132,458

¹ Some key words were changed in the table for formatting purposes, they were either abbreviated or alternatives were removed

² In order to be as inclusive as possible, no restrictions were imposed in any of the databases on date of publication. Lastly, the search was ran again in November 2015 and again in June 2016 to ensure that between scoping and writing up of the SRR no pertinent articles were released. Upon this second and third searches, no difference in the end count was found. The numbers found in the tables thus reflect the search ran in August/September 2015.

24.Abort*	3,585	278500	23830	9,613	272,947	96757	8165	217,195
25.Baby OR Babies	4,635	204493	22252	20,679	185,002	1037549	7968	222,259
26.Birth OR Born	17,567	1012925	128866	64,003	2,134,827	338757	61752	1,161,273
27.Breastfed	3,993	135934	7278	16,531	103,518	42583	11850	92,198
28.F?Etal OR F?Etus*	801	940220	3847	884	60,974	409116	8888	77,638
29.Mother* Experience* (ADJ6)	215	20166	6270	3,757	12,555	17119	776	22,585
30.Mother* Phase* (ADJ6)	26	1600	244	154	852	3547	731	2,114
31.Mother* Role* (ADJ6)	74	13415	7133	2,052	9,255	20057	4263	22,803
32.Mother* Transition* (ADJ6)	20	2438	1102	478	1,123	2765	229	5,602
33.Neonatal*	18,181	470940	16408	31,363	603,279	193285	625	709,183
34.Newborn*	18,565	1371946	12622	71,100	1,054,289	646918	5121	977,098
35.Pregnan*	31,448	1980403	56986	115,024	1,795,817	822799	62424	1,306,543
36.Child*	101012	5288775	821469	586,698	5,011,378	2196073	104247	4,714,068
37.Cope OR Coping OR Coped	5157	269491	70718	41,508	238,289	148142	2498	527,097
38.Development*	50476	6470517	1671203	323,096	12,339,031	2315981	30084	12,242,802
39.Educat*	46765	2499163	2220169	494,778	2,120,666	941981	31640	3,491,572
40.Experience*	51857	2631114	629788	224,130	2,672,661	769758	7053	3,676,982
41.Famil*	26343	2844706	684849	251,525	4,178,319	313770	176312	4,302,824
42.Health Visitor* (ADJ6)	291	9498	2749	3,268	3,128	4016	692	13,907
43.Infan*	41593	2244510	82383	247,182	2,131,700	1093491	39637	1,897,865
44.Kid OR Kids	458	39655	10117	7,174	29,992	6938	317	74,497
45.Midwi*	2026	95170	13123	34,407	46,314	51374	6656	110,872
46.Postnatal* OR Post-Natal*	2832	273867	13082	12,728	374,815	95861	150	355,107
47.Prenatal* OR Pre-Natal*	4150	405226	14554	23,355	352,466	924	547	390,576
48.Raising	2012	132272	67492	10,388	2,277,595	38773	10495	158,117
49.Toddler OR Toddlers	879	27150	9803	5,108	25,275	6774	211	55,421
50.Doula OR Doulas	41	1097	115	597	339	347	17	5,589
51.Deliver*	37150	1549697	174421	104,971	1,911,788	546124	137594	2,336,732
52.Labor OR Labour	46399	431147	447035	34,990	457,682	825493	29419	677,870
53.23-52 (Or)	521241	19788084	4475003	1,547,037	<u>29,193,844</u>	7337811	303181	22,169,066
54.Content Analys* (ADJ6)	827	122822	48615	24,297	175,032	15221	2543	215,624
55.Discourse OR Discourses	148	75135	150727	9,925	120,916	10457	1254	369,534
56.Focus Group OR Focus Groups (ADJ6)	1517	71500	45714	28,476	106,093	70472	13332	101,642
57.Framework Analys* (ADJ6)	346	30515	17089	2,629	60,408	701	3121	194,226
58.Grounded Theor* (ADJ6)	189	34949	15701	11,851	37,947	7128	498	78,988
59.Interpretat*	16369	693160	132983	28,436	920,469	267199	804	1,766,119
60.IPA (abbreviated for format)* (ADJ6)	20	3210	1099	696	1,228	798	13	4,354
61.Interview*	16127	1015751	361559	180012	801,623	276538	27705	787,848
62.Diaries OR Diary	7461	59784	14091	11,435	72,933	17243	418	98,696

63.Lived Experience* (ADJ6)	46	17517	9937	4,324	27,359	2976	1131	26,031
64.Phenomenolog*	195	78581	23981	14,462	109,718	18429	110	329,792
65.Psychoanaly*	411	191374	20482	5,093	78,925	34935	81	141,190
66.Qualit* Approach* (ADJ6)	1318	52618	17420	7,830	72,086	113555	5418	206,948
67.Qualit* Research* (ADJ6)	8574	172534	71677	20,821	161,814	495955	24413	601,199
68.Qualit* Stud* (ADJ6)	30855	357019	101496	81,763	425,265	78862	19073	736,910
69.Qualit* Method* (ADJ6)	1191	88440	48945	25,424	312,820	125475	23393	20,456,471
70.Subjective Experience* (ADJ6)	639	26801	4877	1,850	18,479	3282	445	30,112
71.Thematic Analys* (ADJ6)	250	28734	8233	32,953	20,626	6548	460	28,577
72.54-71 (Or)	66870	2521130	846512	310,943	<u>3,031,635</u>	164174	65872	3,658,771
1-14 And 15-21 And 23-53 And 54-71	19,728	1,316	187	106	8,735	271	0	28,256

Appendix C CASP Scoring and Evaluation Forms

Liss and Sharma (1969): Multi-generational dynamics in a case of Ulcerative Colitis		
Appraisal questions	Comments	P/F*
<i>Screening: Was there a clear statement of the aims of the research?</i>	“This paper will describe some of the determinants and reverberations of Ulcerative Colitis in a 36-year-old woman, in light of four generations of her family life” p 461 “However, the important question of the relationship between the patient’s mother and her mother (the maternal grandmother) is not touched upon in their report. Only when this relationship is examined can one fully understand "who" the patient is for the mother in the development of their intense, ambivalent relationship. Another un-examined dimension in the above two family-studies is the question of the specific causes and consequences of the Ulcerative Colitis Symptomatology.” p463-4	P
<i>Screening: Is a qualitative methodology appropriate?</i>	Yes	P
<i>Was the research design appropriate to address the aims of the research?</i>	Case Study	P
<i>Was the recruitment strategy appropriate to the aims of the research?</i>	Not mentioned –convenience	F
<i>Were the data collected in a way that addressed the research issue?</i>	Face-to-face interviews separate and group Gathered interviews with all relevant parties	P
<i>Has the relationship between researcher and participants been adequately considered?</i>	Not mentioned	F
<i>Have ethical issues been taken into consideration?</i>	Not mentioned	F
<i>Was the data analysis sufficiently rigorous?</i>	Yes a summary and discussion provide insight into researcher’s conclusion	P
<i>Is there a clear statement of findings?</i>	The report in and of itself reflects the findings	P
<i>How valuable is the research?</i>	Interesting point of view on early views of UC familial patterns and mother role with her children	P
Total passes out of 10		7

* *Pass/Fail column added for the purpose of the current study.

Mukherjee et al. (2002): The meaning of parental illness to children: the case of Inflammatory Bowel Disease		
Appraisal questions	Comments	P/F*
<i>Screening: Was there a clear statement of the aims of the research?</i>	P. 480	P
<i>Screening: Is a qualitative methodology appropriate?</i>	Yes	P
<i>Was the research design appropriate to address the aims of the research?</i>	Yes	P
<i>Was the recruitment strategy appropriate to the aims of the research?</i>	Yes	P
<i>Were the data collected in a way that addressed the research issue?</i>	Yes	P
<i>Has the relationship between researcher and participants been adequately considered?</i>	No	F
<i>Have ethical issues been taken into consideration?</i>	Yes	P
<i>Was the data analysis sufficiently rigorous?</i>	Yes	P
<i>Is there a clear statement of findings?</i>	Yes	P
<i>How valuable is the research?</i>	Yes	P
	Total passes out of 10	9

* *Pass/Fail column added for the purpose of the current study

Cooper et al. (2011): Living with inflammatory bowel disease: diagnosis during pregnancy		
Appraisal questions	Comments	P/F*
<i>Screening: Was there a clear statement of the aims of the research?</i>	Vague comment on p 28	F
<i>Screening: Is a qualitative methodology appropriate?</i>	Yes	P
<i>Was the research design appropriate to address the aims of the research?</i>	Yes	P
<i>Was the recruitment strategy appropriate to the aims of the research?</i>	Yes	P
<i>Were the data collected in a way that addressed the research issue?</i>	Yes	P
<i>Has the relationship between researcher and participants been adequately considered?</i>	No	F
<i>Have ethical issues been taken into consideration?</i>	Yes	P
<i>Was the data analysis sufficiently rigorous?</i>	Yes	P
<i>Is there a clear statement of findings?</i>	Yes	P
<i>How valuable is the research?</i>	Yes	P
	Total passes out of 10	8

* *Pass/Fail column added for the purpose of the current study

Mukherjee et al. (2002): An insight into the experience of parents with Inflammatory Bowel Disease		
Appraisal questions	Comments	P/F*
<i>Screening: Was there a clear statement of the aims of the research?</i>	This study represents the first investigation into the impact of IBD on patients in their parenting role and on their children. It was therefore appropriate to carry out a small-scale exploratory study to give parents an opportunity to provide an account of their experience	P
<i>Screening: Is a qualitative methodology appropriate?</i>	Yes	
<i>Was the research design appropriate to address the aims of the research?</i>	Yes	
<i>Was the recruitment strategy appropriate to the aims of the research?</i>	Yes	
<i>Were the data collected in a way that addressed the research issue?</i>	Yes	
<i>Has the relationship between researcher and participants been adequately considered?</i>	Yes	
<i>Have ethical issues been taken into consideration?</i>	Yes	
<i>Was the data analysis sufficiently rigorous?</i>	Yes	
<i>Is there a clear statement of findings?</i>	Yes	
<i>How valuable is the research?</i>	Yes	
	Total passes out of 10	10

* *Pass/Fail column added for the purpose of the current study

Lewis et al. (2009): Genetic testing for IBD: Focus Group Analysis of Patients and Family Member		
Appraisal questions	Comments	P/F*
<i>Screening: Was there a clear statement of the aims of the research?</i>	Yes p. 495-6	
<i>Screening: Is a qualitative methodology appropriate?</i>	Yes	
<i>Was the research design appropriate to address the aims of the research?</i>	Yes	
<i>Was the recruitment strategy appropriate to the aims of the research?</i>	Yes	
<i>Were the data collected in a way that addressed the research issue?</i>	Yes	
<i>Has the relationship between researcher and participants been adequately considered?</i>	No	
<i>Have ethical issues been taken into consideration?</i>	Yes	
<i>Was the data analysis sufficiently rigorous?</i>	Yes	
<i>Is there a clear statement of findings?</i>	Yes	
<i>How valuable is the research?</i>	Yes	
	Total passes out of 10	9

* *Pass/Fail column added for the purpose of the current study

Kimura and Ohmori (2014): Health of Women with IBD coping with challenges from pregnancy to child rearing		
Appraisal questions	Comments	P/F*
<i>Screening: Was there a clear statement of the aims of the research?</i>	“An exploratory design was employed, in order to elucidate the ascribed significance and perspectives of IBD women based on their experiences from pregnancy to child rearing” P.37	P
<i>Screening: Is a qualitative methodology appropriate?</i>	Yes	P
<i>Was the research design appropriate to address the aims of the research?</i>	Yes	
<i>Was the recruitment strategy appropriate to the aims of the research?</i>	Purposive: They were given the formal request for this study including the email address of the primary investigator by a gastroenterologist, the second investigator, at a gastroenterology clinic in Saitama, Japan, or through internet sites where women could link to this study via the representative of the Society of Patients with Intractable Diseases. Although, ten women with IBD expressed their will to participate in the study, two abstained from interviews due to serious health conditions, and eight participated in the study	P
<i>Were the data collected in a way that addressed the research issue?</i>	Semi-structured interview with interview schedule	P
<i>Has the relationship between researcher and participants been adequately considered?</i>	No	F
<i>Have ethical issues been taken into consideration?</i>	Ethical permission was obtained from the Tokyo Metropolitan University Ethics Committee. We assured the participants of their voluntary participation, protection of confidentiality/privacy, and right to withdraw participation whenever they want. Moreover, we explained that they could choose the date of the interview, and could suspend the interview at any time according to their physical condition. Lastly we explained the possibility of publishing our research findings in the future	P
<i>Was the data analysis sufficiently rigorous?</i>	Yes p. 38	P
<i>Is there a clear statement of findings?</i>	Yes	P
<i>How valuable is the research?</i>	Yes	P
Total passes out of 10		9

* *Pass/Fail column added for the purpose of the current study

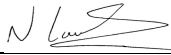
Dudley-Brown (1996): Living with Ulcerative Colitis		
Appraisal questions	Comments	P/F*
<i>Screening: Was there a clear statement of the aims of the research?</i>	p.61 both aim and research question are laid out	P
<i>Screening: Is a qualitative methodology appropriate?</i>	Describe the themes and interpretation of individuals with UC	P
<i>Was the research design appropriate to address the aims of the research?</i>	In depth interviews	P
<i>Was the recruitment strategy appropriate to the aims of the research?</i>	Not specified – Convenience	F
<i>Were the data collected in a way that addressed the research issue?</i>	Interviewed in her home, in depth semi structured interview p.61	P
<i>Has the relationship between researcher and participants been adequately considered?</i>	No	F
<i>Have ethical issues been taken into consideration?</i>	Some, verbal consent and use of pseudonyms, preserve anonymity and erase audiotape p.61	P
<i>Was the data analysis sufficiently rigorous?</i>	Themes generated	P
<i>Is there a clear statement of findings?</i>	Sectioned appropriately	P
<i>How valuable is the research?</i>	Informative of the view of mother with UC	P
	Total passes out of 10	8



* *Pass/Fail column added for the purpose of the current study

Fieldwork Project Details (FMDH – SPS – JGAM- EXIBD)	
Faculty School/Service	Faculty of Medicine and Health/ Institute of Psychological Sciences
Location of Fieldwork	The fieldwork will involve travelling within the United Kingdom
Brief description of Fieldwork activity and purpose	<p>One-on-one interviews with participants at their preferred date, location and time. Each participant will be interviewed once. The interviewer will collect qualitative data about the transition to motherhood within the context of Inflammatory Bowel Disease (IBD). The data will be recorded via audio or video recording in a quiet and suitable place.</p> <p>The fieldwork will constitute meeting with adult mothers with Inflammatory Bowel Disease (IBD) to discuss the challenges and personal experience of motherhood within the context of IBD. Through various recruitment procedures (snowballing, local groups, and newsletter article) the participants were approached and an initial contact has been established before the face-to-face interview. The interview will only occur face-to-face if the participants requested to do so, phone interviews will be conducted in the latter case. The location will be off campus as the lead researcher is trying to accommodate to the participants' preference in order to establish a good initial rapport. Furthermore, allowing the participants to choose the location whether their home or a nearby public place may put them at ease. It is the firm belief of the lead researcher that only within such relaxed and natural environment can the participants disclose about their personal experience. This level of relaxation will not be achieved in a formal setting such as the lead researcher's office or in laboratory.</p>
Fieldwork itinerary <i>e.g. flight details, hotel address</i>	The field researcher will travel by means of local public services either train or bus and will restrict the time away from university to working time. No down time or personal time will be used during the field work.
Organiser Details	Contact details <i>Name, email, telephone</i>
Fieldwork Activity Organiser / Course Leader	Professor Anna Madill, email. A.L.Madill@leeds.ac.uk
Departmental Co-ordinator	Neil Lowley Health and Safety Coordinator Telephone: 0113 343 5705 Email: n.a.lowley@leeds.ac.uk
Nature of visit <i>Size of Group, lone working, staff, postgraduate, undergraduate</i>	The postgraduate student will conduct the interview on a one-to-one basis. Some lone working may be required.
Participant Details <i>Attach information as separate list if required</i>	Contact details <i>Name, Address, email, telephone, Next of Kin contact details</i>
	<p><u>Participant Contact Details</u> Name: Jihane Ghorayeb Address: Shay Street, St Marks Court, Studio 45, LS62QJ, Leeds, UK Email: ps12jg@leeds.ac.uk Mobile: +44(0)776 357 5105</p> <p><u>Next of Kin Contact Details</u> Name: Richard Ghorayeb Relationship: Father Address: Sami el Solh Boulevard, Ghorayeb Building 7th floor, 9911, Beirut, Lebanon Email: richard.obs@gmail.com Mobile: +961(0)3 688 829</p>

Appendix D Risk Assessment for Fieldwork and Lone Working (Medium Risk Activities)

HAZARD IDENTIFICATION	
<i>Identify all hazards specific to fieldwork trip and activities, describe existing control measures and identify any further measures required.</i>	
HAZARD(S) IDENTIFIED	CONTROL MEASURES <i>(e.g. alternative work methods, training, supervision, protective equipment)</i>
<p>Nature of the site <i>School, college, university, remote area, laboratory, office, workshop, construction site, farm, etc</i></p> <p>Participants home or agreed upon public spaces (coffee shops, mall area community centre etc.)</p>	<p>Control measures</p> <ul style="list-style-type: none"> • Use of BUDDY system to monitor whereabouts of researcher (A phone call or text message will be sent informing the named contact about the safe arrival at a participants home or other arranged public space, and subsequent leaving of the same). • Check bus/train timetable before travel • Take reasonable precautions when visiting unfamiliar locations e.g. no valuables on display, use of backpack secured on the waste to carry the recording equipment <p>Work in participants' homes – control measures</p> <ul style="list-style-type: none"> • The researcher will let supervisor know when and where she is interviewing and a safety protocol has been completed. • Carrying of mobile phone with battery charger at all times by lone worker • Take reasonable precautions when working in participants' homes (e.g. identify safe means of exit, elevators and/or stairs) <p>If the researcher feels at all uncomfortable during a home visit (or other location) from:</p> <ul style="list-style-type: none"> • pets (i.e., aggressive dogs), she should politely ask if the animal can be put in another room/outside • other people, she should consider bringing the testing to a close and leaving the premises
<p>Process <i>Operating machinery, electrical equipment, driving vehicles, handling or working with animals etc</i></p> <p>Battery recorder – Laptop</p>	<p>Operating recorder (iPad) – ensure these are safety checked before commencing field work. Laptop will be encrypted and temporarily stored data on recorder will be transferred to secure storage immediately following visit.</p> <p>Any mains supplied equipment will be PAT's before taken off campus.</p>
<p>Transport <i>Mode of transport</i></p> <p>Public Transport - By foot or taxi</p>	<p>Check bus/train timetables before travel and use taxis when needed if bus routes do not offer easy walking access to participants' homes or preselected location.</p>
<p>Equipment <i>manual handling risks, operation of machinery, tools, use of specialist equipment etc</i></p> <p>Minimal Manual handling</p>	<p>Minimal equipment will be carried – a tripod, a laptop and/or iPad (battery operated), all of which can be transported in a secure regular backpack.</p> <ul style="list-style-type: none"> • iPad, tripod, and laptop – previously checked and secured by the IT department • The equipment poses no more risk than usual for handling or carrying the tripod or electronic tablets. • The equipment will be carried in a suitable backpack adapted for the equipment that is secured on the waste • The researcher will practice before the interview how to handle the tripod and how to run the recording device
<p>Violence <i>potential for violence (previous incidents etc)</i></p> <p>None foreseen except working in an unfamiliar location</p>	<p>An initial contact with the participants will have been established before interview (either through local groups or via telephone/email)</p> <p>Researcher will inform the lead supervisor of her whereabouts and estimated time of leaving interview and will phone to confirm when she is on her way home</p> <p>Researcher will not attend interview if at all concerned about safety in area on arrival</p> <p>Researcher will be carrying of a fully charged mobile phone at all times</p> <p>Researcher will take reasonable precautions when visiting unfamiliar locations e.g. no valuables on display</p> <p>Researcher will take reasonable precautions when working in participants' homes e.g. identify safe means of exit</p>
<p>Individual(s) <i>medical condition(s), young, inexperienced, disabilities etc</i></p> <p>Female, young, relatively inexperienced</p>	<p>The researcher is a young female and relatively inexperienced. A safety protocol has been established (see attachment) to secure health and safety at all times during lone working</p>
<p>Work Pattern <i>time and location e.g. shift work, work at night</i></p>	<p>There is a potential out of hours work – addressed when setting the meeting, preferably will be set during daylight hours. The researcher might have to travel and sleep in hotel the night before to accommodate for early hour meetings. The meetings</p>

Whenever feasible week days during daylight hours	will be held during week days whenever feasible. However, potential out of hour work (weekends and past 1700) might occur to accommodate to the participants preference. Whenever the researcher is undertaking fieldwork, she will limit the time to work time and return to base.	
Other <i>e.g. temperature, humidity, confined spaces</i>	The interview will be conducted in English and potential participants have been previous screened to be UK citizens fluent in English. The researcher will be aware of cultural differences and respect the culture adopted within the participants' home (removal of shoes etc.) The researcher comes from a Lebanese (Arab) background and is aware that differences might arise. The research will attempt to be respectful and considerate of all customs within reasonable limits.	
Cultural Consideration – The Researcher is a Lebanese Female of Arab background		
Additional Control Measures		
Pre-departure Briefing <i>Carried out and attended</i>		
Training <i>Identify level and extent of information; instruction and training required consider experience of workers</i>	Introduction to Risk Assessment – Level 1 <ul style="list-style-type: none"> • Know the definition of terms such as accident hazard, risk, likelihood, severity • Know the approach to risk assessment process • Have an understanding of the 5 steps to risk assessment Risk Assessment Workshop: Fieldwork Activities – Level 2 <ul style="list-style-type: none"> • Develop an awareness of the University Standard and Guidance on Fieldwork • Develop an understanding of the University's requirement for Fieldwork risk assessment • Identify activities that require a Fieldwork risk assessment and their corresponding risk level (Low, Medium, High) 	
Through the University of Leeds website two trainings have been identified to better prepare the inexperienced researcher. Bookings will be made to attend the trainings. Note, they are optional and not mandatory prior to the start of the research		
Supervision <i>Identify level of supervision required e.g. full time, Periodic telephone/radio contact</i>	As part of the lone working and previously highlighted. Telephone contact in line with BUDDY system procedures. As follows: <ul style="list-style-type: none"> • Researcher sends text to supervisor outlining – time of departure from home, time of arrival at participants home*, time of departure from participants home*. (* = or other location) • Supervisor confirms the text and awaits confirmation of safe arrival/departure • Participant address*, mobile phone of the participant and name will be placed in a sealed envelope handed to lead supervisor (or sent via a confidential email). A safety protocol has been attached to determine when the envelope can be opened. • If expected communication is not received supervisor will decide when and what appropriate escalation steps to take (discussed in advance with researcher). • See attached safety protocol 	
Telephone call in/call out and use of BUDDY system		
Other Controls <i>e.g. background checks for site visits</i>	Location checks prior to visit (online searches, individual feedback etc.)	
Identify Persons at Risk <i>This may include more individuals than the fieldwork participants e.g. other employees of partner organisations</i>	Jihane Ghorayeb – PhD Student Psychology University of Leeds.	
<i>Copy of other Organisation's risk assessment attached?</i> N/A		
Additional Information <i>relevant to the one working activity including existing control measures; information instruction and training received, supervision, security, increased lighting, emergency procedures, first aid provision etc.</i>	Additional information on a separate protocol sheet.	
Residual Risk <i>Is the residual risk acceptable with the identified controls?</i>	Yes	
	No	
Assessment carried out by	Name:	Neil Lowley – HS&FACILITIES OFFICER
	Signature:	
	Date:	02 – 08 - 2014
	Name:	Jihane Ghorayeb

Names of person(s) involved in Fieldwork <i>N.B: This can take the form of a signed class register when large group work</i>	Signature:	
	Date:	07-08-2014
Fieldwork Activity Organiser / Course Leader <i>e.g. PI, etc</i>	Name:	Professor Anna Madill
	Signature:	
	Date:	7/8/14

Appendix E Safety Protocol for Risk Assessment

Research Interview Safety Protocol (Home Visit) Researcher Trainee and Research Tutor or Research Supervisor

- Researcher to pre-arrange call-in/call-out system with Tutor/Supervisor a few days before each scheduled home visit, to ensure Tutor/Supervisor is available.
- Should there be a time when Tutor/Supervisor is unable to be the contact person then the researcher will arrange call-in/out system with a colleague/friend, who will also have access to the following protocol. The Researcher will subsequently inform Tutor/Supervisor of the name of the person 'standing in'.
- Researcher will email Tutor/Supervisor (University and home email) the day before the visit with details of the address she is to visit, the name of the person she is visiting, a contact phone no for that person, and the time the interview is to commence, and therefore the time to expect the first phone call.
- Tutor/Supervisor will confirm receipt of this email by phoning Researcher's mobile.
- On arriving at the address of the interview, Researcher will phone Tutor/Supervisor (mobile or home phone no – pre-arranged) to say she is about to start the visit, and agree a time when the interview should be finished and she will call to say she has left the interview.
- Researcher will explain to the interviewee before the start of the interview that the University/Trust insists on this call-in /call-out system and that if the interview over-runs she will need to make a quick phone call.
- Researcher will then phone Tutor/Supervisor when the interview is finished, and she has left the house, at the pre-arranged time.
- If the interview over-runs for any reason, the researcher will take a break from the interview and phone Tutor/Supervisor to let her know this, and a second finish time will be agreed.
- If, on arrival at the address, the researcher has any concerns for her safety (location, environment, other persons at address, or interviewee), she will not proceed with the interview, informing the interviewee and Tutor/Supervisor, return to base, and attempt to re-schedule the interview at an alternative location.
- Researcher will endeavour to do home visit interviews during the day /early evening, rather than later on in the evening, or at weekends.
- If the Researcher is having trouble with her phone, or does not/cannot make the interview for some reason, or the interviewee cancels the interview, the Researcher has responsibility to let the Tutor/Supervisor know this asap, and will continue to attempt to make contact with Tutor/Supervisor until Tutor/Supervisor confirms the message by phoning Researcher's mobile, or another contact number.
- In the very, very unlikely situation that the Researcher is being held against her will, but is allowed to make/receive phone calls because the call-in and out system has been explained, the researcher will say in her phone call with Tutor/Supervisor "Ok, I will see you tomorrow at 6 PM at the department" (a time never arranged for meetings). In this unlikely event Tutor/Supervisor will immediately phone the police.
- In the event that the researcher does not phone at the agreed time:
 1. Tutor/Supervisor is to phone the Researcher on their mobile phone (details found at the bottom of the protocol)
 2. If no response, Tutor/Supervisor will phone the interviewee
 3. If no response, Tutor/Supervisor is to phone the police to report the researcher missing, giving details of address, person interviewed, and Researcher's personal mobile number.
 4. If appropriate, Tutor/Supervisor/police is to contact relative (emergency contact person)

Researcher's Contact details

Mobile number: 0776 357 5105

Address: 13, St Marks Court, Shay Street, Leeds, UK, LS6 2QJ

Emergency Contact Number:

Brother: +1 409 370 3944 (Ghassan Ghorayeb)

Father: +961(0) 368 8829 (Richard Ghorayeb)

Tutor or Supervisor Contact details:

Mobile: +44 (0) 792 933 9982

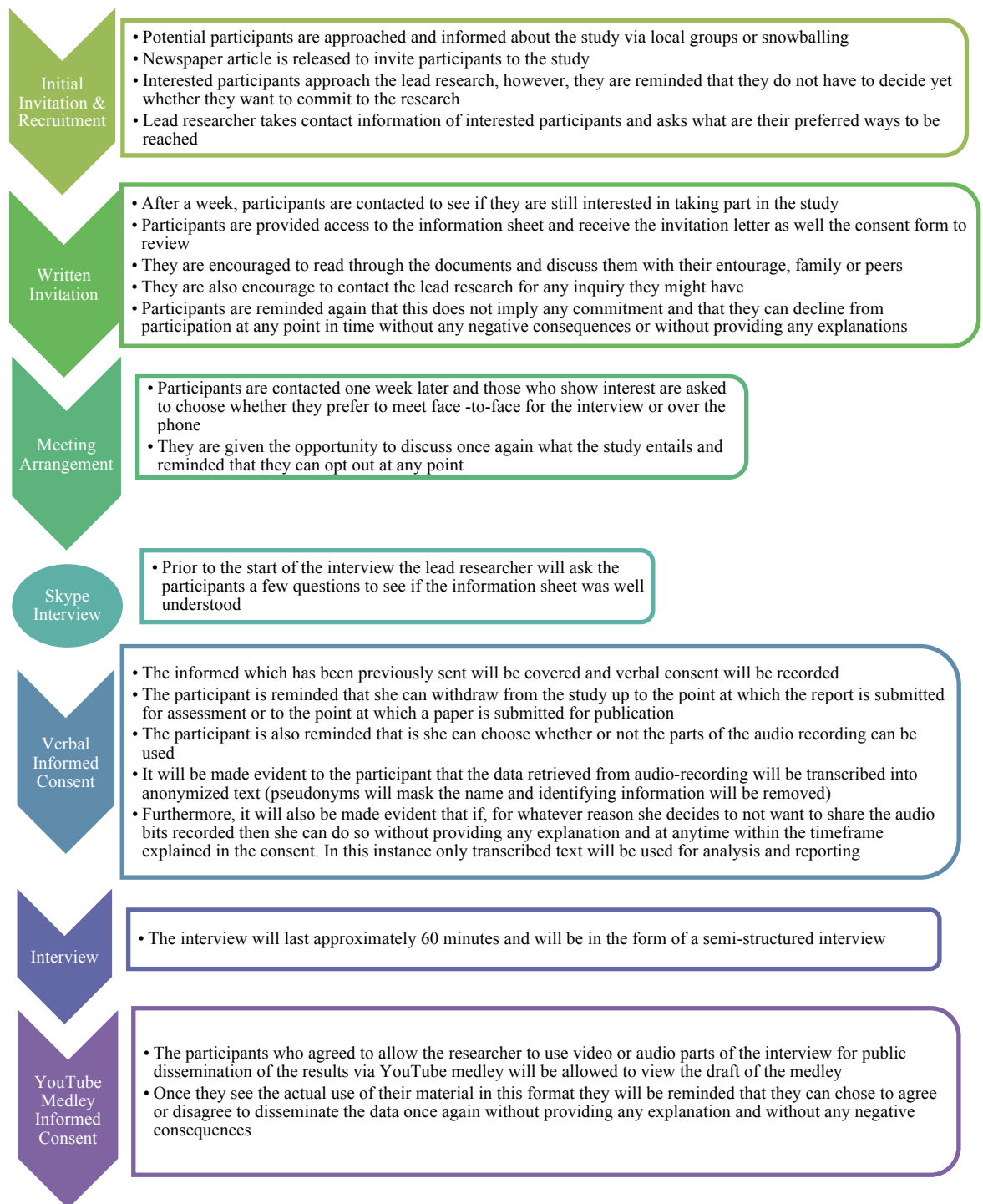
University Phone: +44 (0)113 343 5750

University Ext: 35750

Email: a.l.madill@leeds.ac.uk

Agreed by Researcher and Tutor – 07- AUG- 2014

Appendix F Flowchart of the Process of Consent for Participants Interviewed on Skype



Appendix G Invitation Letter

School of Psychology
University of Leeds
Leeds LS2 9JT, UK
Tel. +44 (0) 113 3435719

Dear [Insert Name],

I am writing to invite you to take part in a research interview inquiring about the unique experience of motherhood within the context of Inflammatory Bowel Disease (IBD). My name is Jihane Ghorayeb. I am a doctoral research student at the University of Leeds and I am particularly interested in the experience of starting a family, as well as coping with young children, in the context of maternal IBD.

The study is funded by the National Association of Crohn's and Colitis UK (NACC). The NACC – mostly known under its working name Crohn's and Colitis UK. CCUK is a British charity that supports individuals diagnosed with IBD as well as their families, friends, and care providers. It also supports research that will enhance the wellbeing of all those affected by IBD. The aim of my research is to provide more information to women with IBD, their partners, and healthcare providers about the specific challenges and distinctive experiences of having a baby. I would be extremely grateful if you could take the time to read the content of the documents I have enclosed:

- Participant Information Sheet: This document gives you detailed information about the purpose, risks, benefits, as well as conduct of the research.
- Informed Consent Form: Should you decide to take part in the study, we will go over this form to insure you are making an informed decision and that you are aware of your rights to withdraw from the research.
- Demographic Information Sheet: Should you decide to take part in the study this information will allow me to tailor my interview questions to your unique situation. It will also allow me to describe in general the *group* of women who took part in the research.
- Guidance for High-Quality Video-Recording: Should you decide to take part in this study and agree for the interview to be video-recorded this will help us create a good, ethically-sound recording.

The purpose of this letter is to invite you to meet me for an interview at your preferred time and location. I will do my utmost to accommodate to your schedule and agree on a quiet and suitable place to conduct the interview. More details of the process of the interview are found in the information sheet. You can also watch a short video about the study on the CCUK YouTube channel at www.youtube.com/watch?v=P9F0-l-717I and follow us on Facebook and Twitter @IBD and Mums-To-Be for more updates on the research.

I will contact you in about a week to see if you would like to be a part in this research. In the meantime, please feel free to contact me first if you wish to ask questions about the study or to inform me of your decision. You can find my contact details below.

Thank you for your time and consideration of the study,



Jihane Ghorayeb, Lead Researcher

School of Psychology
University of Leeds
Leeds LS2 9JT, UK
Tel. 0113 343 9195 or 0113 343 5750 (Professor Anna Madill, Supervisor)
ps12jg@leeds.ac.uk

Appendix H Information Sheet

1. Purpose of the Information Sheet

You are being invited to take part in a research project investigating the transition to and experience of motherhood within the context of maternal IBD. Before you decide whether you want to take part in this research, it is important for you to understand why the research is being done and what it will involve. Please take a few minutes to read the following information carefully and discuss it with others if you wish. If you have any queries or doubts please feel free to contact me.

2. Purpose of the Project

Background. Pregnancy and early motherhood can be one of the most joyful but also one of the most demanding phases of a woman's life. Pregnancy and early motherhood can be even more challenging when a woman has a serious chronic illness, such as IBD. Even so, a very recent survey concluded that "(t)here is a significant patient knowledge deficit about pregnancy and IBD resulting in unwarranted fears and anxiety" (Toomey & Waldron, 2013, p. 64) and, sadly, women with IBD are more likely than healthy controls to remain voluntarily childless (Beaulieu & Kane, 2011). Hence, it is surprising that there is little research informing women about, and preparing them for, the transition to motherhood with IBD.

Aim. The aim of the proposed investigation is to inform women, their partners, and healthcare providers about the experience of starting a family and coping with young children in the context of maternal IBD. The research also aims to produce short information videos for the CCUK YouTube channel to share the findings of the study.

3. Why have I been chosen?

The study is looking to recruit 20 to 24 women meeting the following criteria: (1) aged 18 years and older and who (2) have a medically-validated diagnosis of IBD, (3) have at least one of their own biological children – child to which she has given birth - around the ages of 2-7 years old, (4) are fluent in English, and (5) are currently living in the UK.

4. Do I have to take part?

It is entirely up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Even after you consent and agree to take part, you can still withdraw without giving a reason up to the point at which the research is submitted for examination or a research report is accepted for publication. If you have agreed for video- or audio-clips of your interview to be included in a YouTube video, we will amend the video to omit your clip at any time on request.

5. What do I have to do?

Step 1 If you have acquired this information sheet and the subsequent consent form through a website or a friend/acquaintance and wish to participate please contact me using the details found at the end. If I was the one to give you the form and already have your contact information, I will contact you within about a week to see whether or not you would like to take part in the study.

Step 2 Once in contact, I will use the opportunity to answer any of your questions regarding this information sheet and the subsequent consent form and, should you show interest, I will invite you to a one-time only, one-to-one interview. The interview length varies from one person to another but will last approximately 60 minutes; however, allowing a total of 2 hours is more cautionary to account for getting introduced and setting up the recording device. The questioning style will be semi-structured, meaning I will be using open-ended questions to enable you to recount your experience with as much or as little details as you desire. The interview format can be either face-to-face or via the telephone depending on your preference. If you choose a face-to-face interview, we will establish together a convenient time and place that is both comfortable to you and suitable for the interview (quiet and private). Please note that I will do my best to accommodate to your preference and will meet you at home or in a public place near your home if need be. If you are happy to be video-recorded, it is probably best if I visit you at your home or other private accommodation, such as a friend's house. If you choose a phone interview, again a convenient time and date will be established to conduct the interview. Obviously, a telephone interview will facilitate only audio-recording.

Step 3 On the day of the interview, we will go over the information sheet and consent form to clarify any questions you might have. The purpose of the consent form is to provide you with as much and as detailed information about what will happen to the data gathered from this interview. If we meet face-to-face, I will ask you to place your initials on each item you consent to; for a telephone interview, with your verbal consent I will start the audio-recording, read out each item on the consent form, and audio-record your verbal consent. If we meet face-to-face you can choose whether you would like to be video- or just audio-recorded. The interviews will be transcribed professionally by a company with whom we have a confidentiality agreement that they will treat the content of interviews as confidential, not divulge the content of the interviews or participant names, and will destroy all materials after they have been transferred to the research team.

Step 4 Once the interview is completed, I will thank you for your participation and time. A summary of the study findings will be available on the CCUK website as soon as possible after the end of the study in 2017/2018 and copyright consistent versions of any reports on Jihane Ghorayeb's website on Academia.edu. Videos summarising study findings will also be available on the CCUK YouTube channel and may be displayed by CCUK at events and workshops.

6. What type of information will be sought from me?

The interview questions will evolve around the experience of motherhood as a woman with IBD. I will ask you to tell your story right through from any plans you made in relation to becoming pregnant, the pregnancy itself, and the early phases of motherhood. The interview may cover both the ups and downs of your journey, your challenges and your triumphs, lessons learnt and the advice you would like to pass to other women starting out on a similar journey. We may therefore touch on painful memories and anxious moments and intimate experiences such as sexual activity, bodily functioning, and relationships with important people in your life. You have control over what line of questioning you are comfortable engaging with, and the amount of detail you give. I will also ask you to complete a short background questionnaire so that I have a few pertinent facts about your unique situation. These questions can be found at the link provided in paragraph 14 of this sheet. You will also find a link to an instruction sheet suggesting how to prepare for a high-quality video recording session.

7. How will the recorded media be used?

I will obtain permission from you via the consent form to record the interview via video- or audio-recording. Recordings will be transcribed (typed up) to allow me to study what you say in detail. I will ask your permission to use anonymised quotes from transcripts in reports of the research which will include my doctoral thesis, publications, and conference presentations. Your identity will be masked through the use of a pseudonym and through omitting or changing details which together might make you relatively identifiable. If you agree to either video- or audio-clips being used in YouTube videos on the CCUK channel, we will contact you again when these have been created to request your consent for this specific use after you have seen which clips have been selected and how, if necessary, highly identifying details (such as use of a name) have been masked.

8. Will my taking part in this project be kept confidential?

Audio- and video-recordings of the interview will be transferred to a password protected drive on the University of Leeds server as soon as possible after the interview and deleted from any other device. Copies of this material will be held on a digital memory device in a locked filing cabinet at the University of Leeds to ensure against loss. A professional transcription company will keep to a confidentiality agreement and delete all copies of material once transcripts have been transferred to the research team. Only anonymised copies of transcripts will be kept and used for analysis. Signed consent forms will be sealed in an envelope and placed in a locked cabinet in the supervisor's office (Professor Anna Madill). Completed background information questionnaires will be kept separately from the transcripts and in a lock filing cabinet so that only the research team will be able to link real participant names with anonymised transcripts for the purposes of the research (e.g., rechecking if participant 'Sarah' has Crohn's Disease or Ulcerative Colitis).

I am obliged to let you know that there are limits to confidentiality in research under some very unusual and specific circumstances: - if, during the interview, you reveal any intentions of harming yourself or others, or tell me about any serious criminal activity that you have been involved in, I will have to consult with my supervisor to decide on what action to take. However, I assure you that this kind of information is not sought in my research and I do not at all expect that this will be an issue.

9. When is the deadline for withdrawing?

You can withdraw at any point before, during and after the interview is conducted up to the point at which my thesis is submitted for examination or articles are accepted for publication – when it would be almost impossible to retract information. If you change your mind about clips from your interview being included in a YouTube video we will remove your clip as soon as we can after you ask us.

10. What are the possible risks of taking part?

In a single session interview the risks are really minimal. The only foreseeable risk would be to recall, through some of the questions, painful past feelings in relation to your journey to motherhood. For example, on the demographic information sheet some personal questions will be asked (i.e., whether you engaged in psychological counseling and the ‘diagnosis’ you might have gotten, the psychotropic medication you might have taken, whether your pregnancy was planned and you have experienced fertility issues). However, you have full control on how much detail you give and over the questions you answer. You may regret consenting to the use of your clips in YouTube videos, but can let us know and we will remove them. What we cannot control, however, is if copies of the videos have been downloaded and the subsequent use of such copies. We will only use your clips if you are still happy with this arrangement near the end of the project in 2017/18 when you have seen the actual clips we would like to use and we will be sensitive with regards to the type of clip we choose. Hence, hopefully, the chance of having later regrets is minimal.

11. What are the possible benefits of taking part?

Whilst there are no immediate benefits from participating in the interview, it is hoped that you will benefit from having a set time to talk about your experiences of becoming a mother to an empathic and interested researcher (me). The research aims to support other women with IBD who are considering making a similar journey, so the sense that you are contributing to their informed decision-making may be pleasing.

12. Ethics

The ethical guidelines for this research have been set out by the British Psychological Society code of ethics. These guidelines include ethical principles such as making sure you know how the interview will be used and that you consent to take part in the research. This research has received ethical approval (ref no: 14-0280 on 10, Nov, 2014). If, however, you have any comments or complaints regarding my conduct you may contact directly my supervisor, Professor Anna Madill, who will be happy to discuss appropriate actions to undertake (contact details below). From this information sheet I hope you have had sufficient information about my study. Please feel free to send me an email or contact me via telephone at any time with your queries (contact details below).

13. Who is organising/ funding the research?

The National Association of Crohn’s and Colitis UK (NACC) are funding the study. The NACC – mostly known under its working name Crohn’s and Colitis UK (CCUK) – is a British charity that supports individuals diagnosed with IBD as well as their families, friends and care providers. They provide both information and funding for research that will enhance the wellbeing of all those affected by IBD.

14. Some resources

- **CCUK website:** www.crohnsandcolitis.org.uk
- **CCUK Facebook:** www.facebook.com/CCUK-Leeds-and-District-Group#!/pages/CCUK-Leeds-and-District-Group/128103847225851
- **CCUK information booklet**
<http://www.crohnsandcolitis.org.uk/Resources/CrohnsAndColitisUK/Documents/Publications/Booklets/Crohns-Disease.pdf>
- **CCUK support-line: 0845 130 3344 or 0121 737 9931.** This service is available Monday to Friday, except English bank holidays, from 1:00pm-3:30pm and 6:30pm-9:00pm
- **CCUK information-line: 0845 130 2233.** This service is available Monday to Friday, except English bank holidays, from 10:00am-1:00pm

- **NHS information-line:** 111, For information on a support centre near you go to:
<http://www.nhs.uk/Service-Search/Information-and-support-for-inflammatory-bowel-disease/LocationSearch/352>
- **Link to demographic questionnaire:**
https://www.academia.edu/7916986/Background_and_Demographic_Information_Sheet
- **Link to instruction for high-quality recording:**
https://www.academia.edu/7917250/Instructions_for_High-Quality_Recording

15. Contact us

Lead Supervisor	Lead Researcher
<p>Professor Anna Madill</p> <p>Professor in Qualitative Inquiry School of Psychology University of Leeds Leeds, UK, LS2 9JT Tel. 0113 343 5750 Email. a.l.madill@leeds.ac.uk</p>	<p>Jihane Ghorayeb</p> <p>PhD Student School of Psychology University of Leeds Leeds, UK, LS2 9JT Tel. 0113 343 9195 Email. ps12jg@leeds.ac.uk</p>

Appendix I Background Information Sheet

Instructions: Please take 5 minutes to fill out to the best of your ability the following questionnaire. You may decide not to complete all the questions. This is quite alright and we still hope you will take part in the interview. This questionnaire is designed to help us describe the *group* of women who wish to take part in the study and will not be used in a way that might lead to the identification of individual women. It is also designed to help inform the interview so that we do not spend a lot of time at the start getting details about you, your IBD and family structure that we can gather in advance.

I. Demographic Information

1. What is your ethnicity?

White	
Mixed / Multiple Ethnic Groups	
Asian / Asian British	
Black / African / Caribbean / Black British	
Prefer not to say	
Other	Please specify

2. What is your marital status?

Single / Not in relationship	
Separated / Divorced	
In long-term relationship /Married /Common law partner	
Prefer not to say	
Other	Please specify

3. What is your highest educational achievement?

Primary school	
Secondary school	
Apprenticeship / City and guilds / NVQ level 2 or 3 / or Similar	
Bachelor	
Master/PhD	
Prefer not to say	
Other	Please specify

4. Are you currently working outside the home?

Yes – working full time	
Yes – working part time	
No – but in full time education	
No – unemployed	
No – home-maker	
Prefer not to say	
Other	Please specify

5. What is your current household income? (Combined, if applicable)

Below 10,000 GBP >	
10,000 GBP < and < 15,000 GBP	
15,000 GBP < and < 30,000 GBP	
30,000 GBP < and < 45,000 GBP	
Above 45,000 GBP <	
Prefer not to say	

6. What is your current country of permanent residence? _____

7. What is your current postcode? _____¹

¹ (We will always keep this **confidential**, but it allows us to describe more about the economic situation in general of the *group* of women who took part in the study)

II. Background and Family Information

1. How many children do you currently have? _____

2. Please provide the following information for each of your children: (including step and adopted):

	Age of the child as of this day (years)	Age at which you had the child (years)	Gender (M/F)	Given Name	Is he or she your biological child? (Yes, No: Adopted, Step)	If you have more than one child, Is he or she from the same father as the others? (Y/N)
First Born						
Second Born						
Third Born						
Fourth Born						
Fifth Born						
Sixth Born						

3. At what age did you receive your diagnosis? _____

4. What is your age as of this day? _____

5. How many of your children were born before your diagnosis was made? _____

6. How many of your children were born after your diagnosis was made? _____

7. How many pregnancies have you had in total (include miscarriages, still pregnancy)? _____

III. Background Information about IBD

1. What form of IBD do you have?

Crohn's Disease (includes Crohn's Colitis)	
Ulcerative Colitis	
IBD-Unclassified / Indeterminate Colitis	
Unsure	
Other	<u>Please specify</u>

2. Do you take any treatment or any form of lifestyle management for your IBD? (Tick where applicable)

1. Yes, I am currently under treatment		
	I currently take medication	<u>Which ones:</u>
	I am scheduled to receive surgery	
	I manage my dietary intake	
	I am in psychological therapy (counselling)	
	If Yes, did you receive a diagnosis?	Yes No
	<u>Please specify</u>	
	Have you been prescribed some form of medication?	Yes No
	<u>Please specify</u>	
2. I have previously received treatment		
	I took medication	<u>Which ones:</u>
	I received a surgical intervention	Yes No
	Removal of the large bowel with pouch [Restorative proctocolectomy, also known as ileoanal pouch anal anastomosis (IPAA)]	
	Removal of large bowel with stoma [Colectomy with stoma bag (external pouch)]	
	Removal of small bowel [Resection]	

	Widening the narrowing of the bowel caused by scar tissue [Strictureplasty]	
	Other—(Please specify)	
	I used to manage my dietary intake	
	I was in psychological therapy (counselling)	
	If Yes, did you receive a diagnosis?	Yes No
	<u>Please specify</u>	
	Have you been prescribed some form of medication?	Yes No
	<u>Please specify</u>	
3. Never had any form of treatment		

3. Did you take any medication or receive any form of treatment while pregnant?
No, Yes, Please specify _____

IV. General Inquiry

1. How did you hear about the study IBD and Mums-To-Be? (Tick where applicable)

CCUK Support Group	
CCUK Article	
Facebook Group	
Twitter	
Academia.edu Website	
Other	

Appendix J Consent Form

		Add your initials next to the statement if you agree
1	I confirm that I have read and understood the information sheet version 3 explaining the above research project and I have had the opportunity to ask questions about the project	
2	I confirm that I have received satisfactory answers to all of my questions (if any)	
3	I confirm that I am at least 18 years old and currently residing in the United Kingdom	
4	I confirm that I am a mother with at least one biological child – child to which I have given birth – currently aged around 2-7 years old	
5	I confirm that I have a medically-validated diagnosis of Inflammatory Bowel Disease (IBD)	
6	I understand that my participation is voluntary and that I am free to withdraw at any time, up until the point at which the thesis is submitted for examination or reports accepted for publication, without having to give a reason	
7	I understand that, if I do not wish to answer any particular question or questions, I am free to decline without providing any reason and can stop the interview at any time	
8	I agree to the interview being video-recorded (which includes audio-recording)	
9	I agree to the interview being audio-recorded only	
10	I grant permission for transcribed extracts from the interview to be used in reports of the research on the understanding that my anonymity will be maintained to the extent possible	
11	I understand that, if clips from the interview are selected for inclusion in short, informative YouTube videos for CCUK, I will be re-contacted to request permission for this use and provide access to the actual clips to allow me to make an informed decision	
12	I give permission for members of the research team (Jihane Ghorayeb, Professor Anna Madill, and Dr Peter Branney) to have access to all my research data on the condition that they keep my identity confidential - this will help validate analysis of the data	
13	I agree for the data collected from me to be used and shared in relevant future research with other researchers on the condition that my identity will not be revealed	
14	I agree to take part in this research	
15	If I have agreed to be re-contacted about the use of clips, I will inform the lead researcher should my contact details change before the end of 2018	

16	<p>Lead researcher: Jihane Ghorayeb Tel. 0113 343 9195 Email. ps12jg@leeds.ac.uk</p> <p>If you wish to decline or withdraw from participation at any time, up until the deadline specified here above, all data gathered up until that point will be destroyed with respect to the RCUK guidelines. Paper-based materials will be shredded and electronic data will be overwritten. Please contact the primary researcher to inform her of your decision.</p>	
Signatures		
Name of participant:		
Address:		
Telephone/Mobile:		
Email		
Preferred way to be reached		
Participant's signature		
Date		
Jihane Ghorayeb		
Signature		
Date		

Appendix K IBD and Mums-To-Be: Confidentiality Agreement Form

Ethics Committee, Institute of Psychological Sciences, University of Leeds

The British Psychological Society has published a set of guidelines on ethical principles for conducting research. One of these principles concerns maintaining the confidentiality of information obtained from participants during an investigation.

As a transcriber you have access to material obtained from research participants. In concordance with the BPS ethical guidelines, the Ethics Committee of the Institute of Psychological Sciences requires that you sign this Confidentiality Statement for every project in which you act as transcriber.

General

- ◆ I understand that the material I am transcribing is confidential
- The material transcribed will be discussed with no-one
- ◆ The identity of research participants will not be divulged

Transcription Procedure

Transcription will be conducted in such a way that the confidentiality of the material is maintained

I will ensure that audio-recordings cannot be overheard and that transcripts, or parts of transcripts, are not read by people without official right of access

All materials relating to transcription will be returned to the researcher

Signed



Date 27/10/14

Print Name

Adele Herson

Project IBD and Mums-To-Be: Transition to motherhood with IBD

Lead Researcher Jihane Ghorayeb

Appendix L The Typing Works: Confidentiality Agreement Form

CONFIDENTIALITY AGREEMENT

Unless we are notified otherwise in writing, all documents and information that we see or hear whilst working for Jihane Ghorayeb shall be treated as confidential. Such documents or information shall not be used except for the purposes for which they were made available to us and such documents and information shall not be disclosed to any other person without your prior written consent. Likewise, projects worked upon on behalf of Jihane Ghorayeb cannot be used to promote ourselves or our company in any form of publicity campaign or promotion without the written consent of Jihane Ghorayeb.

On completion of the project all transcriptions and digital audio files will be deleted from our system unless requested otherwise.

I accept the terms of the above confidentiality agreement and am authorised to accept it on behalf of the company named below. I will ensure that all personnel working on this project for the company are also bound by this agreement.

Company: The Typing Works Limited

Name: Adèle Herson

Signature: 

Date: 27th October 2014

The Typing Works Limited
Registered Office: 8th Floor, Elizabeth House, 54-58 High Street, Edgware, Middx HA8 7EJ
Registered in England No. 6870523 VAT No: 152 1369

Crohn's and Colitis UK Website, Autumn 2014

<http://www.crohnsandcolitis.org.uk/whats-new/ibd-and-mums-to-be-research-study>

IBD and mums-to-be research study

Pregnancy and early motherhood can be one of the most joyful but also one of the most demanding phases of a woman's life. Pregnancy and early motherhood can be even more challenging when a woman has a serious chronic illness, such as Inflammatory Bowel Disease (IBD).

However, even if a woman has active IBD at the time of conception, 1/3 will get no worse and 1/3 will actually experience improvement in their symptoms during pregnancy.

Nevertheless, women with IBD are more likely to remain voluntarily childless or, on average, have fewer children compared to women in the general population.

Moreover, a recent survey by Toomey and Waldron concluded that "there is a significant patient knowledge deficit about pregnancy and IBD resulting in unwarranted fears and anxiety".



Crohn's and Colitis UK has funded Professor Anna Madill (University of Leeds) and Dr Peter Branney (Leeds Beckett University) to research the transition to motherhood with IBD.

The aim of this research is to inform women, their partners, and healthcare providers about the experience of planning and starting a family, and coping with young children in the context of maternal IBD.

If you are a mum with IBD with at least one birth child between the ages of 2 and 7 years old, we would like to invite you to take part in a 60-minute interview about your experiences.

Find more information about the study at leeds.academia.edu/JihaneGhorayeb, or email the project researcher, Jihane Ghorayeb at ps12jg@leeds.ac.uk.

This research received ethical approval on 08 August 2014, reference 14-0141.

news 

IBD and mums-to-be

Researchers are hoping to improve the amount of information available about IBD and pregnancy and motherhood.

Having a baby brings major lifestyle changes and can be even more demanding for those with Crohn's Disease or Ulcerative Colitis. However, there is relatively little information available for people with IBD.

A group of researchers at the University of Leeds are hoping to remedy this. A new research study, funded by Crohn's and Colitis UK, has been designed to gather information from new mothers to develop helpful information for mums-to-be, and their healthcare providers.




Photo: Alan Jackson

The researchers would like to interview 20 to 24 women living in the UK who have IBD, and have at least one child aged 2-7 years old. The one-to-one interview will last an hour and will be videoed or audio recorded. It can take place in the mother's home or another quiet location if preferred. It can also be carried out on Skype or over the phone.

If you are interested in taking part or would like further information, contact Lead Researcher Jihane Ghorayeb on ps12jg@leeds.ac.uk or Professor Anna Madill (Lead Supervisor) on a.l.madill@leeds.ac.uk

Appendix O Mumsnet Advertisement



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Mumsnet Talk

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This is page 1 of 1 (This thread has 1 message)

This topic is for non-members looking for MN users' input; there is a £30 fee.

IBD and Mums-To-Be Research Study (1 Post)

MEDIA: IBD and Mums-To-Be Research Team Tue 21-Oct-14 [Add message](#) | [Report](#) | [Message poster](#)
 11:14:25

Pregnancy and early motherhood can be one of the most joyful but also one of the most demanding phases of a woman's life. Pregnancy and early motherhood can be even more challenging when a woman has a serious chronic illness, such as Inflammatory Bowel Disease (IBD).

However, even if a woman has active IBD at the time of conception, 1/3 will get no worse and 1/3 will actually experience improvement in their symptoms during pregnancy. Nevertheless, women with IBD are more likely to remain voluntarily childless or, on average, have fewer children compared to women in the general population. Moreover, a recent survey by Toomey and Waldron concluded that *"there is a significant patient knowledge deficit about pregnancy and IBD resulting in unwarranted fears and anxiety"*.

Crohn's and Colitis UK has funded Professor Anna Madill (University of Leeds) and Dr Peter Branney (Leeds Beckett University) to research the transition to motherhood with IBD. The aim of this research is to inform women, their partners, and healthcare providers about the experience of planning and starting a family, and coping with young children in the context of maternal IBD.

If you are a mum with IBD with at least one birth child around the ages of 2 and 7 years old, we would like to invite you to take part in a 60-minute interview about your experiences.



Find more information about the study on [Facebook/IBDandMumsToBe](#), [Twitter/IBDandMumsToBe](#), [Academia/JihaneGhorayeb](#), or email the project researcher, Jihane Ghorayeb at ps12jg@leeds.ac.uk

This research received ethical approval on 08 August 2014, reference 14-0141.

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UNIVERSITY OF LEEDS

IBD AND MUMS-TO-BE

Research Study

Sept 2014- Sept 2016

Ethics Reference No: 14-0141-date approved: 08-Aug-2014

-  Are You A Mum With IBD?
-  Do You Live In The UK?
-  Do You Have A Birth Child Between 2 To 7 Years Old?
-  Are You Willing To Tell A Researcher About Your Experiences Of Becoming A Mum?

Contact Us For a 60 minutes Interview



JIHANE GHORAYEB LEAD PROJECT RESEARCHER PS12JG@LEEDS.AC.UK

ANNA MADILL LEAD PROJECT SUPERVISOR A.L.MADILL@LEEDS.AC.UK

Appendix Q Conferences, Symposiums, and Oral Presentations

• 2015

Oral Presentations and Symposium

- o Resonances Qualitative Research Group (March 17): Led a 1-hour discussion on reflexivity
- o Presented preliminary themes and results using thematic analysis at QMiPaL (April 20)
- o Health and Social Research meeting (May 18): I had a mock trial to present my Transfer Viva report
- o Qualitative Meeting (June 2): I had a second mock trial to present my Transfer Viva report
 - o Transfer Viva Talk (June 3): Provided insight on my personal experience to first year PG
 - o BPS Oral presentation and Symposium (September 6&7)
- o Annual White Rose PGR conference (September 30): I presented to the new PGR my findings and worked carried out in the past 15 months
 - o PG-Led Presentation at the University of Leeds: Conducting Thematic Analysis (December 14)

Invited Talk

- o Crohn's and Colitis Forum Talk at St. James Hospital (April 25)

Award

- o LeedsforLife Bursary – Santander's – Bursary to attend the BPS Conference (Sept. 2015)

• 2016

Invited Talks

- o IBD Summit 20 min Oral Presentation (January 30) – received an honoraria from Takeda to present the findings at the annual IBD Summit in Birmingham.
- o IBD New Nurse Study Day: Presented the 5-phases model in Manchester (April 14) – Honorarium invitation
 - o Presented at the CCUK Open Forum Day – Blurred Lines at St James Hospital Leeds (April 16th)
- o Lunch and Learn (October 6), interview with CCUK members Q&A with audience about the study
 - o Attended the Patient Engagement Day held at Headingley Leeds (October 29)

Awards

- o Merck Sharp Dohme (MSD) Honorarium – New IBD Nurse Study Day (Apr. 2016)
- o Takeda Honorarium – IBD Summit (Jan. 2016)

• 2017

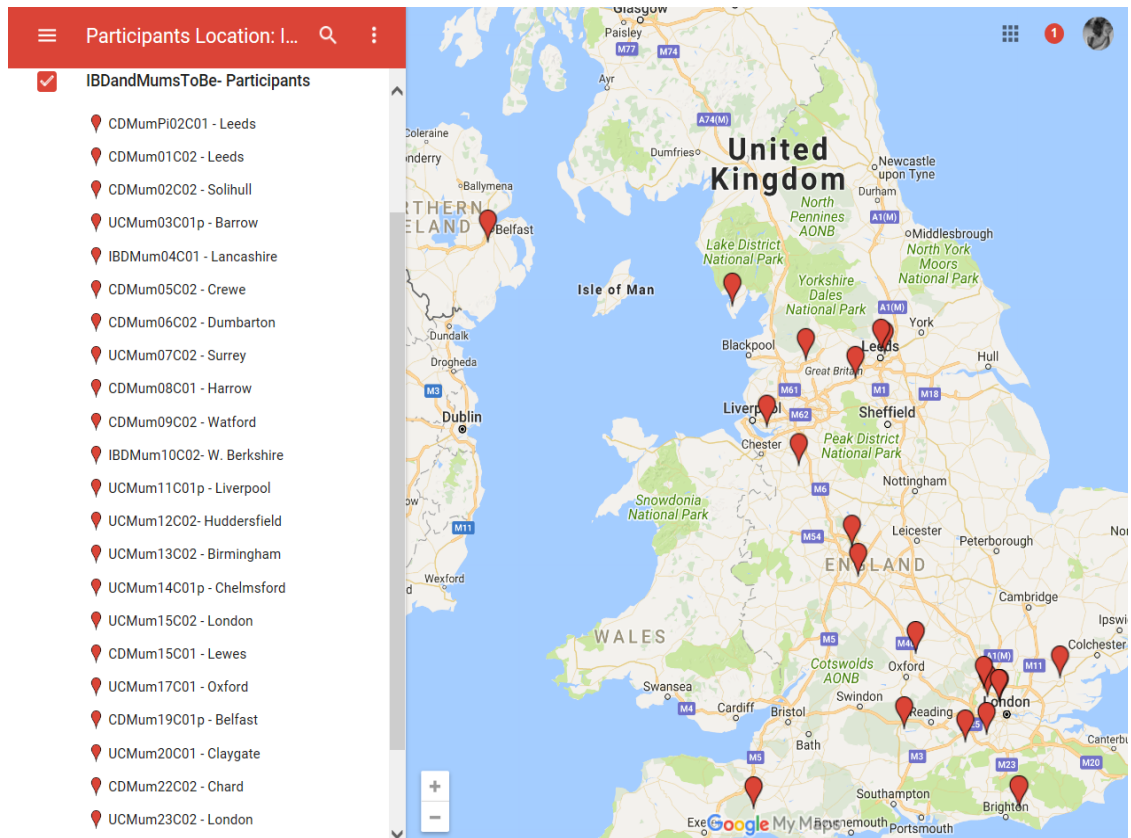
Oral Presentation

- o International Conference for Applied Counselling and Psychology 2017: Similarities between Motherhood and IBD (February 7&8)

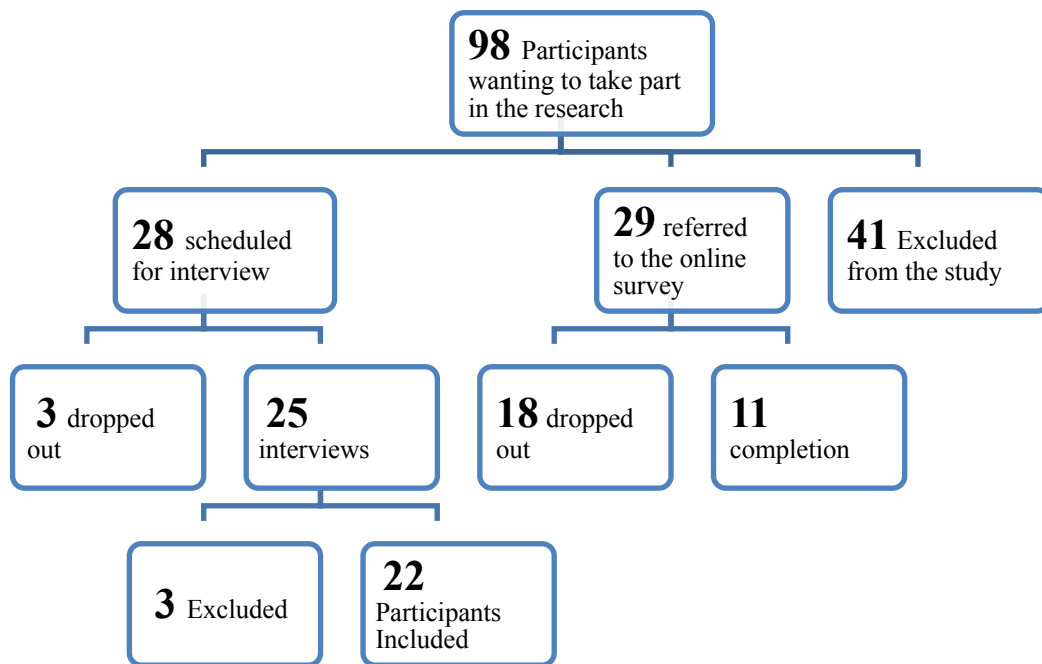
Award

- o Impact Acceleration Account – Research Grant (Jul. 2017 - Aug. 2017)

Appendix R Map of the Geographical Location of the Sample



Appendix S Recruitment Map



Appendix T Online Survey



IBD and Mums-To-Be

0% complete

Page 1: Welcome

Welcome to **IBD and Mums-To-Be** Online Survey.

This survey aims to get a better understanding of the experience of planning and starting a family, as well as coping with young children, in the context of maternal IBD.

This research is funded by Crohn's & Colitis UK and has ethical approval from the School of Psychology, University of Leeds (Number: 14-0280, date: 21-Nov-2014). The study is lead by Professor Anna Madill (A.L.Madill@leeds.ac.uk) and researcher Jihane Ghorayeb (P.s12jg@leeds.ac.uk).

Please note that this survey is completed **confidentially** and can be saved part way through. The first part consists of 9 questions about your experience of being a mother with IBD and there is room for written responses from you. The second part consists of a few demographic questions to help us describe the group of women who took part in the study. All questions are **optional**, so please feel free to write as little or as much as you want.

The data collected in this survey will be held and downloaded **anonymously** and **securely**. Potentially identifying information you might mention in your answers (such as names and locations) will be appropriately masked once the responses are retrieved for analysis.

Please be aware that once you have clicked on the CONTINUE button at the bottom of each page you cannot return to review or amend that page.

Submit and continue >

If you submit your answers you will **not** be able to return to this page.



IBD and Mums-To-Be

50% complete

Page 3: IBD and Mums-To-Be

The following questions are about your unique experience of becoming a mother within the context of IBD.

Note that once you have clicked on the "CONTINUE" button your answers are submitted and you can not return to review or amend that page.

The **"MORE INFO"** button next to each question offers some advice about what you might like to tell us. This is just to help you get started, so please do not feel limited by what we suggest.

- 1 Can you tell us about the context and background to you becoming diagnosed with IBD?

More info

- 2 Can you tell us about the context and background to your pregnanc(ies)?

More info

3 Can you tell us how IBD impacted your pregnanc(ies) and how your pregnanc(ies) impacted your IBD?

[More info](#)

4 Did you discuss 'being pregnant with IBD' with anyone - both before and during your pregnanc(ies)?

[More info](#)

5 Can you describe who and what was most helpful to you in coping with being pregnant with IBD?

[More info](#)

6 In what ways did having IBD impact the actual process of giving birth?

[More info](#)

7 Can you tell us about the most difficult aspects of becoming and being a mother with IBD?

[More info](#)

8 Can you tell us what have been the most positive aspects of becoming and being a mother with IBD?

[More info](#)

9 If you were to share any advice with other women with IBD who are considering setting out on the journey to motherhood, what would that be?

[More info](#)

[Submit and continue >](#)

[Finish later](#)

IBD and Mums-To-Be

75% complete

Page 4: Demographic Information

The following questions will gather some information about your background and demographics so that we can describe the group of women who took part in the research.

No identifying information is sought and all questions are **optional**.

Please refer to the **More Info** box for more details regarding Q. 16 and Q.24

Background Information

10 What is your ethnicity?

- White
- Mixed / Multiple Ethnic Groups
- Asian / Asian British
- Black / African / Caribbean / Black British
- Prefer not to say
- Other

a If you selected Other, please specify:

11 What is your marital status?

- Single / Not in relationship
- Separated / Divorced
- In long-term relationship /Married /Common law partner
- Prefer not to say
- Other

a If you selected Other, please specify:

12 What is your highest educational achievement?

- Primary school
- Secondary school
- Apprenticeship / City and guilds / NVQ level 2 or 3 / or Similar
- Bachelor
- Master/PhD
- Prefer not to say
- Other

a If you selected Other, please specify:

13 Are you currently working outside the home?

- Yes -- working full time
- Yes -- working part time
- No -- but in full time education
- No -- unemployed
- No -- home-maker
- Prefer not to say
- Other

a If you selected Other, please specify:

14 What is your current household income ? (combined, if applicable)

- Below 10,000 GBP >
- 10,000 GBP < and < 15,000 GBP
- 15,000 GBP < and < 30,000 GBP
- 30,000 GBP < and < 45,000 GBP
- Above 45,000 GBP <
- Prefer not to say

15 What is your current country of permanent residence?

a If you selected Other, please specify:

16 What is your current postcode?

More info

Family Information

17 Please provide the following information for each of your children:

Having trouble with the format of this question? [View in tableless mode](#)

	Gender		Is he or she your biological child?			Birthdate of the child	Age at which you had the child/became the child's step or adoptive mother?	If you have more than one child, is he or she from the same father as any of your other children?	
	Male	Female	Yes	No, Adopted child	No, Step child			Yes	No
First Born	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="text" value="dd/mm/yyyy"/>	<input type="text" value="Please select"/>	<input type="radio"/>	<input type="radio"/>
Second Born	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="text" value="dd/mm/yyyy"/>	<input type="text" value="Please select"/>	<input type="radio"/>	<input type="radio"/>
Third Born	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="text" value="dd/mm/yyyy"/>	<input type="text" value="Please select"/>	<input type="radio"/>	<input type="radio"/>
Fourth Born	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="text" value="dd/mm/yyyy"/>	<input type="text" value="Please select"/>	<input type="radio"/>	<input type="radio"/>
Fifth Born	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="text" value="dd/mm/yyyy"/>	<input type="text" value="Please select"/>	<input type="radio"/>	<input type="radio"/>
Sixth Born	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="text" value="dd/mm/yyyy"/>	<input type="text" value="Please select"/>	<input type="radio"/>	<input type="radio"/>

18 At what age did you receive your diagnosis of IBD?

Please select ↓

19 What is your age as of this day?

Please select ↓

20 How many of your children were born before your IBD diagnosis was made?

Please select ↓

a If you selected Other, please specify:

21 How many of your children were born after your IBD diagnosis was made?

Please select ↓

a If you selected Other, please specify:

22 How many pregnancies have you had in total (include miscarriages, still pregnancy)?

Background Information on Your IBD

23 What form of IBD do you have?

- Crohn's Disease (includes Crohn's Colitis)
- Ulcerative Colitis
- IBD-Unclassified / Indeterminate Colitis
- Unsure
- Other

a If you selected Other, please specify:

24 Please complete the following grid:

Having trouble with the format of this question? [View in tableless mode](#)

	Are you receiving treatment for your IBD?	Can you list what medically-prescribed medications you have ever had for your IBD?	What surgical interventions have you had for your IBD?	If you selected Other, please specify:
Please describe your treatment history	Please select ↓		Please select ↓	

25 Do you undertake any form of lifestyle management?

- I manage my food intake
- I used to manage my food intake
- I am in psychotherapy (counselling)
- I used to be in psychotherapy (counselling)
- N/A

26 Did you take any medication or receive any form of treatment while pregnant?

- Yes (please specify the type in "Other")
- No
- Other

a If you selected Other, please specify:

General Inquiry

27 How did you hear about the study IBD and Mums-To-Be?

- CCUK Support Group
- CCUK Article
- Facebook Group
- Twitter
- Academia.edu Website
- Other



IBD and Mums-To-Be

100% complete

Thank You

Your responses to this survey have been submitted.

If you need a formal record of your submission, please use the following details:

Completion receipt

Receipt number: 51995-51989-3818326
Submission time: 2015-02-11 17:56:41 GMT

[Print](#) [Download PDF](#) [Email](#)

Download my responses

You have 15 minutes to view this data

[My responses](#)

Thank you for taking the time to complete this survey and for sharing your experiences with us.

CCLUK agreed with the 'IBD and Mums-To-Be' team that it is really important to know more about women's experiences of pregnancy and early motherhood with IBD in order to inform services and provide more information for women about to set out on this journey.

If you wish for your answers to be excluded from the research at any point in time please email us at the address provided below

Jihane Ghorayeb (project researcher: Ps12jq@leeds.ac.uk)

Professor Anna Madill (project supervisor: A.L.Madill@leeds.ac.uk)

Thank you again.

Should you wish to know more about the research or the findings, you can follow us on:



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Appendix U Description Table of Online Sample

Demographics of Online Sample	
Average Age	34.91
Ethnicity	
White	11
Marital status	
Single/Not in a relationship	1
Single/Divorced	1
Married/Long-term relationship	9
Education level	
Apprenticeship/ NVQ level 2 or 3	4
Bachelor	7
Work status	
Full Time	1
Part Time	7
House Person	1
Maternity Leave	1
Missing	1
Household income	
Above 45,000 GBP <	9
30,000 GBP > and > 45,000 GBP	1
Below 10,000 GBP <	1
Number of children per household	
Single child	6
Two children	4
Three children	1
IBD type	
Crohn's Disease	6
Ulcerative Colitis	5

Appendix V Guidelines for High-Quality Video-Recording

I. Before the interview

1. Dress Code¹

a. What to Wear?

- Clothing in solid bold colours (blue, green, red)

b. What NOT to Wear?

- Pastel, light, tan, or earth-colour shirt or blouse
- Branded, naming or logo expressive cloth or jewellery
- Clothing with tight patterns (e.g., stripes, herringbones, checks, or tiny red roses) or high-contrast patterns
- White or black colours
- Highly contrasting patterns
- Highly reflective materials
- Clothes that make noise when you move
- Jewellery that makes noise when you move your arms or head. Remember that jewellery, especially bracelets and heavy earrings, can cause glaring reflections
- Hats

2. Make-up

a. Recommended

- Light make-up as the face will appear slightly paler than in reality

b. Advised against

- Heavy make-up and contours that will distract the viewer and create a big emphasis on facial features

3. Eyesight Correction

a. Recommended

- Wear contact lenses

b. NOT Recommended

- Glasses. Glass glare can be adjusted by tilting the camera and adjusting to surrounding light, but should preferably be avoided
- Polaroid glasses must be removed

II. During the Interview

1. Positioning

a. Background, Lighting, and Surrounding Noise

- No family photographs should be in-shot
- Background photos are to be avoided and neutral plain ones are favoured
- The sitting will preferably be perpendicular to a light source or window to avoid glares
- The surrounding must be a quiet one to allow audible recording
- We would recommend turning any telephone or mobile phone on silent during the recording

b. Face Shot

- Look at the researcher who will be positioned near the lens

2. Dialogue

a. The researcher discourse

- The researcher will ask the main questions and any arising questions during the interview
- The researcher will remain quiet during your response

¹ Some of the content was retrieved and adapted from the Florida Institute of Technology's (FIT) website, http://it.fit.edu/instructional/video_prep.php on 2-Oct-2014

- It might appear unnatural for the researcher to make no comments or express any emotions at some points of the discussion, however, bear in mind that the aim is to avoid voice-overlapping and unclear recording
- b. How to Speak to the Camera
 - Speak at your normal pace
 - Express emotions as they come along
 - Pause if need be for as long as you need
 - Use your usual wording and expressions as they are indicative of your inner state
 - All the data gathered from the recording will be transcribed verbatim
- c. Pauses and Interruptions
 - Taking a break is always possible and recommended although the camera will keep rolling
 - If other household members enter the room or outsiders approach in local community area the researcher will insure to mask their faces and voices from the recording
 - Pets are allowed to be present as long as they do not create a distracting noise masking your voice

III. After the Interview

1. Can I See the Video?
 - To avoid consuming anymore of your precious time, the researcher will send you the video upon your request

Appendix W Interview Schedule: First Draft

PLANNING
<ul style="list-style-type: none"> • Can you tell me about your experience of becoming a mum? <ul style="list-style-type: none"> ○ What kinds of thoughts were going through your head? ○ Can you tell me how you felt when you found out you were pregnant with (name of first born)? <ul style="list-style-type: none"> ▪ Emotionally ▪ Physically ○ Can you tell me what you did after you found out? • Can you tell me how did you feel about your pregnancy given that you have IBD? • Can you tell me about your expectations about pregnancy? <ul style="list-style-type: none"> ○ About motherhood? ○ About IBD and motherhood?
NEEDS, CHALLENGES AND RESILIENCE
<ul style="list-style-type: none"> • Did you seek to discuss being pregnant with IBD with anyone? <ul style="list-style-type: none"> ○ Did you receive any suggestions from your GP/Partner/Friend(s)/Family? ○ How did they respond? • What was considered helpful to you during this transition phase? <ul style="list-style-type: none"> ○ Can you give me specific examples? • What would have been the most difficult time? <ul style="list-style-type: none"> ○ Can you give me specific examples? • Can you tell me what has been the most positive aspect? <ul style="list-style-type: none"> ○ Can you give me specific examples?
IMPACT AND COMMUNICATION
<ul style="list-style-type: none"> • Can you tell me how IBD has affect your role as a mother? <ul style="list-style-type: none"> ○ Can you give me specific examples? • Can you discuss IBD with your children (child)? <ul style="list-style-type: none"> ○ How did you go about telling them (him/her) ○ What was the response?
FUTURE CONSIDERATION
<ul style="list-style-type: none"> • If you were to name one thing you know now you wish you knew before what would it be? • Can you share any advice with Mums-To-Be that have IBD? • Is there anything you would like to add?

Appendix X Brainstorm Facebook Group: Questions and Excerpt Example from Friend

Hi Everyone, I need your help with a little project of mine (my PhD!). I am designing a questionnaire to tap into the experience of becoming a mother. As you have reached that stage your opinions and input on the following questions is very valuable to me. I need to make sure I am not missing out on any particular theme. So, if you can take a moment to think about the following questions and answer them (either in a comment or in a private message), I would be extremely grateful. Thank you

A. What was it like when you find out you were pregnant?

Unanswered

B. Can you tell me about the thoughts you had when/if you planned the pregnancy?

Unanswered

C. What were your fears/expectations/concerns? Did they change over time? How so?

Unanswered

D. When did you reach out for support? Who did you turn to?

I was lucky in that I didn't have to reach out for support, despite being around the other side of the world to my support network. My mum immediately offered to fly out to [Town Name] for the birth and the first couple of weeks, which is exactly what she did. This was hugely important, and something she wishes her mother had done for her when she had my brother and me. She stayed with us in [Town Name] for 3 weeks, helped with washing, cooked us delicious food, and answered all the typical new parent medical questions we had, particularly helpful, as she is a GP. In terms of my close friends, they were mostly in [Other Town Name], so are a major part of my current support network, particularly one girlfriend who has a little boy 5 months older than [Husband Name].

E. In terms of considerations and planning, did you attend to your food intake, medication, alcohol, and smoking? What was it like?

As soon as we had decided to try for children I was conscious of my alcohol intake, though didn't cut out alcohol completely. I got pregnant within a few weeks, and one of the signs for me was a fairly strong aversion to alcohol, which continued throughout my pregnancy. I have always been conscious about eating healthily so didn't change much in the way of diet, and was keen to keep eating healthily and stay fit and strong, rather than eating for two. I continued to run until I was 36 weeks pregnant, although the runs were significantly shorter and slower by the end!

F. Thinking back on the delivery day what was it like? Before? After?

We had a scheduled caesarean section, so we knew a week before [Child Name] was born exactly what day and what time he would be delivered. It was very civilized, and very quick! We had to go to hospital two hours before the operation, but the operation itself was only around 40 minutes – far quicker than I had imagined! I was awake (had a local anaesthetic) so the whole experience was very surreal! I remember feeling very excited and couldn't stop smiling. [Husband name] was by my side for the whole thing, which was massively important as I think I would have felt very lonely otherwise. [Child Name] was taken out and checked by the paediatrician for 5 minutes before being handed back to me for skin-to-skin time. I heard his cry before I saw him, which was when the tears started flowing! It was all very fascinating that this little person, in fact a stranger to both me and [Husband Name], had made a home in my belly for 9 months!

G. Did you breastfeed? What were your pros and cons?

I did and still do breastfeed, and for me there are only pros really, as [Child Name] got the swing of it very quickly. I never had any pain, and it is the most portable and stress free way to feed him on the go. No washing up or refrigeration required. Now that I am weaning him and fiddling around with baby food, I definitely appreciate how easy breastfeeding was, for me anyway.

H. What were the other changes that occurred? Lifestyle change, work status, identity as a woman, as mother etc.

Other changes have mainly been in terms of lifestyle. I gave up work when I was 37 weeks pregnant, and I have always worked and enjoyed working and earning, so this has been new for me. I definitely plan on going back, and part of me would like to sooner rather than later, just to make sure that I could get back into the workforce! However, I always wanted children and I am determined to fully engage with this

chapter of my life, take my time and enjoy it, and so far, I have. It is most definitely harder than I had anticipated. People told [Husband Name] and I that [Child Name] would be life-changing and we insisted that he would fit nicely into our lives as they were. In hindsight this was a little naive, but I think it is difficult to comprehend how life changing having children is until you do. Personally, I think [Child Name] has changed my life, both in a practical, every day sense and in making me less selfish and judgmental. The biggest challenges for me have been the sleep deprivation and almost non-existent free time. I was always a big fan of fairly regular pockets of 'me time' just a chance to time out and process the world, so the loss of this came as a bit of a shock. The loss of couple time has also been a struggle, and parenthood has necessitated a higher degree of thought organization and effort to keep the cogs of our relationship turning smoothly. While [Child Name] is a focus, it was always important for both of us that we kept our relationship alive, maintaining an interest in each other outside of parenthood. In terms of the sleep deprivation, I wasn't a stranger to poor sleep but the challenge has been one broken night following another, and the necessity to function and be there for Harvey in spite of feeling tired and run down. All of these challenges have been alleviated by reaching out to our support network, something we both should have done more, and have only relatively recently started to do. Needless to say, the challenges pale in comparison to the rewards and I am surprised every day by how much I can love.

If you can think of anything else that was prominent to you in this transition phase please jot it down, even in the form of bullet points. I only need to make sure I did not miss out on any important part.

Unanswered.

Appendix Y Interview Schedule: Second Draft – Tested on Pilots

Research Question: What is the lived experience of women with IBD transitioning into motherhood?
BACKGROUND: YOUR IBD
<ul style="list-style-type: none"> • Can you tell when you discovered that you have IBD? <ul style="list-style-type: none"> ○ What form of IBD do you have? ○ What treatments were you on – did you have – before you had any children? ○ How severe was your illness in the year or so before your (first) pregnancy?
FINDING OUT: DEALING WITH THE NEWS
<ul style="list-style-type: none"> • Can you tell me about your experience of becoming a mother with IBD? <ul style="list-style-type: none"> ○ Can you tell me the background to your pregnancy? <ul style="list-style-type: none"> ▪ <i>Was the pregnancy planned? (If not, explore the impact of this)</i> ▪ <i>Was fertility an issue? (If yes, explore this)</i> ▪ <i>If planned: How long were you trying before you get pregnant?</i> ○ What was it like when you found out you were pregnant? ○ What kinds of thoughts were going through your head? (<i>opinions are included</i>) ○ Can you tell me how you felt when you found out you were pregnant with (name of first born)? <ul style="list-style-type: none"> ▪ <i>Emotionally</i> ▪ <i>Physically</i> ▪ <i>Practical consideration</i> ○ Can you tell me what you did after you found out? <i>(if more than one child, take into account the ones that fit into the 2-7 brackets, if they all fit, ask if these thoughts and feelings apply across the births)</i> • Can you tell me what this experience was like given that you have IBD? <ul style="list-style-type: none"> ○ How did you feel? <ul style="list-style-type: none"> ▪ <i>Emotionally</i> ▪ <i>Physically</i> ▪ <i>Practical consideration</i> ○ What kind of thoughts were going through your head? • Can you tell me about your expectations about pregnancy? <ul style="list-style-type: none"> ○ About motherhood? ○ About IBD and motherhood? ○ About your life in general <ul style="list-style-type: none"> ▪ <i>Did these changes across time? Trimester? nutrition? sleep? Body change?</i>
NEEDS, CHALLENGES AND RESILIENCE
<ul style="list-style-type: none"> • Did you seek to discuss 'being pregnant with IBD' with anyone? (If not:- To what extent was it relevant to you that you have IBD in relation to your pregnancy(ies)?) <ul style="list-style-type: none"> ▪ <i>Did you receive any suggestions from</i> <ul style="list-style-type: none"> • <i>GP</i> • <i>Partner/Father of the child</i> • <i>Friend(s)</i> • <i>Family?</i>

- Did you seek to discuss 'being pregnant with IBD' with anyone? (If not:- To what extent was it relevant to you that you have IBD in relation to your pregnancy(ies)?)
 - *Did you receive any suggestions from*
 - *GP*
 - *Partner/Father of the child*
 - *Friend(s)*
 - *Family?*
 - How did they respond?
 - What were your thoughts on their responses?
 - How did it make you feel?
- Who was most helpful to you during this first pregnancy?
 - *Can you give me specific examples?*
- What was considered helpful to you during this first pregnancy?
 - *Can you give me specific examples? – books, internet, meetings*
 - *Take into consideration geo-time factors in support and decision making selection*

BIRTH: LABOUR DAY

- Can you tell me how you first envisioned labour/delivery day?
 - *Can you give me specific examples?*
- Can you tell me how IBD has impacted that day? (hindsight)
 - *Can you give me specific examples?*
- Can you tell me how feeding went? For a start, did you want to breastfeed?
 - *Yes, no – what made you decide?*
 - *How did that make you feel?- guilt, proud, father excluded*
 - *What were your thoughts?*

MOTHERHOOD WITH IBD

- What has your IBD been like since you have become a mother?
 - *Can you give me specific examples?*
- Can you tell me about the most difficult aspects of becoming a mother with IBD?
 - *Can you give me specific examples?*
- Can you tell me what have been the most positive aspects of becoming a mother with IBD?
 - *Can you give me specific examples?*
 - *This about inserting the timeline*
- Were there any key turning points in your journey to becoming a mother with IBD?
 - *Can you give me specific examples?*
- Can you discuss IBD with your children (child)?
 - *How did you go about telling them (him/her)*
 - *What was the response?*
- If you have not do you anticipate doing so? How? What will you say?

IMPACT: IDENTITY

- Can you tell me how becoming a mother has impacted your identity: that is, who you feel yourself to be?
 - *As a woman? As an adult? As a mother?*
 - *Can you give me specific examples?*

- Can you tell me how IBD has impacted some of the decisions and choices you had to make as a mother?
 - *Can you give me specific examples?*
 -

- Can you tell me how IBD played a role with regards to who you feel yourself to be?
 - *As a woman? As an adult? As a mother?*
 - *Can you give me specific examples?*

FUTURE CONSIDERATION

- If you were to describe one thing you know now you wish you knew before you became a mother with IBD what would it be?

- Can you share any advice with Mums-To-Be that have IBD?

- Is there anything important to becoming a mother with IBD that we have covered that you would like to add?

Appendix Z Interview Schedule: Third Draft

Research Question: What is the lived experience of women with IBD transitioning into motherhood?
BACKGROUND: YOUR IBD
<ul style="list-style-type: none"> • Can you tell when you discovered that you have IBD? <ul style="list-style-type: none"> ○ What form of IBD do you have? ○ What treatments were you on – did you have – before you had any children? ○ How severe was your illness in the year or so before your (first) pregnancy?
FINDING OUT: DEALING WITH THE NEWS
<ul style="list-style-type: none"> • Can you tell me about your experience of becoming a mother with IBD? <ul style="list-style-type: none"> ○ Can you tell me the background to your pregnancy? <ul style="list-style-type: none"> ▪ <i>Was the pregnancy planned? (If not, explore the impact of this)</i> ▪ <i>Was fertility an issue? (If yes, explore this)</i> ▪ <i>If planned: How long were you trying before you get pregnant?</i> ○ What was it like when you found out you were pregnant? ○ What kinds of thoughts were going through your head? <i>(Opinions are included)</i> ○ Can you tell me how you felt when you found out you were pregnant with (name of first born)? <ul style="list-style-type: none"> ▪ <i>Emotionally</i> ▪ <i>Physically</i> ▪ <i>Practical consideration</i> ○ Can you tell me what you did after you found out? <i>(If more than one child, take into account the ones that fit into the 2-7 brackets, if they all fit, ask if these thoughts and feelings apply across the births)</i> • Can you tell me what this experience was like given that you have IBD? <ul style="list-style-type: none"> ○ How did you feel? <ul style="list-style-type: none"> ▪ <i>Emotionally</i> ▪ <i>Physically</i> ▪ <i>Practical consideration</i> ○ What kinds of thoughts were going through your head? • Can you tell me about your expectations about pregnancy? <ul style="list-style-type: none"> ○ About motherhood? ○ About IBD and motherhood? ○ About your life in general <ul style="list-style-type: none"> ▪ <i>Did these changes across time? Trimester? Nutrition? Sleep? Body change?</i>

NEEDS, CHALLENGES AND RESILIENCE

- Did you seek to discuss 'being pregnant with IBD' with anyone? (If not:- To what extent was it relevant to you that you have IBD in relation to your pregnancy(ies)?)
 - Did you receive any suggestions from:
 - *GP*
 - *Partner/Father of the child*
 - *Friend(s)*
 - *Family?*
 - How did they respond?
 - What were your thoughts on their responses?
 - How did it make you feel?
- How did IBD pain compare to pregnancy pain?
 - How do you tell the difference?
 - How did/do you cope when you were/are alone with your child when he/she was very young with regard to the symptoms of your IBD?
 - *For example, going to the toilet in rush or when you are out?*
 - *Can you give me specific examples?*
 - (If participant has other children) How do you cope managing all your children at the same time with regard to the symptoms of your IBD?
 - *For example, going to the toilet in rush or when you are out?*
 - *Can you give me specific examples?*
- Who was most helpful to you during this first pregnancy?
 - *Can you give me specific examples?*
- What was considered helpful to you during this first pregnancy?
 - *Can you give me specific examples? – Books, internet, meetings*
 - *Take into consideration geo-time factors in support and decision making selection*

BIRTH: LABOUR DAY

- Can you tell me how you first envisioned labour/delivery day?
 - *Can you give me specific examples?*
- Can you tell me how IBD has impacted that day?
 - *Can you give me specific examples?*
- Can you tell me how feeding went? For a start, did you want to breastfeed?
 - Yes, No – what made you decide?
 - How did that make you feel?
 - *Guilt, proud, father excluded*
 - What were your thoughts?

MOTHERHOOD WITH IBD
<ul style="list-style-type: none"> • What has your IBD been like since you have become a mother? <ul style="list-style-type: none"> ▪ <i>Can you give me specific examples?</i> • Can you tell me about the most difficult aspects of becoming a mother with IBD? <ul style="list-style-type: none"> ▪ <i>Can you give me specific examples?</i> ○ What are the lows of being a mum with IBD on a day-to-day basis? ○ How did play out in the end? What were the fixes? <ul style="list-style-type: none"> ▪ <i>Can you give me specific examples? (How do you go to the loo if you are alone with your child?)</i> • Can you tell me what have been the most positive aspects of becoming a mother with IBD? <ul style="list-style-type: none"> ▪ <i>Can you give me specific examples?</i> ○ What are the highs of being a mum with IBD on a day-to-day basis? ○ What were the coping strategies? <ul style="list-style-type: none"> ▪ <i>Can you give me specific examples? On a day-to-day basis (friend around?)</i> • Were there any key turning points in your journey to becoming a mother with IBD? <ul style="list-style-type: none"> ▪ <i>Can you give me specific examples?</i> • Can you discuss IBD with your children (child)? <ul style="list-style-type: none"> ○ How did you go about telling them (him/her) ○ What was the response? • If you have not do you anticipate doing so? How? What will you say? <ul style="list-style-type: none"> ▪ <i>Can you give me specific examples?</i>
IMPACT: IDENTITY
<ul style="list-style-type: none"> • Can you tell me how becoming a mother has impacted your identity: that is, who you feel yourself to be? <ul style="list-style-type: none"> ○ As a woman? As an adult? As a mother? <ul style="list-style-type: none"> ▪ <i>Can you give me specific examples?</i> • Can you tell me how IBD has impacted some of the decisions and choices you had to make as a mother? <ul style="list-style-type: none"> ▪ <i>Can you give me specific examples?</i> • Can you tell me how IBD played a role with regards to who you feel yourself to be? <ul style="list-style-type: none"> ○ As a woman? As an adult? As a mother? <ul style="list-style-type: none"> ▪ <i>Can you give me specific examples?</i>
FUTURE CONSIDERATION
<ul style="list-style-type: none"> • If you were to describe one thing you know now you wish you knew before you became a mother with IBD what would it be? <ul style="list-style-type: none"> ○ <i>As a mum with IBD what would you like tell other women setting out on this journey?</i> • Can you share any advice with Mums-To-Be that have IBD? <ul style="list-style-type: none"> ○ <i>Any tips from one mum to another? Dos and Don'ts?</i> • Is there anything important to becoming a mother with IBD that we have covered that you would like to add?

Appendix AA Interview Schedule: Fourth Draft

Research Question: What is the lived experience of women with IBD transitioning into motherhood?
BACKGROUND: YOUR IBD
<ul style="list-style-type: none"> • Can you tell when you discovered that you have IBD? <ul style="list-style-type: none"> ○ What form of IBD do you have? ○ What treatments were you on – did you have – before you had any children? ○ How severe was your illness in the year or so before your (first) pregnancy?
FINDING OUT: DEALING WITH THE NEWS
<ul style="list-style-type: none"> • Can you tell me about your experience of becoming a mother with IBD? <ul style="list-style-type: none"> ○ Can you tell me the background to your pregnancy? <ul style="list-style-type: none"> ▪ <i>Was the pregnancy planned? (If not, explore the impact of this)</i> ▪ <i>Was fertility an issue? (If yes, explore this)</i> ▪ <i>If planned: How long were you trying before you get pregnant?</i> ○ What was it like when you found out you were pregnant? ○ What kinds of thoughts were going through your head? (<i>Opinions are included</i>) ○ Can you tell me how you felt when you found out you were pregnant with (name of first born)? <ul style="list-style-type: none"> ▪ <i>Emotionally</i> ▪ <i>Physically</i> ▪ <i>Practical consideration</i> ○ Can you tell me what you did after you found out? <ul style="list-style-type: none"> ○ Did you tell people straight away when you found out? <i>(If more than one child, take into account the ones that fit into the 2-7 brackets, if they all fit, ask if these thoughts and feelings apply across the births)</i> • Can you tell me what this experience was like given that you have IBD? <ul style="list-style-type: none"> ○ How did you feel? <ul style="list-style-type: none"> ▪ <i>Emotionally</i> ▪ <i>Physically</i> ▪ <i>Practical consideration</i> ○ What kinds of thoughts were going through your head? • Can you tell me about your expectations about pregnancy? <ul style="list-style-type: none"> ○ About motherhood? ○ About IBD and motherhood? ○ About your life in general <ul style="list-style-type: none"> ▪ <i>Did these changes across time? Trimester? Nutrition? Sleep? Body change?</i> • <i>If you were on treatment at the time of conception, and maintained during pregnancy, (taken from Demographic information sheet) what were your thoughts around taking pills whilst pregnant?</i> <ul style="list-style-type: none"> ○ Emotions
NEEDS, CHALLENGES AND RESILIENCE
<ul style="list-style-type: none"> • Did you seek to discuss 'being pregnant with IBD' with anyone around you? (If not:- To what extent was it relevant to you that you have IBD in relation to your pregnancy(ies)?) <ul style="list-style-type: none"> ○ Did you receive any suggestions from:

- Did you seek to discuss 'being pregnant with IBD' with anyone around you? (If not:- To what extent was it relevant to you that you have IBD in relation to your pregnancy(ies)?)
 - Did you receive any suggestions from:
 - GP
 - Partner/Father of the child
 - Friend(s)
 - Family?
 - How did they respond?
 - What were your thoughts on their responses?
 - How did it make you feel?
- Who was most helpful to you during this first pregnancy, **in terms of resources?**
 - *Can you give me specific examples?*
- What was considered helpful to you during this first pregnancy?
 - *Can you give me specific examples? – Books, internet, meetings*
 - *Take into consideration geo-time factors in support and decision making selection*
- How did IBD pain compare to pregnancy pain?
 - How do you tell the difference?
 - How did/do you cope when you were/are alone with your child when he/she was very young with regard to the symptoms of your IBD?
 - *For example, going to the toilet in rush or when you are out?*
 - *Can you give me specific examples?*
 - (If participant has other children) How do you cope managing all your children at the same time with regard to the symptoms of your IBD?
 - *For example, going to the toilet in rush or when you are out?*
 - *Can you give me specific examples?*

BIRTH: LABOUR DAY

- Can you tell me how you first envisioned labour/delivery day?
 - *Can you give me specific examples?*
- Can you tell me how IBD has impacted that day?
 - *Can you give me specific examples?*
 - ***If no impact, what did you think about that?***
- Can you tell me how feeding went? For a start, did you want to breastfeed?
 - Yes, No – what made you decide?
 - How did that make you feel?
 - *Guilt, proud, father excluded*
 - What were your thoughts?

MOTHERHOOD WITH IBD

- What has your IBD been like since you have become a mother?
 - *Can you give me specific examples?*
- Can you tell me about the most difficult aspects of becoming a mother with IBD?
 - *Can you give me specific examples?*
 - What are the lows of being a mum with IBD on a day-to-day basis?
 - How did play out in the end? What were the fixes?
 - *Can you give me specific examples? (How do you go to the loo if you are alone with your child?)*
- Can you tell me what have been the most positive aspects of becoming a mother with IBD?
 - *Can you give me specific examples?*

- What has your IBD been like since you have become a mother?
 - *Can you give me specific examples?*
- Can you tell me about the most difficult aspects of becoming a mother with IBD?
 - *Can you give me specific examples?*
 - What are the lows of being a mum with IBD on a day-to-day basis?
 - How did play out in the end? What were the fixes?
 - *Can you give me specific examples? (How do you go to the loo if you are alone with your child?)*
- Can you tell me what have been the most positive aspects of becoming a mother with IBD?
 - *Can you give me specific examples?*
 - What are the highs of being a mum with IBD on a day-to-day basis?
 - What were the coping strategies?
 - *Can you give me specific examples? On a day-to-day basis (friend around?)*
- **Would you say they were some key turning points in your journey to becoming a mother with IBD?**
 - *Can you give me specific examples?*
- Can you discuss IBD with your children (child)?
 - How did you go about telling them (him/her)
 - What was the response?
- If you have not do you anticipate doing so? How? What will you say?
 - *Can you give me specific examples?*

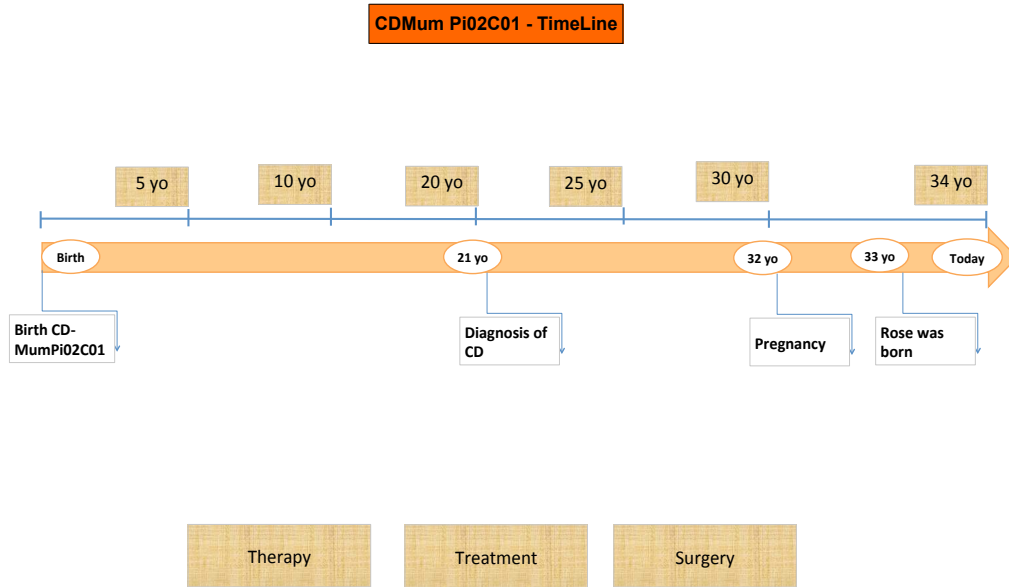
IMPACT: IDENTITY

- Can you tell me how becoming a mother has impacted your identity: that is, who you feel yourself to be?
 - As a woman? As an adult? As a mother?
 - *Can you give me specific examples?*
- Can you tell me how IBD has impacted some of the decisions and choices you had to make as a mother?
 - *Can you give me specific examples?*
- Can you tell me how IBD played a role with regards to who you feel yourself to be?
 - As a woman? As an adult? As a mother?
 - *Can you give me specific examples?*
- **How did this transition to motherhood and IBD impact your couple's relationship? (judgment call if this question can be asked)**
 - **How you connect? How you relate?**
 - **Intimacy and sexuality**

FUTURE CONSIDERATION

- If you were to describe one thing you know now you wish you knew before you became a mother with IBD what would it be?
 - As a mum with IBD what would you like tell other women setting out on this journey?
- Can you share any advice with Mums-To-Be that have IBD?
 - Any tips from one mum to another? Dos and Don'ts?
- Is there anything important to becoming a mother with IBD that we have covered that you would like to add?

Appendix BB Timeline



Appendix CC Contribution Table of Blurred Line: Theme 1 Need for Readiness

Concept	Blurred Lines				
Theme	Need for Readiness				
<u>Subthemes</u>	Shocks and secrets (S)	Need for maturity (L) & (S)	Identifying blame (S)	Fear of mortality (L) & (S)	Seeking others' experience (S)
CDMumPi02C01	X	X	X	X	X
CDMum01C02	X	X	X	X	X
CDMum02C02	X	X	X	X	X
UCMum03C01p	X	X	X	X	X
IBDuMum04C01	X	X	X	X	X
CDMum05C02	X	X	X	X	X
CDMum06C02	X	X	X	X	X
UCMum07C02	X	X	X	X	X
CDMum08C01	X	X	X	X	X
CDMum09C02	X	-	X	X	X
CDMum10C02	X	X	X	X	X
UCMum11C01p	X	X	X	X	X
UCMum12C02	X	X	X	X	X
UCMum13C02	X	X	X	X	X
UCMum14C01p	X	X	X	X	X
UCMum15C02	X	X	X	-	X
CDMum16C01	X	X	X	X	X
UCMum17C01	X	X	X	X	X
CDMum19C01p	X	X	X	X	X
UCMum20C01	X	X	X	X	X
CDMum22C02	X	X	X	X	X
UCMum23C02	X	X	X	X	X

Appendix EE Contribution Table of Blurred Line: Theme 3 Monitoring Personal and
Physical Development

Concept	Blurred Lines				
Theme	Monitoring Personal and Physical Development				
Subthemes	Close scrutiny (S)	Weight changes (S)	Symptom confusion (L) & (S)	Seeking respite (L) & (S)	Identity change (S)
CDMumPi02C01	X	-	X	X	X
CDMum01C02	X	-	X	X	X
CDMum02C02	X	X	X	X	X
UCMum03C01p	X	X	X	X	X
IBDuMum04C01	X	X	X	X	X
CDMum05C02	X	X	X	X	X
CDMum06C02	X	X	X	X	X
UCMum07C02	X	-	X	X	X
CDMum08C01	X	X	X	X	X
CDMum09C02	X	X	X	X	X
CDMum10C02	X	X	X	X	X
UCMum11C01p	X	X	X	X	X
UCMum12C02	X	X	X	X	X
UCMum13C02	X	X	X	X	X
UCMum14C01p	X	X	X	X	X
UCMum15C02	X	X	-	-	X
CDMum16C01	X	X	X	X	X
UCMum17C01	X	X	X	X	X
CDMum19C01p	X	X	X	X	X
UCMum20C01	X	X	X	X	X
CDMum22C02	X	X	X	X	X
UCMum23C02	X	X	X	-	X

Appendix GG Contribution Table of Transitional Challenges: Planning for Pregnancy
(Phase 2)

Concept	Transitional Challenges						
Themes	Burden of Knowledge		Weighing Decision-Making		Blame and Guilt		Ambivalence towards HCP
<u>Subthemes</u>	Assumption of IBD interference (L) & (S)	Lack of information (S)	Improving odds (L) & (S)	Alternatives and acceptance (S)	Selfish desire (L) & (S)	Social pressures (L)	Mixed support (S)
CDMumPi02C01	X		X				X
CDMum01C02	X	X					
CDMum02C02	X			X	X		X
UCMum03C01p	X	X	X	X			X
IBDuMum04C01	X	X	X	X	X		X
CDMum05C02		X	X	X			X
CDMum06C02	X		X	X			X
UCMum07C02		X	X	X	X		X
CDMum08C01	X		X	X	X		X
CDMum09C02	X		X	X	X		
CDMum10C02	X		X	X			
UCMum11C01p			X		X		X
UCMum13C02			X			X	X
UCMum14C01p	X		X	X	X		X
UCMum15C02	X	X	X	X	X	X	X
CDMum16C01	X		X	X			X
UCMum17C01		X		X	X		X
CDMum19C01p	X	X	X				X
UCMum20C01	X		X	X	X		X
UCMum23C02	X		X	X			X

Appendix II Contribution Table Transitional Challenges: Labour and Breastfeeding
(Phase 4)

Concept	Transitional Challenges						
Themes	Burden of Knowledge		Weighing Decision-Making		Blame and Guilt		Ambivalence towards HCP
Subthemes	Labour apprehensions (S)	Mother earth (S)	Unplanned labour events (S)	Feeding choices (S)	Easing guilt (L) & (S)	Societal pressures (S)	Speciality-focused (S)
CDMumPi02C01	X	X	X	X			
CDMum01C02	X	X	X	X	X	X	X
CDMum02C02	X	X	X	X		X	X
UCMum03C01p	X	X	X	X	X		X
IBDuMum04C01	X	X	X	X	X		X
CDMum05C02	X	X	X	X	X	X	X
CDMum06C02	X	X	X	X	X	X	X
UCMum07C02	X	X	X	X		X	X
CDMum08C01	X	X	X	X	X	X	X
CDMum09C02	X	X	X	X	X		
CDMum10C02	X	X	X	X	X	X	X
UCMum11C01p	X	X	X	X		X	X
UCMum12C02	X	X	X	X			X
UCMum13C02	X	X	X	X	X	X	X
UCMum14C01p	X	X	X	X	X		X
UCMum15C02	X	X	X	X			X
CDMum16C01	X	X	X	X	X	X	X
UCMum17C01	X	X	X	X	X	X	X
CDMum19C01p	X	X	X	X	X	X	X
UCMum20C01	X	X	X	X	X	X	X
CDMum22C02		X	X	X			
UCMum23C02	X	X	X	X	X	X	X

Appendix JJ Contribution Table Transitional Challenges: Early Years of Motherhood
with IBD (Phase 5)

Concept	Transitional Challenges					
Themes	Burden of Knowledge	Weighing Decision-Making		Blame and Guilt		Ambivalence towards HCP
Subthemes	Performing mother role (S)	IBD management (S)	Communicating need for help (S)	The good mum (L) & (S)	Invisible illness (S)	Lack of integration (S)
CDMumPi02C01	X	X	X	X	X	X
CDMum01C02	X	X	X	X	X	X
CDMum02C02	X	X		X	X	X
UCMum03C01p	X	X	X	X	X	X
IBDuMum04C01	X	X	X		X	X
CDMum05C02	X	X			X	X
CDMum06C02	X	X	X	X	X	X
UCMum07C02	X	X	X	X	X	X
CDMum08C01	X	X	X	X	X	X
CDMum09C02	X				X	
CDMum10C02	X	X	X	X	X	X
UCMum11C01p	X	X	X		X	X
UCMum12C02	X	X	X		X	X
UCMum13C02	X	X	X		X	X
UCMum14C01p	X	X	X		X	X
UCMum15C02	X	X	X	X	X	
CDMum16C01	X	X	X		X	X
UCMum17C01	X	X		X	X	
CDMum19C01p	X	X		X	X	
UCMum20C01	X	X	X	X	X	X
CDMum22C02	X	X	X	X	X	
UCMum23C02	X	X	X	X	X	X

Appendix KK Contribution Table Reflecting on Others: Theme 1 Shielding Child

Concept	Reflecting on Others		
Theme	Shielding Child		
Subthemes	Child as a shield (L) & (S)	Shielding child from IBD (S)	Reflecting IBD (L) &(S)
CDMumPi02C01	X	X	X
CDMum01C02	X	X	X
CDMum02C02	X	X	X
UCMum03C01p	X	X	X
IBDuMum04C01	X	X	X
CDMum05C02		X	X
CDMum06C02	X	X	X
UCMum07C02		X	X
CDMum08C01		X	X
CDMum09C02		X	X
CDMum10C02	X	X	
UCMum11C01p	X	X	X
UCMum12C02	X	X	X
UCMum13C02	X	X	X
UCMum14C01p		X	X
UCMum15C02		X	X
CDMum16C01	X	X	X
UCMum17C01		X	X
CDMum19C01p		X	
UCMum20C01		X	
CDMum22C02	X		X
UCMum23C02	X	X	X

Appendix LL Contribution Table Reflecting on Others: Theme 2 Comparative
Normality

Concept	Reflecting on Others		
Themes	Comparative Normality		
Subthemes	People and me (S)	Mothers and me (S)	Myself and me (S)
CDMumPi02C01	X	X	X
CDMum01C02	X	X	X
CDMum02C02	X	X	X
UCMum03C01p	X	X	X
IBDuMum04C01	X	X	
CDMum05C02		X	X
CDMum06C02	X	X	X
UCMum07C02	X	X	X
CDMum08C01	X	X	X
CDMum09C02	X	X	X
CDMum10C02	X	X	X
UCMum11C01p	X	X	X
UCMum12C02	X	X	X
UCMum13C02	X	X	X
UCMum14C01p	X	X	X
UCMum15C02	X	X	X
CDMum16C01	X	X	X
UCMum17C01		X	X
CDMum19C01p	X	X	X
UCMum20C01	X	X	X
CDMum22C02	X	X	X
UCMum23C02	X	X	X

Appendix MM Contribution Table Reflecting on Others: Theme 3 Two-Sided Mirror

Concept	Reflecting on Others		
Theme	Two-Sided Mirror		
Subthemes	Confiding Platform (S)	Wallow window (S)	Staged performance (S)
CDMumPi02C01	X	X	X
CDMum01C02	X	X	X
CDMum02C02	X	X	X
UCMum03C01p	X	X	X
IBDuMum04C01	X	X	X
CDMum05C02	X		X
UCMum07C02	X	X	X
CDMum08C01	X	X	X
CDMum09C02	X		X
CDMum10C02	X	X	X
UCMum11C01p	X	X	X
UCMum12C02	X	X	X
UCMum14C01p	X		
UCMum15C02	X	X	X
CDMum16C01	X	X	X
UCMum17C01	X		X
UCMum20C01	X		
CDMum22C02	X	X	X
UCMum23C02	X	X	X

Appendix NN Number of Glances per Recording

Participants	Number of Glances	Length of Interview (min)
Average	67.84	70.68
Range	6-147	39 - 113
Participants		
CDMumPi02C01	15	53.00
CDMum01C02	9	52.00
CDMum02C02	100	74.00
UCMum03C01p	49	84.00
IBDuMum04C01	67	61.00
CDMum05C02	31	50.00
CDMum06C02	N/A Audio recording	74.00
UCMum07C02	126	76.00
CDMum08C01	105	91.00
CDMum09C02	94	50.00
CDMum10C02	105	39.00
UCMum11C01p	82	45.00
UCMum12C02	37	67.00
UCMum13C02*	N/A (Skype)	108.00
CMum14C01p	6	73.00
UCMum15C02	102	65.00
CDMum16C01	147	90.00
UCMum17C01	38	85
CDMum19C01p*	N/A (Skype)	113.00
UCMum20C01	122	66.00
CDMum22C02	7	71.00
UCMum23C02	47	68.00

Appendix OO Transcript Video 1: Planning for a Baby

Did you ever ask yourself how IBD can come in the way of having family?
Here's what mums with IBD had to say...

To start, IBD and its symptoms can be difficult to disclose
Particularly when you first meet a new romantic partner

Clip: Mum 1: I was just glad I wasn't in the dating scene and having to go through that with strangers or meeting people and having that embarrassing thing at the time (.) when I first had it (.) to find a toilet now and have to go (.) you know (.) like (.) when I first had it and we'd be out for the day (.) I'd literally have to run to a toilet (.) When you don't know someone very well (.) it would have been very embarrassing to go through that
Thankfully, it was not the case for her...

IBD can also be isolating
Making it hard to meet someone in the first place...

That said, even for those who had a partner, IBD can halt their desire to plan for a family

Clip: Mum 2: Husband Name and I were ready to have a child that year and so it was just delaying things for the camera test umm and so that really knocked everything back a whole year so did a lot of reading and research, went through a lot of pouting, feeling sorry for myself and I looked a lot into adoption, trying to convince my husband that would be the better route because I work in adoption anyway and I still think that would have been a really good way to go forward but if one of your partners isn't equally excited about adoption, he didn't want to consider it until we'd ruled out if this would or wouldn't work so that's when I looked more into if we should or shouldn't get pregnant

When thinking of having a baby some mums were worried to pass on IBD to their child

Clip: Mum 3: and (.) I was also very conscious of what might happen just generally how much chance a child of mine would have to have Crohn's Disease so we saw a geneticist and investigated a little bit what the chances were of a child, and a young child, a baby, getting Crohn's Disease from a mother who had Crohn's Disease and that was quite positive really, so we decided to go ahead, we spoke to my Crohn's specialist about that and the research had changed and actually they said that it was OK to get pregnant whilst taking Azathioprine, and that it was better for the child, for the pregnancy if the mother wasn't in a flare up so it was safer to stay on the medication

Others thought IBD would make it harder to get pregnant
So we asked mums if they had any issues getting pregnant

Clip: Mum 4 Yeah, no...definitely, absolutely no issues which shocked me, bearing in mind my body had gone through so much previously I thought it'd be quite hard to get pregnant, but no, absolutely no problems.

And how long did it take?

Clip: Mum 4 continued: No first time, first try pregnant, first try pregnant, husband was gutted ((both laugh)), yeah.

These mums did face some challenges planning for a child, but overall it was a positive experience

If you want to find out more about being pregnant with IBD or motherhood with IBD Click on the links below [Credits]

Appendix PP Transcript Video 2: Pregnancy with IBD

Are you curious to find out what it would be like to be pregnant with IBD?

We asked a few mums with IBD to tell us their stories

Here's what they had to say...

Clip: Mum 5: from the beginning of the pregnancy I knew pretty much from day one that I was pregnant Umm and within a couple of weeks that's when the pain started in my wrists and my hands and my joints and they said it was probably linked to the Crohn's Disease, they couldn't define it but (.) they said it was most likely linked, so it was just getting on with it as best I could really (laugh)! At the twenty week point I sort of just suddenly bloomed and everything was absolutely fine so (.)

So how was it afterwards?

Clip: Mum 5 continued: I think because of having Crohn's as well it, you automatically do that 'cos you think, you're looking after yourself constantly, I was, ate as healthy as I possibly could, I did everything by the book, I was, didn't drink, I didn't hardly ever have caffeine or anything like that, I really looked after myself (laugh)! And that's probably why I got so big (laugh) towards the end of the pregnancy which is a shock for me from going from eight and a half stone and I went up to about twelve and a half stone while I was pregnant so

Most mums feared having a flare during pregnancy

And some were worried about taking IBD medication during their pregnancy

Clip: Mum 6: I was absolutely fine during pregnancy um with both of them, so I wasn't worried about the pregnancy, I was worried about being on the tablets that I was on during the pregnancy um [...]so (.) that kind of scared me a little bit but I knew that to be, to have a healthy baby I needed to be healthy so I couldn't stop these tablets, so that was a bit worrying. Um (.) But because I'd had [First Daughter Name] I knew that, you know, she was OK so I thought it would probably be OK.

Some mums had a stoma bag before getting pregnant, and worried about changing their appliance...

Clip: Mum 7: Having an ileostomy was fine, I was concerned about how my tummy would change and whether I'd be able to change my appliance, or whether I'd (.) whether it would give me any problems, but it didn't. So that was my main concern, being pregnant, how my tummy might change

So what do mums with IBD recommend to other mums about to embark on the journey?

Clip: Mum 8: I would just say go with it, I think you have to not be hung up on things like wanting the perfect pregnancy, because it might not happen, (...) and I think you kind of have to be a bit open-minded to the fact that it might not go the perfect way, i.e. be able to give birth or being able to breastfeed or not having to take drugs, and actually well from my perspective being pregnant itself is the miracle enough, so actually just go with it and do the best for you and the baby and try not to worry too much about being the perfect mum or having the perfect pregnancy I guess I would say.

So even though there is no way to tell how you as a mum with IBD might feel during your pregnancy...

The overall message is that women in general do feel equally well or better whilst pregnant Ultimately the decision is yours but the stories are encouraging...

If you want to find out more about the early years of motherhood with IBD or planning with IBD Click on the links below

[Credits]

Appendix QQ Transcript Video 3: Motherhood with IBD

The early years with a young child can be particularly challenging....
 But what about going through motherhood with IBD?
 Here's what some mums who have undergone the journey had to say...

Clip: Mum 9: motherhood for me, I always knew it would be difficult because you go into eyes wide open, you think it's going to be tiring, it's going to be (.) expensive, it's going to change your social life, etc., (.) but the fatigue that came after having [Daughter Name] just made me (.) really think, you know, how am I going to get through, 'cos once you're a mother you're a mother, it was a day-to-day struggle at times and it really really bothered me, it became a really big issue because there were days when I was so tired I don't think (.) I trusted myself to drive, so I wouldn't go anywhere with [Daughter Name], and when you're a mum you want to get out and about, you want to meet other mums, you want your children to socialise with other children

Motherhood was tiring but the IBD symptom of fatigue added another layer...
 Also, some mums mentioned the adjustments they had to make around feeding time..

Clip: Mum 10: I have to say [Son's Name]'s been fed in the toilet quite a lot because um (.) obviously you're starting and there was sometime he wasn't very happy because I had to just drop off let him in the middle, when you start feeding them and stop in the middle, they're not happy ((laugh)).

But equally mums had to adjust their own schedules and routines...

Clip: Mum 11: It's the... the issues of... constantly, now for me constantly having those moments where I'll go to the toilet, you know, lots of times, so the children can kind of just be left in in this room and if I'm lucky I'll be able to go to the loo all by myself, but if I'm not and they're wanting my attention it's not the nicest experience in the world. And they don't understand what it's like for me, that's probably the hardest bit is just the interruption in your normal life when you've got to keep going to the loo, and the same when you're out and about, when you've got a new baby and you just want to go shopping or something and I pretty much know where the best toilets are in the city centre because I've been to all of them and I know...I knew the ones that I get a pushchair in, you know, all the practicalities that come with having to know where toilets are all the time.

However, some mentioned how having IBD prepared them for the changes of being a mum
 Clip: Mum 12 I think it's, I think there's a 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 and that there will be times where one day you might have organised something and you really want to do it but you wake up and you're incredibly ill and you can't. And... I've got used to kind of trying to adapt my life around ...my illness more over the years and really I think that ...is a very helpful skill for the baby as well because I think people aren't prepared for how massive, what a massive change it is to your life and umm...and then it's about being adaptable and, you know, babies do not do what you want them to do (laughs). They have their own routine and it...if anyone's child's like mine she changes it every day so [laughs]

So we asked mums what they could advise other mums to do

Clip: Mum 13: And just do what's right for you and I think yeah (.) don't beat yourself up if you can't always do things (.) if you do need to have a nap (.) have a nap (.) you know (.) And I think people with children sometimes they struggle to try and do it all

And remember...

Clip Mum 14: children are very resilient and you can, you know (.) you shouldn't feel that

because you've got IBD and because you've got so many health challenges and things to go through every day that you wouldn't be able to be a good mum because that's not true, you can definitely do both, [...] I managed with twins and it really wasn't so challenging it was much, for me it was much more challenging to have flare-ups of my colitis than (.) managing to look after twins, that was plain sailing ((laugh)) I think you can imagine anything once you've had IBD, once you've got it it's (.) yeah, you can cope with more I think.

The take home message is that there is no right or wrong way to cope with a young one

You ultimately have to make the choices that work best for you and your family

And take good care of yourself to face the highs and lows of this new phase in your life...

If you want to find out more about planning for a family or pregnancy with IBD Click on the links below

[Credits:

Thank You

To all the mums who shared their stories

- Crohn's and Colitis UK Sponsors
- Leeds Social Science Institute Sponsors
- Anna Madill Editor
- Peter Branney Editor
- Christian Selinger Editor
- CCUK Leeds & District Network Evaluation
- Jihane Ghorayeb Producer

Showing CCUK Logo, followed by LSSI logo]

Appendix RR Three Press Releases on Publication

<http://www.independentnurse.co.uk/news/women-with-ibd-should-be-given-more-pregnancy-advice/172585/>

https://www.academia.edu/36049183/Ghorayeb_J._Branney_P._Selinger_C._P._and_Madill_A._2018_in_press_.When_your_pregnancy_echoes_your_illness_Transition_to_motherhood_with_Inflammatory_Bowel_Disease_Qualitative_Health_Research

Women with IBD should be given more pregnancy advice

Written by: [Rebecca Gilroy](#) | Published: 13 April 2018



IBD is an overarching term that defines severe digestive disorders such as Crohn's disease and ulcerative colitis
[Comment on this article](#)

Women with inflammatory bowel disease (IBD) need more [advice](#) about pregnancy in order to make informed choices about their pregnancy.

A research project that documented the experiences of 22 women and found that some had decided not to have children, or restrict their family size, and many women feared the [consequences of pregnancy](#).

'It is desperately sad that women are opting to remain childless because they are unable to get an accurate picture of the risks they face,' said Anna Madill, a supervisor of the research.

'If they have access to that information, they may make an entirely different choice. The healthcare system needs to make sure that women living with IBD have access to all the facts necessary to make a fully informed decision.'

Participants were concerned that they would pass down the condition to their children as well as worried that they would be unable to cope with a small child during periods when their condition would flare-up.

IBD is an overarching term that defines severe digestive disorders such as Crohn's disease and ulcerative colitis, both of which can cause severe stomach pains, weight loss, and recurring diarrhoea.

There is no cure for IBD and people living with the condition will experience periods of stability, with no symptoms, and then periods of flare-ups which be debilitating and affect quality of life. In the UK, 1 in 250 people have the condition and its incidence is increasing.

The researchers, from the University of Leeds, made three films featuring participants describing their experiences of living with, being [pregnant](#) with, and being a mother with IBD.

'One of the main points to emerge from the study is that learning to live with a chronic illness has helped the women prepare for motherhood,' added Ms Madill.

'These women coped well with becoming parents.'

Yorkshire Post

[https://www.academia.edu/36049183/Ghorayeb J. Branney P. Selinger C. P. and Madill A. 2018 in press . When your pregnancy echoes your illness Transition to motherhood with Inflammatory Bowel Disease. Qualitative Health Research](https://www.academia.edu/36049183/Ghorayeb_J._Branney_P._Selinger_C._P._and_Madill_A._2018_in_press_.When_your_pregnancy_echoes_your_illness_Transition_to_motherhood_with_Inflammatory_Bowel_Disease._Qualitative_Health_Research)

Health matters

[Yorkshire Post](#) 10th April – Print p7

Jihane Ghorayeb and Professor Anna Madill (both Psychology - Medicine & Health) have led a study chronicling the experiences of women with inflammatory bowel disease (IBD) during and after pregnancy, which found that nurses and midwives were often unable to provide information and advice.

Health Matters

Pregnancy appeal: Women with inflammatory bowel disease (IBD) should be given more advice about pregnancy so they can make informed choices about whether to have a family, say researchers. In their paper in the journal *Qualitative Health Research*, scientists from the University of Leeds draw on evidence that women with the disease often decide not to have children, or to restrict the size of their family, because of fears the pregnancy would affect their health or that of their baby. Although inflammatory bowel disease can cause complications during pregnancy, research shows that one third of women with the condition will not get worse and another third will actually see an improvement in their health. The study, led by the University of Leeds, chronicled the experiences of 22 women who have had children, to plug an information gap about the realities of becoming a mother and living with IBD.

RESEARCH: Advice is needed for IBD sufferers considering getting pregnant.

<https://www.rcm.org.uk/news-views-and-analysis/news/women-with-ibd-need-more-pregnancy-advice>

https://www.academia.edu/36049183/Ghorayeb_J._Branney_P._Selinger_C._P._and_Madill_A._2018_in_press_.When_your_pregnancy_echoes_your_illness_Transition_to_motherhood_with_Inflammatory_Bowel_Disease_Qualitative_Health_Research



News

Women with IBD need more pregnancy advice

[Hollie Ewers](#)

9 April, 2018

[IBD ADVICE RESEARCH](#)



Researchers say that women with inflammatory bowel disease should be given more advice about pregnancy, so that they can make informed choices about their options and care.

The study, led by the University of Leeds, chronicled the experiences of 22 women who have had children, to plug an information gap about the realities of becoming a mother with IBD.

The research, published in the journal *Qualitative Health Research*, draws on the evidence that women with the disease often decide not to have children, or to restrict the size of their family, because of fears for their health during pregnancy and that of their baby too.