

**THE EXPERIENCE OF STIGMA
IN PEOPLE WITH
INFLAMMATORY BOWEL DISEASE,
WITH OR WITHOUT
INCONTINENCE:
A HERMENEUTIC
PHENOMENOLOGICAL STUDY**

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Abstract

A stigma is ‘*an attribute that is deeply discrediting,*’ often contravening social norms, and perceived by others as being undesirable. Inflammatory Bowel Disease (IBD) is a chronic illness characterised by symptoms of diarrhoea, urgency, and vomiting occurring in a relapsing and remitting pattern. Regular or temporary loss of bowel control is a prominent feature of the disease and may lead to stigmatisation through infringement of social hygiene rules. Although stigma in IBD has been measured in quantitative studies, there is a dearth of qualitative evidence. This Heideggerian (hermeneutic) phenomenological study explores the lived experience of IBD-related stigma.

Using purposive stratified sampling, 40 members of a national IBD charity were recruited. Participants did or did not experience faecal incontinence, and did or did not feel stigmatised. Unstructured individual interviews (digitally recorded and professionally transcribed) took place in consenting participants’ homes between May and November 2012. Data were analysed using Diekelmann’s hermeneutic method.

Seven relational themes (present in some transcripts) and three constitutive patterns (present in all transcripts) emerged. IBD-related stigma is a complex experience, mostly of anticipated or perceived stigma, which often decreases over time. Stigma changes according to social settings and relationships, but arises from the challenges the disease presents in maintaining social privacy and hygiene rules. Stigma resilience appears most likely in those with a positive sense of control, a support network (particularly of close and intimate others) which suits their needs, and mastery over life and illness.

IBD-related stigma occurs regardless of continence status and can cause emotional distress. Time, experience, and robust social support enhance stigma resilience. Further research is needed to confirm features which enable resilience, and to develop stigma-reduction strategies that will promote resilience in this patient group.

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Author's declaration

I declare that all material in this thesis is original, is all my own work, and has not been presented previously.

Contents

Abstract	ii
Acknowledgements	iii
Author’s declaration	iv
Contents	v
List of Illustrations	xii
List of Tables	xiii
Abbreviations and Notes	xv
1. Introduction	1
1.1. Developing an interest in inflammatory bowel disease	1
1.2. Introducing stigma language and theory definitions	3
1.3. The role of reflexivity in managing my position in the research	4
1.4. The scholarly personal narrative approach	4
1.5. Research aims and questions	5
1.5. Summary	6
2. Stigma	7
2.1. Stigma as a social phenomenon	7
2.2. Theories and definitions of social and health-related stigma	15
2.2.1. Erving Goffman (1922-1983)	16
2.2.2. Jones, Farina, Hastorf, Markus, Miller and Scott (1984)	19
2.2.3. Crocker, Major and Steele (1998)	21
2.2.4. Link and Phelan (2001)	22
2.3. Selecting a definition of stigma for this study	22
2.4. The language of stigma	24
2.4.1. Concepts related to stigma	25
2.5. Stigma, society and health	27
2.6. The link between stigma and health	31
2.7. Summary	32
3. Inflammatory bowel disease	33
3.1. Inflammatory bowel disease – an overview	33
3.2. Inflammatory bowel disease and stigma	35

3.3.	The aims of the study	39
3.4.	Research questions	39
3.5.	Summary	40
4.	Literature search and review	41
4.1.	The literature search strategy	42
4.1.1.	The literature review process	45
4.2.	Results of Search 1.....	45
4.2.1.	Characteristics of included studies	46
4.2.2.	Quality of included studies	46
4.2.2.1.	Research paradigm and fit with methods	47
4.2.2.2.	Sampling methods	48
4.2.2.3.	Ethical considerations	49
4.2.2.4.	Data collection, analysis and reporting	49
4.2.2.5.	Weaknesses and limitations	50
4.2.3.	Findings of included studies	51
4.2.3.1.	Containment and control	51
4.2.3.2.	Stigma and taboo	52
4.2.3.3.	Illness credibility	53
4.2.3.4.	Measuring stigma	53
4.2.3.5.	Stigma in inflammatory bowel disease	54
4.3.	Discussion of findings from reviewed papers.....	55
4.4.	Conclusions drawn from reviewed papers	57
4.5.	Summary	58
5.	Research methodology	59
5.1.	Critical review of the methodologies (philosophies) guiding previous qualitative health-related stigma studies	61
5.1.1.	Selecting the papers for methodological and method review	61
5.1.2.	Miscellaneous philosophies	61
5.1.2.1.	Ethnonursing, case study and oral history research	62
5.1.2.2.	Narrative research	62
5.1.2.3.	Stigma theory	62
5.1.3.	Grounded theory	63

5.1.4.	Exploratory research	64
5.1.5.	Ethnography	65
5.1.6.	Mixed methods research	66
5.1.7.	Phenomenology	67
5.1.7.1.	Interpretive phenomenological analysis (IPA)	67
5.1.7.2.	Descriptive phenomenology	68
5.1.7.3.	Interpretive (hermeneutic) phenomenology	68
5.1.8.	Methodologies not represented in stigma research	69
5.1.8.1.	Critical social theory	69
5.1.8.2.	Feminist methodology.....	70
5.1.9.	Outcome of critique	70
5.2.	Critical review of phenomenology	71
5.2.1.	Franz Brentano	73
5.2.2.	Edmund Husserl	74
5.2.2.1.	Phenomenological epoché, reduction or bracketing	75
5.2.2.2.	Bringing to consciousness	75
5.2.2.3.	The essence of conscious thought	76
5.2.2.4.	Temporality	76
5.2.3.	Martin Heidegger	77
5.2.3.1.	Background	78
5.2.3.2.	Pre-understanding (fore-structure of understanding)	78
5.2.3.4.	Co-constitution	79
5.3.	The methodological decision	80
5.4.	Summary	81
6.	Research methods	82
6.1.	The population and the sampling frame.....	83
6.1.1.	Sampling, inclusion and exclusion criteria	83
6.1.1.1.	Sampling	83
6.1.1.2.	Inclusion criteria	84
6.1.1.3.	Exclusion criteria	85
6.1.2.	Sample size	86
6.1.3.	Data collection	87

6.1.3.1.	Developing the interview schedule	88
6.1.3.2.	The interview in sensitive research	91
6.1.3.3.	Data capture and transcription	92
6.2.	Co-constitution and data analysis	93
6.2.1.	Co-constitution	94
6.2.2.	Data analysis framework	96
6.3.	Ethical considerations and issues of rigour	99
6.3.1.	Ethical considerations	99
6.3.1.1.	Researcher capability	99
6.3.1.2.	Benefits of the research	99
6.3.1.3.	Informed consent	100
6.3.1.4.	Data protection	100
6.3.1.5.	Risk to participants	101
6.3.1.6.	Researcher (interviewer) safety	102
6.3.2.	Rigour, or trustworthiness	102
6.3.2.1.	Insider status and reflexivity	103
6.4.	Summary	106
7.	Method of data analysis	108
7.1.	The rationale for not using NVivo	108
7.2.	The data analysis process	109
7.2.1.	Stage 1: Read transcripts (individually and as a whole) to gain overall understanding	111
7.2.2.	Stage 2: Write summary of each transcript; begin to identify themes and patterns; and Stage 3: Agree summaries to reach consensus; conflict by returning to the original data	111
7.2.3.	Stage 4: Re-read all transcripts; identify hidden meanings and relational themes	113
7.2.4.	Stage 5: Describe constitutive patterns	120
7.2.5.	Stage 6: Verify results by returning to interview transcripts	121
7.2.6.	Stage 7: Integrate and synthesize findings into an interpretive structure...	121
7.3.	Summary	122

8. Findings and analysis (i): Being in or out of control	123
8.1. Study participants	125
8.2. Interviews	128
8.3. Constitutive pattern: Being in or out of control	128
8.3.1. Relational theme: Risk and readiness	130
8.3.2. Relational theme: Impression management	133
8.3.3. Relational theme: Revealing IBD	144
8.3.4. Relational theme: Social expectations and norms	149
8.4. Summary	150
9. Findings and analysis (ii): Relationships and social support	152
9.1. Constitutive pattern: Relationships and social support	152
9.1.1. Relational theme: Revealing IBD	155
9.1.2. Relational theme: Social expectations and norms	163
9.1.3. Relational theme: Responsibility and blame	170
9.1.4. Relational theme: State and flux of stigma	174
9.1.4.1. Anticipated stigma	177
9.1.4.2. Perceived stigma	181
9.1.4.3. Enacted stigma	183
9.1.4.4. Courtesy stigma	187
9.1.4.5. Kinship stigma	190
9.2. Summary	194
10. Findings and analysis (iii): Mastery and mediation	195
10.1. Constitutive pattern: Mastery and mediation	196
10.1.1. Relational theme: State and flux of stigma	201
10.1.1.1. Self stigma	202
10.1.1.2. Stigma fluctuates	204
10.1.2. Relational theme: Resilience	208
10.1.2.1. Personality	208
10.1.2.2. Mental health	211
10.1.2.3. Humour	214
10.1.2.4. Perspective	216

10.1.3.	Relational theme: Upbringing	220
10.2.	Summary of Mastery and mediation	225
10.3.	Vignettes	225
10.3.1.	Tamsin [No FI, stigma]	226
10.3.1.1.	Tamsin's story and the study findings	227
10.3.2.	Kevin [FI, no stigma]	227
10.3.2.1.	Kevin's story and the study findings	228
10.3.3.	Vera [FI, stigma]	228
10.3.3.1.	Vera's story and the study findings	229
10.3.4.	Esther [No FI, no stigma]	230
10.3.4.1.	Esther's story and the study findings	231
10.4.	Summary of Chapters 8, 9 and 10	231
11.	Discussion and conclusions	233
11.1.	The key findings	235
11.1.1.	What is the experience of stigma in people with inflammatory bowel disease, with or without incontinence?; and In what ways does stigma affect the social, emotional and personal wellbeing of people with IBD, and how do they manage these issues?	235
11.2.	Study findings in relation to the wider literature	239
11.2.1.	The everyday of bowel control	241
11.2.2.	The social power of the everyday	246
11.2.3.	The everyday of language	248
11.2.4.	The everyday of chronic illness management and stigma resistance	248
11.2.5.	Profiles of those with IBD who do and do not feel stigmatised	251
11.3.	Critique of the methodology.....	253
11.3.1.	Heideggerian phenomenology	254
11.3.1.1.	Recognising oneself	254
11.3.1.2.	Making an intelligible interpretation and dealing with differences and similarities in the data concurrently	255
11.3.1.3.	Narrating others' stories and narrating one's own identity	256
11.3.2.	Sampling bias	257
11.3.3.	Data collection bias	258

11.4.	Critique of the data analysis method	258
11.4.1.	Suitability of data analysis method	258
11.4.1.1.	Balanced integration	259
11.4.1.2.	Openness	260
11.4.1.3.	Concreteness	260
11.4.1.4.	Resonance	261
11.4.2.	Challenges of the data analysis method	261
11.4.2.1.	Analysis as a thief of time	261
11.4.2.2.	The emotional challenge	262
11.4.2.3.	Loose ends	262
11.4.2.4.	Crossing over of themes	263
11.4.3.	Summary of the data analysis method critique.....	264
11.5.	Trustworthiness (rigour) of the study	264
11.5.1.	Critique of reflexivity in this study	267
11.5.1.1.	Reflexivity during data collection	268
11.5.1.2.	Reflexivity during data analysis	268
11.6.	Recommendations for future research and practice	270
11.7.	Implications for researchers	272
11.8.	Limitations	273
11.9.	Contribution to knowledge	273
11.10.	Summary.....	274
11.11.	Conclusion	275
References		277
Appendix 1	Characteristics of studies included in the literature review	319
Appendix 2	Philosophy and design quality of studies included in the literature review.....	326
Appendix 3	Characteristics of the research methodology review papers.....	332
Appendix 4	Updated literature review.....	340
Appendix 5	Study information leaflet, consent form, and ethics approvals.....	353

Appendix 6	Examples of field notes made during interviewing, and reflexive journal entries made during the study	363
Appendix 7	Description of relational themes and constitutive patterns, with examples	379
Appendix 8	Andrea’s interview transcript	385
Appendix 9	Carl’s interview transcript	399

List of Illustrations

Figure 4-1	Flow chart detailing process of searching for and selecting papers to support study rationale (Search 1) and study design (Search 2).....	44
Figure 7-1	The wall display, demonstrating organisation of themes and positioning of strips	115
Figure 7-2	Detail of one relational theme in the wall display indicating transcript / interview number, colour coding, background fill to identify interpretations from second analysis, and theme name on each of the cut strips	116
Figure 7-3	Distribution of themes from the Miscellaneous category across existing relational themes, and creation of four new relational themes	117
Figure 7-4	First review of relational themes from 24 down to 14, and emerging constitutive patterns	118
Figure 7-5	Second review of relational themes from 14 down to 8, and confirmation of constitutive patterns	120
Figure 8-1	The inter-relationship of relational themes and constitutive patterns in the experience of stigma in inflammatory bowel disease	124
Figure 8-2	The geographic distribution of study participants with subgroups indicated by colour	127
Figure 8-3	The relational themes of Risk and readiness, Impression management, Revealing IBD, and Social expectations and norms informing the constitutive pattern of Being in or out of control	129
Figure 9-1	The relational themes of Revealing IBD, Social expectations and norms, Responsibility and blame, and State and flux of stigma informing the constitutive pattern of Relationships and social support	153

Figure 10-1	The relational themes of State and flux of stigma, Resilience, and Upbringing informing the constitutive pattern of Mastery and mediation	196
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List of Tables

Table 2-1	Goffman's stigma framework identifying three types of stigma and the ways in which these can be carried	17
Table 2-2	The six dimensions of stigma, with assessment of the effect each has on the development of stigma within relationships	19
Table 2-3	Types of stigma, with definitions and examples of research or expert opinion on each	24
Table 4-1	Analysis framework used to review selected papers arising from literature searches, based on CASP guidelines for reviewing qualitative and quantitative studies	44
Table 6-1	Original interview schedule, with opening and closing prompts and probes regarding potential issues of interest	89
Table 6-2	Stages of the research interview detailing the purpose of each stage and the actions taken by the researcher for this study	101
Table 7-1	The seven stages of the interpretive hermeneutic phenomenology analysis method (Diekelmann et al. 1989) with procedure of each stage and how this was auctioned in the current study	110
Table 7-2	Example of identification of potential themes by each analyst (student and both supervisors) from a single transcript, and agreement of early relational themes	112
Table 7-3	Early relational themes established from comparing, discussing and agreeing independent findings across five interview transcripts	113
Table 7-4	Method of recording and tracking interpretive findings within a transcript	114
Table 8-1	Demographic details of study participants	126
Table 9-1	Participants, their self assigned subgroups, and types of stigma present in their interview transcripts	176

Table 11-1	Key study findings mapped onto Goffman's stigma framework	240
Table 11-2	Tentative suggestion of profiles of people with IBD who are more or less likely to feel stigmatised by their disease, related incontinence, or both ...	252
Table 11-3	Strategies to determine trustworthiness (rigour) and methods for achieving this in the current study	260

Abbreviations and Notes

Abbreviations: the following are used regularly throughout the text:

Abbreviation	Meaning
CD	Crohn's disease
FI	Faecal incontinence
IBD	Inflammatory bowel disease
UC	Ulcerative colitis

Abbreviations used in tables are explained in the footnotes of each table.

Notes:

1. Throughout, quoted matter of less than two full lines in length is incorporated into the main body of the thesis; quoted matter of more than two lines in length is set in its own indented paragraph.
2. Square brackets [...] are used throughout to provide in-text explanatory detail, as needed
3. In verbatim extracts from interviews, my voice is represented in bold.

1. Introduction

I came to stigma research via a life path which has challenged, inspired and sustained me throughout this study. Erving Goffman's seminal 1963 text *Stigma: Notes on the Management of a Spoiled Identity* illuminated my own experiences and understanding of being different, and inspired my journey into the world of those who live with a stigmatising bowel disorder.

This thesis presents a Heideggerian hermeneutic phenomenological study of stigma in inflammatory bowel disease, an illness often accompanied by faecal incontinence. The study design embraced me as researcher, recognising my pre-understandings - my 'being-in-the-world' - as integral to the project, but this connectedness required careful reflexivity to ensure that credible, trustworthy and transferable research was produced.

This chapter introduces the study by:

- tracing the development of my interest in stigma associated with inflammatory bowel disease
- introducing key themes and definitions relating to stigma language and theory
- introducing the role of reflexivity in managing my position in the research
- defending the scholarly personal narrative approach evident within the thesis
- presenting the aims of the study and the research questions

1.1. Developing an interest in stigma in inflammatory bowel disease

In 2008, after several years in clinical practice and nurse education, I became a research associate at King's College, London. The first two years in post provided a sound research apprenticeship, consolidating my research theory knowledge base. Professor Norton and I developed and conducted the *Continence in Inflammatory Bowel Disease* (IBD) project, the first stage in a long-term plan to develop continence support services

for people with IBD. As my knowledge of IBD and associated bowel control issues developed, I noticed some comparisons with my earlier MPhil work on minority groups (Dibley 2007; Dibley 2009), and began formulating ideas about stigma and marginalisation amongst people with IBD.

I came out as lesbian at age 17. Since then, the social world has changed beyond recognition from one of stigmatisation, prejudice and discrimination to one of equality, inclusion, and acceptance. I did, and still do, choose who I come out to but no longer need to conceal my identity for my own protection. People with IBD live with a condition which is simultaneously concealable and visible. IBD itself may go unnoticed by the public, but associated symptoms of diarrhoea, foul-smelling wind, noisy bowel actions and faecal incontinence (FI) can attract unwanted attention. Difficulties controlling these symptoms may result in shame and embarrassment: the potential for stigma amongst people with IBD appears unquestionable.

The *Continence in IBD* study was completed in 2011. This large (n=3264) mixed methods project collected self-reported data from participants using a series of made-for-study surveys, validated bowel symptoms and quality of life questionnaires, free-text response options to open questions about experiences of FI, and qualitative interviews. Seventy-four percent of participants (n=2391) reported some experience of FI ranging from rarely occurring episodes to regular, sometimes daily, events. The risk of FI was shown to increase following some standard surgical interventions for IBD. Analysis of 28 qualitative interviews and 583 sets (18%) of questionnaire free-text responses revealed that incontinence, and fear of it, limits social, working, and personal lives, impacting on people with IBD in complex ways. Key strategies, including situation avoidance and dietary restrictions, are used to cope. Incontinence is degrading and humiliating for most people, although a small number approach their situation positively. 'Feelings of stigma' emerged as one of seven themes contributing to the overall experience of faecal incontinence in IBD, as concerns about others' opinions of them should the FI associated with IBD become known resulted in people feeling stigmatised (Dibley and Norton 2013). Fear of incontinence concerned respondents even if they were never or rarely troubled by this symptom (Norton et al. 2013). Many

did not receive satisfactory help for their FI, often because they were too embarrassed to ask (Norton and Dibley 2013). These findings provoked my curiosity about IBD-related stigma – is stigma dependent on the occurrence, or fear of FI, or does it occur simply due to the diagnosis? How do people experience and live with the phenomenon? What is different about those who are able to overcome stigma and how might this help those who do feel stigmatised? This thesis addresses these questions.

1.2. Introducing stigma language and theory definitions

The language of stigma and its many definitions are addressed in detail in Chapter 2, but Goffman's simple definition of stigma as '*an attribute which is deeply discrediting*' (Goffman 1963a:9) guides this study, with an appreciation that deviance (contravening expected social group behaviour), prejudice (unfavourable opinions, often based on inaccurate facts), discrimination (unfair treatment of a person, group or minority based on prejudice), embarrassment (feeling self-conscious, disconcerted or flustered), and shame (feeling disgraced, humiliated) all contribute to the development of stigma. Goffman's definition is the simplest and most flexible. It encourages an open-minded approach to research, giving space for potentially discreditable attributes to be defined by participants' expressions of their own experiences. Goffman proposed that to understand stigma, it should be investigated from the position of the stigmatised. Logically, we should accept that stigma arises for people through whichever attribute they say it does, and that this may not be consistent for everyone.

The word *stigma* is seldom used in modern everyday language, either to describe behaviours or attitudes of stigmatisers, or experiences of the stigmatised, but has itself become a stigmatising label (Link and Phelan 2010). Stigma communication in non-stigmatised groups involves verbal and non-verbal messages, the former rarely including the word *stigma* (Smith 2007). In this study, participants rarely used the words *stigma*, *stigmatised*, or *stigmatising* to describe their experiences. Instead, they expressed related terms of shame, embarrassment, of being thought badly of, or being discovered. Locating and interpreting these terms reveals stigma in their narratives.

IBD, and related incontinence, may be deeply discrediting attributes due to the association with dirt and poor control. Faeces are universally considered the most repellent of all dirty matter (Curtis and Biran 2001). Excrement must be controlled to conform to social rules of hygiene and privacy (Elias 2000). Many people with IBD suffer bowel control problems during active disease [See Chapter 3: p. 35] making them vulnerable to accusations of deviance, and feelings of shame and embarrassment.

1.3. The role of reflexivity in managing my position in the research

Phenomenology is the preferred approach when investigating lived experience. Hermeneutic (interpretive) phenomenology, the philosophy which guides this study, embraces the contribution of the researcher and recognises the potential positive influence of pre-understanding. Link and Phelan (2001) argue that social scientists studying stigma who do not belong to stigmatised groups may not notice the detail hidden in the words and perceptions of those they study, but an 'insider' position must be carefully managed for the study to benefit (Finlay and Gough 2003). Through reflexivity, researchers can control distorting influences and enhance positive effects of their role by making their own knowledge, understanding, perceptions and beliefs transparent [See Chapter 6: p. 103]. Interpretation and trustworthiness are augmented by evidencing *how* one pre-understands (Holroyd 2007), requiring an honest openness which explicates the researcher's position.

1.4. The scholarly personal narrative approach

Demonstrating and defending a personal connection with research requires use of the personal pronoun, but academic work traditionally uses the third person, breaking the intimate connection between researcher and subject. The opportunity to present the intricate, interwoven aspects of a study is denied, potentially undermining the researcher's philosophical perspective (Sandelowski 1991). Use of the narrative self in qualitative work is familiar to social scientists as autoethnography where the

researcher's story becomes the data which is used to explore a related concept. To avoid self-indulgence, personal telling must be academic and benefit the study. For example, Plummer (1995) opens his '*Telling Sexual Stories*' with a scholarly autobiographical re-telling of his own coming-out story. His perceptions, understandings, and interpretations of others' stories then make more sense to the reader *because* his own position is clarified. Scholarly personal narratives enable authors to make narrative sense of, and use personal experience to illuminate broader understanding for readers:

scholarly personal narrative writing is the unabashed, up-front admission that your "own life signifies,"... that your own life has meaning, for you and for others. Your own life tells a story that, when narrated well, can deliver to your readers those delicious aha! moments of self and social insight that are all too rare in more conventional forms of research (Nash 2004:23-24).

The approach has been used in a range of social science, anthropology and health studies (Eaves and Kahn 2000; Neville-Jan 2003; Reddick and Sáenz 2012, for example). Of particular relevance to this study, scholarly personal narratives have been used in a hermeneutic phenomenological study addressing caring in nursing (Nelms 1996), in an auto-ethnographic journey to discover her IBD identity through her ill body (Defenbaugh 2011), and in a single case-study exploring her own 'coming-out' about IBD to academic colleagues (Myers 2004). In this IBD stigma study, the self is not so prominent, yet the above examples provide rationale for occasional use of the personal pronoun and reference to personal experience.

1.5. Research aims and questions

Stigma would seem to be likely in some of those living with IBD, and understanding the impact of stigma on wellbeing, illness experience and help-seeking can inform design and delivery of specialist IBD nurse and continence services for those with IBD.

The research aims are therefore to:

1. explore the experience of stigma in IBD, with and without faecal incontinence, and the impact this has on wellbeing
2. generate findings to inform future studies into patient experience and management of the social aspects of IBD.

These aims will be achieved by asking the following research questions:

- What is the experience of stigma in people with inflammatory bowel disease with or without FI?
- In what ways does stigma affect the social, emotional and personal wellbeing of people with inflammatory bowel disease, and how do they manage these issues?

1.6. Summary

This chapter has explained how I came to research stigma in IBD, and confirmed the working definition of stigma for the purposes of this study. The use of the personal pronoun is defended, and presented as a necessary means of evidencing the impact of my own experiences on the study. The use of reflexivity to manage self enhances rigour, credibility and trustworthiness as my influence on the study is made explicit. My presence in the research narrative supports the philosophy of hermeneutic phenomenology, which embraces and acknowledges the potentially positive effect of my role by enabling use of pre-existing knowledge, experience and understanding to interpret data and present meaning to a new audience. The research aims and questions are introduced.

Chapter 2 presents a consideration of stigma theory and definitions to inform the choice of underpinning theorist for this study, as well as a critique of stigma in society, health and ill-health. History and description of IBD, the potential for IBD-related stigma, and the subsequent confirmation of the research aims and questions, follows in Chapter 3.

2. Stigma

Identified as a topic of interest by Durkheim in 1895, the exploration of stigma across a wide range of sociological and illness topics has progressed increasingly since Erving Goffman's seminal 1950-60s work. Parsons' (1951) analysis of the sick role (Scambler 1997) linked stigma with illnesses, particularly those which observers do not understand, assume are perilous through contagion, or consider the sufferer responsible for due to lifestyle behaviours. Examples include epilepsy, leprosy, HIV/AIDS, lung cancer, or liver failure. Stigma research is guided by numerous theories, with a specific language describing the components. This chapter provides theoretical background for the study by:

- charting the historical development of stigma as a social phenomenon
- critiquing a range of theories and definitions of stigma
- evidencing the rationale for selecting Goffman's definition of stigma to guide this study
- clarifying the language of stigma, and
- demonstrating the relationship between stigma, society and health.

2.1. Stigma as a social phenomenon

A stigma is a mark, originally given by Greeks to their servants to physically brand ownership on their skin (Falk 2001). The word arises from the Greek *stizein* – to tattoo, and from the Latin *stigmat-*, to mark or brand. Stigma can be defined as:

- 1) a distinguishing mark of social disgrace: the stigma of having been in prison; 2) a small scar or mark such as a birthmark; 3 a) any mark on the skin such as one characteristic of a specific disease, b) any sign of a mental deficiency or upset.

(The Collins English dictionary, Butterfield 2003)

In the plural (stigmata) and with Christian interpretations, it refers to the crucifixion nail marks in Christ's hands, with connotations of holy self-sacrifice for the good of others. Usually, however, the term is associated with people being visibly or invisibly marked negatively as different for wide-ranging reasons.

Stigma as a social phenomenon was originally described in 1895 by the French sociologist Emile Durkheim [1858-1917]. Academic sociology was developing in Europe through the efforts of Durkheim in France, and Marx and Weber in Germany (Falk 2001). It was Durkheim who first noted that the arbitrary rules that create the social norm exist, and are defined by, the contrast with 'outsiders.' Group unity is maintained by making a cohesive stand against those who are different. By stigmatising others, boundaries of the group norm are strengthened.

The development of sociology as a scientific discipline in the Western world is largely attributed to endeavours at the University of Chicago (UoC) in the early 1900s (Faris 1970). The then new city of Chicago became the scientific laboratory from which data were drawn. These origins of sociological field work are attributed to the Head of Faculty, Albion Small, who brought German sociology (emphasising philosophical orientation, epistemological reflection, and understanding of human actions through the context in which these occur) to America. Prior to this, sociology - guided only by uninformed and opinionated debate - lacked academic rigour.

On joining the faculty, Thomas and Znaniecki introduced the concept of social disorganisation, turning scholars away from addressing social problems and towards considering the chaotic sociological processes which generate such problems (Faris 1970). Their major work, *The Polish Peasant* (Thomas and Znaniecki 1958), also focussed scholars' attention on methodology, especially on the management, sorting and re-presentation of massive amounts of gathered data. Thomas' early work and concern for attitudes and values had a long-lasting, pervasive impact on sociology at UoC (Faris 1970), and laid the foundations for the seminal work which would be carried out by scholars of the second Chicago School, between about 1946 and 1960. George Mead also had a similar impact on the future direction of sociology. His presentation of

the way humans use symbols to give and create meaning, and of the interaction between humans and the society they inhabit which creates the self, laid the cornerstone for the symbolic interactionism and dramaturgy which later guided scholars including Howard Becker, Erving Goffman and Ken Plummer.

The Second Chicago School, established in late 1940s post-war America, championed exploration of themes of deviance, race and ethnic relations, urban life and collective behaviour, and renewed interest in participant observation (method) and symbolic interaction (theory) (Fine 1995). Herbert Blumer advanced Mead's work, insisting that understanding the social act, the players, and the environment in which it takes place, are central to understanding social issues (Colomy and Brown 1995).

Blumer, with his colleague Everitt Hughes, influenced students' exploration of criminal behaviour and deviance (Galliher 1995). With others, Howard Becker and Erving Goffman had a major impact on the field of criminology despite the majority of their work focussing on deviant (and not necessarily criminal) behaviour, and the labelling of such behaviours as deviant. These scholars constantly took the side of the underdog, and for the first time, deviance was understood from the perspective of the labelled person, rather than that of the labeller. Interest in this area of research may have been influenced by the lower than usual social-class backgrounds of many of the students in the Faculty after the Second World War and the plentiful examples of the use of power over people offered by the Third Reich (Galliher 1995).

I should clarify why Goffman became my influence for understanding stigma and not Becker, when Becker graduated first [1951, Goffman 1953] and was the first, in his 1966 speech as president of the Society for the Study of Social Problems, to publicise the need to understand oppression from the oppressed person's point of view:

... it is essential that we consciously take the perspective of the oppressed rather than the oppressor ... since the views of the powerful are given more credibility, we have more to learn from those without power (Becker, cited in Galliher 1995:169).

In his seminal text '*Outsiders*' Becker briefly proposes a labelling theory of deviant behaviour, postulating that deviance becomes a consequence of other peoples' reactions to the behaviour, not of the behaviour itself. Only if the reaction is negative, does the behaviour become labelled as deviant. He explains that:

Whether an act is deviant, then, depends on how other people react to it. You can commit clan incest and suffer no more than gossip as long as no one makes a public accusation, but you will be driven to your death if the accusation is made. The point is that the response of other people has to be regarded as problematic (Becker 1963:11-12).

The similarities between deviants and non-deviants, rather than on what separated them then became the focus of research (Becker 1964). Edwin Schur contributed to this work by addressing the political dimensions of deviance – that once a behaviour has been identified as deviant, those in power, and the power of public systems, come into force to regulate and control the deviant offender (Schur 1980). Although Becker undoubtedly triggered deviance research, Sumner (1994) demonstrates that Becker never created a fully developed theory relating to labelling, and a single remark: 'the deviant is one to whom that label has successfully been applied; deviant behavior [sic] is behavior that people so label' (Becker 1963:9) appears to have prompted the later extensive work in the field. Ongoing enquiry into how a label itself creates stigma indicates a close relationship between the two concepts of stigma and deviance (Link and Phelan 2010).

Goffman, concentrating on the perspectives of the stigmatised, explored the influence of the powerful over the powerless by addressing issues of control over patients in mental institutions. Informing his first text (Goffman 1959), this work was later developed in *Stigma: Notes on the Management of a Spoiled Identity* (Goffman 1963a). Goffman's representation of stigma as an emotional response to others' reactions to a feature of difference, rather than the deviance of behaviours described by Becker, is the reason why Goffman, and not Becker, informs my understanding of stigma. Goffman's preliminary concepts are that:

Society establishes the means of categorizing persons and the complement of attributes felt to be ordinary and natural for members of each of these categories. Social settings establish the categories of persons likely to be encountered there. The routines of social intercourse in established settings allow us to deal with anticipated others without special attention or thought. When a stranger comes into our presence, then, first appearances are likely to enable us to anticipate his category and attributes, his 'social identity' we lean on these anticipations that we have, transforming them into normative expectations, into righteously presented demands (Goffman 1963a:11).

Majority social groups, then, decide and define expected behaviours that function in given social settings and new entrants are expected to fit with these expectations. Those within the setting who witness a new arrival automatically draw on these expectations to make assumptions about that person. Goffman then moved his focus away from isolated institutions and specific situations and into daily social interaction, and demonstrated that the behaviours used to control social self in concentrated situations such as mental institutions also existed - albeit in diluted form - in wider society. He presented the notion that everyone, for some reason and in some situation, can be viewed negatively by another person - and in this way we may all be stigmatised.

This fundamental point, that: 'stigma and stigmatisation is everywhere because almost any conduct or any characteristic can be seen as deviant by some audience' (Falk 2001:25) is re-iterated in many stigma texts. Understanding the experience of the stigmatised is essential, otherwise as Goffman (echoing Becker) insisted, it is only those in positions of authority who inform our understanding of reality. The relationship between stigma and power is addressed again in Chapter 11.2.2: p. 246].

Goffman's stigma theory developed from his work on 'normal' community behaviours (Goffman 1959), to examining how people change the way they manage information about themselves in different social and public settings (Goffman 1963b), through to his most widely-cited and accessible *Stigma: Notes on the management of a spoiled identity* (Goffman 1963a). The latter clarifies the origins of stigma, the consequences of

difference, and the options for managing that difference. Yet despite his popularity, Goffman has been criticised for simply putting into words what was already known, for focussing on the ‘quirks and mishaps’ of the individual in society instead of on ‘the framework of society itself’ (Burns 1992:2), and for his writing style. In comparing him with Becker, Sumner (1994:231) claimed that:

Becker had the great merit of being able to express the ideas of the labelling perspective with great simplicity and clarity ... he was a social deviant, in Goffman’s sense of that term, and you could feel it in his writing, whereas Lemert and Goffman always read like straight, albeit cynical, academics ...

suggesting that Goffman’s style is academic and obscure. Burns, however, argues that Goffman’s style is careful and open, making his work more accessible. It was certainly Goffman’s great skill in describing the ordinary, minute aspects of interactions so clearly which resonated with me when I first read his text. I felt he *understood* me, his descriptions and explanations of stigma and of being different from the majority matching my own experiences precisely. If experience is not described in accessible language it remains unseen, unheard, and ignored. Goffman’s writing style ensures that anyone – academic or lay – can access to his ideas and recognise the parallels with their own lives:

It is that Goffman saw the practice of social science as discovery. This is not to say that he brought new facts to light or revealed information which was previously unknown, but that he made clear what was previously unclear, pointed to the significance of things which had been regarded as of little or no consequence, and disentangled what was previously an indiscriminate muddle (Burns 1992:6).

Further criticisms of Goffman’s literary style and scientific approach (Ditton 1980) include charges of obscurity - that he ‘is never very clear about what he is up to’ (Lofland 1980:27). Psathas (1980) suggests that Goffman’s failings are those of all symbolic interactionists who, he feels, base loose insights on commonsense

interpretations of everyday life. Psathas further suggests that instead of simplifying social interaction down to an exchange between two actors, as Goffman frequently did, a phenomenologically-grounded investigation of face-to-face interactions would be more useful for exposing the structure of such interactions and developing related concepts. There is no right or wrong in these debates: differences of opinion add richness and texture to the overall picture, enabling people to access, interpret and understand the issues in many ways. However, although only a small portion of Goffman's work focussed on deviant behaviour and social control it remains dominant in the field, providing the foundation for decades of ongoing diverse research which continues to explore stigma in a wide range of everyday social situations (Fine 1995).

Since the 1980s, theorists have attempted to explain the emergence, control and resistance of stigma. Stigmatisation is proposed to be self-protective and positive when it results in a recognised social identity; those who stigmatise benefit from group cohesion and belonging, as do the stigmatised if they find their identity with an 'out-group' (different from the norm) (Heatherton et al. 2000). Dovidio et al. (2000) study the psychosocial processes involved in stigma, recognising the three way interaction between individual, social group and social behaviours. Link and Phelan's (2001) concept of stigma incorporates the simultaneously occurring components of labelling, stereotyping, separation, status loss and discrimination [see Chapter 2: p. 22]. Their work underpinned a consequent surge in interest in stigma and prejudice (Guimón 2010; Phelan et al. 2008; Stuber et al. 2008; Thornicroft et al. 2007). They, in particular, have extended Becker's original work by addressing the role of labelling in constructing stigma (Link and Phelan 2010). By 2006, stigma research was suggesting that a person's response to stigma is shaped by: 'the characteristics of the stigma, the characteristics of the person, and the characteristics of the situation' (Levin and van Laar 2006:4). Goffman's original observation of the particular problems facing those with hidden issues which can potentially discredit them if revealed, has also been developed further (Chaudoir and Quinn 2010; Quinn 2006; Quinn and Chaudoir 2009).

Stigma theory has extended since Goffman, but his original themes of social reaction, response, and adaptation of behaviours can be traced through to the present day. Stigma

is now widely investigated from the perspective of the stigmatised, increasing our understanding of why and how stigma develops in different settings, how people are affected by it, and how they may adapt to and resist stigmatisation. Social scientists, psychologists and medical sociologists continue to endeavour to illuminate the effect that stigma, arising from an inconsistency between the presented and the actual identity, has on the individual:

[The] discrepancy, when known about or apparent, spoils his social identity; it has the effect of cutting him off from society and from himself so that he stands a discredited person facing an unaccepting world (Goffman 1963a:31)

Stigma isolates, separates and dissociates the marked person, affecting participation in their social world. Humans have always preferred to live in social groups with rules and norms which underpin the expected behaviours of the group. According to bio-cultural models of stigma, a person of difference who threatens group cohesiveness due to physical weakness which prevents them from contributing fully, or by introducing contagion, or through an inability to reciprocate with group activities (perhaps through illness or disability) will be ostracised as a result (Neuberg et al. 2000). A fundamental part of human evolutionary history involves affiliation with one's own group, and mistrust of any other human group with whom there are no social or intimate bonds (Brewer 2001; Fishbein 1996), leading to suspicion towards anything which is, or appears to be, different to one's own group. Natural suspicion towards strangers is a human survival tactic and a key part of childhood socialisation in many cultures. Human suspicion of difference is inbuilt - it helps to define and protect human progress, benefiting the majority group.

Goffman (1963a) indicates that stigma seems to arise when negative attitudes are expressed toward those who appear eligible for group membership. The consequences are that the stigmatised person can become affected by low self-esteem, isolation, having to hide their true self (covering), and a reduction in life chances. In mental health, for example, stigma contributes to a range of associated challenges:

People with mental illness are robbed of the opportunities that define a quality life: good jobs, safe housing, satisfactory health care, and affiliation with a diverse group of people (Corrigan and Watson 2002:16).

Stigma related to illness has been shown to affect access to, uptake and maintenance of essential treatments, for example, for drug user services (Neale et al. 2008), HIV/AIDS (Kebaabetswe 2007; Murray et al. 2009), tuberculosis (TB) (Eastwood and Hill 2004), and psychotherapy (Grofik 2008).

Over time, previously heavily stigmatised marks such as homosexuality and mental illness have become more accepted (Anderssen 2002; Kim and Stout 2010); two approaches - education and contact – are the lynch-pin of stigma reduction strategies for a range of conditions including HIV/AIDS, mental illness, leprosy, TB and epilepsy (Heijnders and van der Meij 2006). However, society is established by creating a set of norms which define one group from another, the contrast with outsiders strengthening and establishing the norm (Becker 1964). There will always be norms and outsiders, there will always be stigma – but research reveals ways of reducing stigma (Pinfold et al. 2005; Quinn and Knifton 2005; Scambler 2006), of recognising it as protective for the stigmatised by creating cohesion and social acceptance within the out-group (Crocker and Major 1989), and of helping the stigmatised manage their situation positively (Corrigan et al. 2009; Miller and Kaiser 2001; Radcliffe and Stevens 2008).

2.2. Theories and definitions of social and health-related stigma

The contribution of Durkheim to stigma theory and the development of sociological scientific investigation of the phenomenon in the Chicago School has been outlined earlier. In determining which definition and theory of stigma to adopt for this study, it would be tempting to simply adopt Goffman: his language, descriptions and explanations appeal personally, but to make an informed, critical choice, a range of theories and definitions must be considered.

2.2.1. Erving Goffman (1922 – 1983)

Erving Goffman, the son of Ukranian Jews who had migrated to Canada, developed his interest in sociology and social anthropology as an undergraduate. Later, while at the Chicago School and influenced by Everitt Hughes, he completed his PhD, conducting field work in the Shetland Islands. Goffman was briefed to study the social structure of the island community, but became side-tracked by the behaviours and relationships between staff and guests in his hotel. These early observations probably became the preliminary processes in development of Goffman's stigma theory (Burns 1992).

Goffman always focussed on the stigmatised, especially on how someone with a feature of difference manages themselves in social settings, and on how others' response towards this differentness *spoils identity*. Goffman (1963a:13) defined stigma as 'an attribute which is deeply discrediting,' explaining that stigma arises when virtual (what society perceives an identity to be) and actual (what the identity actually is) identity do not match. Although it has since been demonstrated that those with the same stigmatising feature can stigmatise others like them, Goffman proposed that stigma is felt when the person owning a feature of difference anticipates or senses disapproval, or experiences exclusion, isolation or disgust from *normals* who do not carry the same feature (Goffman 1963a) and perceive it to be deviant. Visible differences - physical disability or skin colour - can be perceived immediately by the *normals*, but hidden differences such as social class, sexual orientation and unseen illnesses lurk inside the person, waiting to be discovered (Dijker and Koomen 2006; Goffman 1963a; Quinn and Chaudoir 2009). The person is *discreditable*, and should their difference be discovered, they become *discredited* (Goffman 1963a). The risk of discovery, and that *normals* will realise the person is not what they first appeared to be, causes people of difference to hide physically and socially for fear of being exposed, or to pretend to be something other than who or what they are in order to fit the expectations of the *normals* (Joachim and Acorn 2000a). Goffman (1963a: 3) also stressed that 'an attribute that stigmatises one type of possessor can confirm the usualness of another' - it is not the attribute itself that gives rise to stigma, but the relationship between the holder of the attribute, and the observer. For example, an American or European might view illiteracy amongst their

own cultural group negatively, accept it as the norm or view it negatively in remote Indian tribes, who may themselves have no problem with their inability to read or write.

Goffman's theory proposes three types of stigma - physical, conduct, and tribal - and each may be either visible or invisible. Visible stigmas immediately *discredit* the carrier, whilst invisible stigmas make the carrier *discreditable* [Table 2-1]. The theory was based on observations of social interactions, but Weiss et al. (2006), suggest that this does not translate well into health-related stigma research which should focus on the 'indicators, effects, and practical implications of stigma'.

	<i>Types of stigma</i>	<i>Ways in which stigma can be carried</i>	
		Discredited	Discreditable
1	PHYSICAL (abominations: of the body)	Paraplegic in a wheelchair	Woman who has undergone a mastectomy
2	CONDUCT (blemishes: of character)	Well-known criminal e.g. Myra Hindley, Ronald Biggs	'Secret' homosexual
3	TRIBAL (tribal)	Negro	Jew

Table 2-1. Goffman's Stigma Framework identifying three types of stigma, and the ways in which these can be carried (Page 1984:5) The cultural context of 1950s America should be borne in mind when considering Goffman's terminology

Weiss et al. (2006) also identify three shortcomings which they claim limit the usefulness of Goffman's stigma framework for health research: that the language (abominations, blemishes and tribal identities) is antiquated, that the range of phenomena to which stigma can be applied is so vast it cannot possibly adequately address health-related interests, and that the implication of a dominant *normal* culture goes against the reality of current multi-cultural societies. I would argue against this position. Goffman identified the importance of context - including time - in his work, which permits careful modernisation of his original phrases. Page's representation of

Goffman's framework [Table 2-1] demonstrates how recent interpretation of his work easily translates *abominations* (of the body) into *physical*, and *blemishes* (of character) into *conduct*, whilst *tribal* remains unchanged. By addressing what Goffman's original terms meant, it takes little more interpretation to adopt contemporary language appropriate to health-related stigma by equating *physical* with *illness*, *conduct* with *symptoms*, and *tribal* with *cultural*. This enables investigation of health-related stigma through exploring what the illness is, how it shows itself, and the influence of culture on responses to it. Further, the enduring application of Goffman's concept to such a vast range of phenomena demonstrates flexibility rather than unsuitability for health-related stigma research.

Finally, all societies, multicultural or not, have a dominant normal group. Goffman's dominant normal was based on the American middle class of the 1950s, but his framework does not specify dominance, only that culture (tribal influence) is taken into account. For example, White indigenous Britons are the prevailing cultural group in the UK, but other ethnic groups, including Indians (Pakistani, Bangladeshi), Europeans (Polish, Romanians), and Africans (Africans, and Afro-Caribbeans) dominate in different areas of the country. Stigma researchers address culture by conducting their research in specific settings or with specific groups, for example in researching stigma and violence in dealing with madness [sic] in Brazil (Nunes and de Torrenté 2009), Chlamydia-screening services in predominantly Catholic Ireland (Balfe et al. 2010a), and social support for Jordanian women with breast cancer (Alqaisi and Dickerson 2010), and explore the impact of culture on the experience of stigma in these situations. Other cultural aspects of illness may include the non-diseased healthy population as the dominant normal whilst the diseased unhealthy is the deviant, potentially stigmatised, minority - although it is rarely this clear cut, with many degrees of health and illness present simultaneously within a population.

Goffman's theory appeals because it is straightforward, applicable equally to social and health-related situations, and does not over-categorise or complicate issues. This open framework creates theoretical space for exploration of all types of stigma in many situations, whilst providing structure for researchers with no formal sociology training.

2.2.2. Jones, Farina, Hastorf, Markus, Miller and Scott (1984)

There was no real challenge to or development of Goffman's work for two decades, until Jones and colleagues published their 'Six Dimensions of Stigma' in 1984. They describe stigma as a *mark* on a relationship that subsequently has to somehow be managed. Agreeing with Goffman's view that *normal* and *deviant* are not people but perspectives, they emphasise his early point that *marks* (attributes) are relational: 'a condition labelled as discrediting or deviant by one person may be viewed a benign and charming eccentricity by another' (Jones et al. 1984:5). It appears that the word '*mark*' can be used as a verb – to describe the impact of a discrediting attribute on a relationship; as a noun – to name the discrediting attribute as a mark; and as an adjective – to describe the discrediting attribute.

Jones and colleagues offer no new definition of stigma, but build on Goffman's original theories by developing a consensus on the aspects of stigmatising features which govern *how much* of a mark is made. The six dimensions of stigma they present [Table 2-2] are built on critical analysis and synthesis of a convincing body of research (Harper 1987) addressing social and health-related stigma.

<i>Dimension</i>	<i>Assessment of effect on the stigmatising process</i>
1 Concealability	Is the condition hidden or obvious? To what extent is its visibility controllable?
2 Course	What pattern of change over time is usually shown by the condition? What is its ultimate outcome?
3 Disruptiveness	Does it block or hamper interaction and communication?
4 Aesthetic qualities	To what extent does the mark make the possessor repellent, ugly or upsetting?
5 Origin	Under what circumstances did the condition originate? Was anyone responsible for it and what was he or she trying to do?
6 Peril	What kind of danger is posed by the mark and how imminent or serious is it?

Table 2-2. The six dimensions of stigma, with assessment of the effect each has on the development of stigma within relationships (Jones et al. 1984: 24)

The essential premise of the six dimensions is that the less concealable, more uncertain, more disruptive, and less aesthetic a mark is, the more the marked person is seen to be responsible for it, and the more perilous it is to others, the more stigmatising the condition becomes.

A central theme in Jones et al's work, reflecting Goffman, is that stigma is a process:

the dimensions of stigma are especially relevant for aspects of the stigmatizing process ... these include the emergence of a condition as a socially degrading mark, the development of a self-concept by the stigmatised, and self-presentation strategies (Jones et al 1984:24).

People are unlikely to develop feelings of stigma from one negative interaction with others, but from the cumulative effect of repeated negative responses over time. Jones et al. (1984:31) confirm that stigma and stigmatisation are inconsistent in interactions, and that responses depend on different perceptions that may exist:

The first person might talk about defecation, for example, a humorous topic in his circle of friends. In the second person's group, perhaps, the topic is considered extremely bad taste.

In this example, the first person has no awareness, unless the second chooses to reveal it, of the marked nature of the topic being discussed. This supports Goffman's assertion that stigma is a language of relationships, and players in the relationship determine whether stigma arises or not. Jones et al.'s text was well-received on publication, attracting positive reviews for its methodical, rigorously academic contribution to stigma theory at the time (Anon 1986; Del Boca 1985; Harper 1987). The work has been referenced numerous times and used to guide stigma research in, for example, mental health (Day 2004) and disability research (Olsen 2005). Despite these positive aspects, it was not adopted for this study since hermeneutic phenomenology resists the use of formal frameworks which can impose too much structure and blind the researcher to the possibilities present within the data.

2.2.3. Crocker, Major and Steele (1998)

The social psychologists Crocker, Major and Steele (1998) describe a stigmatised person as one whose full humanity is questionable due to a social category which devalues, spoils or flaws them in the eyes of others. They further describe stigma as ‘an attribute or characteristic that conveys a social identity that is devalued in a particular context’ (Crocker et al. 1998:505). Reflecting Goffman’s (1963a:12) explanation that:

While the stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others in the categories of persons available for him to be, and of a less desirable kind - in the extreme, a person who is quite thoroughly bad, or dangerous or weak. He is thus reduced in our minds from a whole and usual person to a tainted, discounted one ...

Crocker and colleagues make the relational aspect of stigma explicit – that whether stigma arises depends on the relationship between the marked person, and the observer(s), as identified elsewhere [This chapter: pp. 19 & 23].

Context includes time, and stigma also has a temporal quality (Falk 2001; Heatherton et al. 2000). What is stigmatising in one time period, may not be in another. For example, pregnancy and childbirth outside of marriage was stigmatising in the 1950s, but is less so now with these behaviours becoming an active choice for women in the 2000s. The reverse can also occur - what was not stigmatising can become so, as in the case of tobacco smoking. Once a sign of social sophistication, recent UK public health laws controlling tobacco smoking in communal public places have resulted in smokers feeling stigmatised in the 21st century (Bell et al. 2010). Crocker et al. build on and expand Goffman’s work by demonstrating many new situations in which the theory is relevant thus confirming, rather than challenging, the relevance of his theory and definition of stigma to guide this study.

2.2.4. Link and Phelan (2001)

Goffman's definition of stigma was based mainly on interactions between individuals and social groups. Almost all commentators who give a clear definition of stigma use Goffman's, but Link and Phelan (2001) argue that the concept is too vaguely defined and individually focussed. When applied to the wide range of circumstances in which stigma can occur, differences in emphasis can lead to different conceptualisations. Bringing a mental health perspective, Link and Phelan argue that since cultural, organisational, governmental, political and institutional influences can generate and perpetuate stigma, a definition addressing these influences is needed. Their concept of stigma involves four components – labelling differences, linking human differences with negative attributes, creating separations between 'us' and 'them,' and status loss and discrimination. They define stigma as: 'the co-occurrence of labelling, stereotyping, separation, status loss and discrimination in a power situation that allows these components to unfold' (Link and Phelan 2001:382), focusing on the forces which lead to stigma, rather than on the individual's experience of stigma. Bell et al. (2010), however, consider Link and Phelan's definition of stigma as more restrictive, potentially limiting interpretation of stigmatising experiences which do not easily fit. This opinion perhaps informs the comment that 'Goffman's conceptualization stands out as the most comprehensive' (Diaz et al. 2008) since in its simplicity, it is more flexible.

2.3. Selecting a definition of stigma for this study

Researchers exploring health-related stigma have identified new aspects, categories and implications that influence experiences and perceptions of the phenomenon, but all are based on Goffman's original work: 'It is a credit to Goffman's insight ... that his definition is still the touchstone that most contemporary researchers reference as the foundation for their own work' (Rintamaki and Brashers 2010:156). Whalley and McManus (2006) verify that 'all recent work builds upon Goffman, although sociologists and social psychologists have different perspectives.' Joachim and Acorn (2000a), and Quinn and Chaudoir (2009), for example, extend Goffman's original

observations regarding overt (discredited) and hidden (discreditable) circumstances and impression management, through their respective work on stigma and (in)visible chronic conditions, and living with a hidden stigmatised identity. Goffman's definition of stigma as 'an attribute that is deeply discrediting' relies on recognising stigma as a 'language of relationships' – that the connection between players in the relationship determines whether an attribute is discrediting, or not. Scambler (2009:443) confirms that 'few sociologists since have disputed this 'relational' anchorage.'

Goffman has been criticised for focussing on the individual (Link and Phelan 2001), but he did propose that players in an interaction can include the marked person, and another individual, group, social network, institution or culture. For this study, relational anchorage means that whether a person with IBD perceives or is stigmatised by others may depend on the relationship they have with the individual, group, social, institutional or cultural representative(s) they are interacting with. Link and Phelan (2001) concede that variation in definition may be acceptable as long as investigators are explicit about what they mean by the term 'stigma.' Their definition is rejected for this study since it focuses on socio-political structures which enable stigma to develop, rather than on the experience of stigma from the individual's perspective.

Later researchers have also stressed the importance of understanding stigma from the perspective of the stigmatised (Dinos et al. 2004; Kiliç and Campbell 2009; Wahl 1999, for example). This hermeneutic phenomenological study aimed to explore stigma from the perspective of those with IBD, to determine whether stigma exists and how it is experienced. Hermeneutics avoids using theoretical frameworks which can obscure potential findings by guiding the researcher in a particular direction, allowing instead an openness of thinking which permits possibilities (within the data) to arise (Smythe et al. 2008). Appreciating this, and mindful that every later development in stigma theory and research is underpinned by Goffman's work, his simple definition of stigma as 'an attribute that is deeply discrediting' was adopted for this study. His theoretical framework, whilst acknowledged and referred to when considering a potential relationship between stigma and IBD [Chapter 3: p. 35], has not been used to guide or inform data analysis, respecting hermeneutic principles – but does inform discussion.

2.4. The language of stigma

Some of the language of stigma has been presented in Goffman's Stigma Framework [Chapter 2: Table 2-1, p. 16], but Goffman also introduced phrases familiar in any situation where personal information management is required – such as 'covering' one's deviance (hiding it from view), and 'passing' (behaving as non-deviant to avoid stigmatising responses). Social inquiry into personal regulation of discreditable information has since increased, including for example, research into how homosexuals (Griffith and Hebl 2002; Platzer 2006), and people with HIV/AIDS (Michaud et al. 2009) and epilepsy (MacLeod 2010) manage information about their sexual, serostatus or seizure identity differently in different settings. Building on Goffman, later theorists have identified and categorised different 'types' of stigma, resulting in several terms which may be used when reporting stigma associated with a wide range of sociological circumstances and health conditions [Table 2-3].

Term	Meaning	Examples
Felt, Self or Internalised stigma	Internalised feelings of stigma; the individual stigmatises themselves independent of others' responses	Taft and Keefer (2010), Taft, et al. (2013) Internalised stigma in IBD
Enacted, Public or Experienced stigma	Publics' (others') negative beliefs, feelings and behaviours expressed towards a person with a feature of difference; often seen as discrimination	Scambler and Hopkins (1986): epilepsy;
Anticipated stigma	The expectation of being stigmatised	Whitehead (2001): teenage pregnancy; Quinn and Chaudoir (2009): impact of stigma on psychological distress and health
Perceived stigma	Believing oneself to be treated in a stigmatising way, even though this may not be the case	Dancey et al (2002): irritable bowel syndrome; Else-Quest (2009): cancer; Rose et al (2011): depression
Courtesy stigma	Being stigmatised due to an association with the bearer of a feature of difference	Kampf (2008): venereal disease contact tracers Chang and Horrocks (2006): family caregivers of mentally ill relatives Israel (2002): studying sexuality

Table 2-3. Types of stigma, with definitions and examples of research or expert opinion on each

In this study, the terms *self*, *enacted*, *anticipated*, *perceived* and *courtesy stigma* are used to interpret and represent participants' experiences [Chapters 8-10: Findings and analysis, pp. 123-231; and Chapter 11: Discussion, p. 233].

2.4.1. Concepts related to stigma

The boundaries between stigma, prejudice, deviance, shame and embarrassment are indistinct, and it is impossible to categorically state 'stigma is this,' and 'it is not that.' If stigma is imagined as a multifaceted phenomenon, then it may be influenced or caused by components of prejudice, deviance, shame and embarrassment (Becker 1964; Phelan et al. 2008; Stuber et al. 2008). Prejudice can be described as:

an avertive [sic] or hostile attitude towards a person who belongs to a group, simply because he belongs to that group, and is therefore presumed to have the objectionable qualities ascribed to the group (Allport 1958:8).

Deviance is a means of describing disapproved behaviours (Aggleton 1991). It arises in an interaction between the deviant and those responding to his behaviour (Becker 1963) which may be proposed as '*a moral deficit*' (Scambler and Paoli 2008). Shame and embarrassment have the same end point but different origins: 'It is possible to be embarrassed only in the presence of real or imagined others, while shame can occur for a private act' (Edelman 1981:126). Shame is the self's emotional response to an action which contravenes one's own moral, ethical, or personal boundaries and can occur with or without the presence of others (Tangney and Miller 1996). The root of shame is not in response to or from others, but in knowing the self has 'done wrong.' Embarrassment though, emerges from a failure to maintain one's social (public) image (Meerabeau 1999) due perhaps to loss of social poise (Gross and Stone 1964), or failure of a social skill (Argyll 1969) which disrupts the desired social image and results in discredit. Embarrassment may however be only temporary: the desired social image can be recovered through social processes of explanation and apology, perhaps accompanied by humour and wit, described as 'jokework' by Edelman (1985).

Stigma perhaps emerges whenever shame endures. The more ashamed people feel about their actions and behaviours, whether or not the transgression becomes known or remains private, the greater the potential for anticipated, perceived or self-stigma to arise. Those who feel ashamed by incontinence, or by bowel disease, may perhaps be more likely to also feel stigmatised. Or perhaps there is no shame in being ill with IBD, since it is not the person's fault that they are ill, but shame may arise from the inability to control basic bodily functions. Discovering whether there are differences, or whether each is equally stigmatising, is one of the purposes of this study.

Clarifying other language at this stage is also important. The words *prejudice*, *discrimination* and *stigma* are commonly used in academic efforts, but lay people may not describe their experiences in the same terms. Participants in the previously reported Continence Study (Dibley and Norton 2013) rarely used the word *stigma* - instead, they described situations in which they imagined others would think badly of them if the truth about them was uncovered - a central feature of being stigmatised:

‘I have so far been lucky on the occasions when it was a bad accident - I have managed to clean up without anyone noticing. My concern is being uncomfortable before cleaning up and people seeing.’

‘It makes you feel dirty. You are unable to control yourself which then adds panic to the situation. You wonder if people around you know what you have done or that you smell. I get very distressed.’

‘Once or twice I've had to throw my pants in the dustbin because I cannot clean them and wash them to hang on the clothes line. However much I try to clean them, I wouldn't like anyone to think I don't wash properly.’

Hiding information about oneself, and presenting a different version of self because of an expectation of negative responses if the truth is revealed is described as ‘*covering*.’ People with IBD-related incontinence attempt to cover themselves so that their true illness identity is not revealed. Goffman (1963a:125-6) explains that:

It is a fact that persons who are ready to admit possession of a stigma ... may nonetheless make a great effort to keep the stigma from looming large. The individual's object is to reduce tension, that is, to make it easier for himself and others to withdraw covert attention from the stigma This process will be referred to as **covering**.’ [emphasis original]

In managing a stigmatised identity, people may also ‘*pass*’ - deliberately choose not to reveal their status even when an opportunity presents itself to do so. They do not adopt a different identity, just quietly let the truth slip by. Goffman (1963a:94) explains that ‘one finds that the individual will occasionally be in a position to elect to conceal crucial information about himself.’ Passing diverts attention from the individual so that they appear to fit in with the majority social group: ‘because of the great rewards in being considered normal, almost all persons who are in a position to pass will do so on some occasion by intent’ (Goffman 1963a:95). An example is that people with IBD rarely explain their illness or need for ready access to the toilet when challenged about using disability toilet facilities. Because they have no visible disability, the person with IBD adopts the majority social identity of a normal person transgressing the expected code of behaviour for using specialist facilities. Projecting an image of self as non-disabled person using accessible toilets is a preferable deviance to being revealed as someone who cannot control their bowels.

The complex interaction between covering, passing, visible and invisible conditions, has been addressed by later researchers (Joachim and Acorn 2000a; Kroeger 2003; Platzer 2006, for example).

2.5. Stigma, society, and health

As a socially constructed concept, stigma has been investigated in connection with a broad range of social issues including poverty (Martins 2008; Reutter et al. 2009), economy (King et al. 2010), and welfare or benefits services (Scholte et al. 1999; Wu and Eamon 2010). Geographical aspects, such as the impact of living in a poorer urban

regeneration area on stigma and health (Kelahar et al. 2010), and how stigmatised people are treated in public spaces (Gardner 1991) have also been explored. Human culture, referring to social rules, norms and expectations, and to ways of living, is entwined with society, but can be conceptually distinguished from it:

Culture consists of the values the members of a given group hold, the norms that they follow and the material goods they create. Values are abstract ideals, while norms are definite principles or rules which people are expected to observe. Norms represent the 'dos' and 'don'ts' of social life (Giddens 1989:31).

Stigma can arise when a person displays or owns a trait which challenges established norms of the cultural majority, for example, having an illness perceived to be caused by reckless behaviour (Else-Quest et al. 2009; Corrigan et al. 2010). Flouting the role conventions of motherhood (Riessman 2000) or sexual orientation (Herek 2010) can also generate stigma. Cultural and social misunderstanding of illness and the sick role, or fear of contagion, may also explain the common relationship between chronic illnesses and stigma. The sick role was originally legitimate, but has become a derogatory term. The ill person was expected to do all within their power to escape from the role, reclaiming their normal position in society as soon as possible (Scambler 1997). As medical expertise and surgical techniques have advanced, so has the expectation of recovery from illness, perhaps explaining why refusing to accept offered treatment can be viewed negatively by society (Mason et al. 2001). Parsons' (1951) work on the sick role proposed that brief illness causes temporary disruption to social order with only minimal impact on others. Chronic illness, however, disrupts wider social and economic networks, affecting the ill person's ability to maintain their social role. If the sick role is considered deviant, stigma may emerge as observers begin to blame the ill person for not making an appropriately paced recovery.

Blame and responsibility go together. The deviant might be seen as responsible, and therefore also blamed for their situation. Failure to recover from illness may suggest that the ill person chooses to stay in the sick role. They may be perceived as being responsible - if not for their situation - then at least for not trying to escape it, and so

become blamed for being sick (Cataldo et al. 2012; Else-Quest et al. 2009). Illness-related blame may be self-inflicted or conferred by others if the individual is held responsible for causing their illness. Blame has been associated with chronic illnesses generally (Delmar et al. 2006, Mantler et al. 2003), and specifically with diabetes (Lawton et al. 2007), HIV/AIDS (Thomas 2008), cancer (Chapple et al. 2004; Gulyan and Youssef 2010; Phelan et al. 2013), obesity (Herrick 2009), genetic disorders (Hall and Marteau 2003), mental illness (Corrigan et al. 2006; Wasserman et al. 2012), irritable bowel syndrome (IBS) (Ali et al. 2000) and IBD (Voth and Sirois 2009). The notion of blame may explain why a war analogy is often linked to cancer. It must be battled, fought against, won over – and those accepting the fight are portrayed as brave and heroic, taking responsibility for defeating the deviant illness (Sontag 1977).

If stigma arises as a result of others' actual or potential responses to a given situation, how well others understand the situation may influence their response. Where there is more understanding, as in public knowledge of diabetes, or breast cancer, there may be less blame, less stigma, and more support. Visible conditions, such as a skin disorder (Uttjek et al. 2007) or paraplegia (O'Connor et al. 2004) generate different stigma reactions amongst observers and owners of these conditions than hidden illnesses, since the latter carry the risk of discovery and discredit (Joachim and Acorn 2000a). When the concealable deficit is exposed, when chronic back pain (Slade et al. 2009) or hearing loss (Wallhagen 2010) disrupts social interaction, or an epileptic fit (Iphofen 1990) or incontinence occurs in public, others become aware of it and their reaction may be influenced by their understanding.

Cultural differences may influence responses to potentially stigmatising events, but the response to dirt is, perhaps, universal. Although for some the anus is an erogenous zone and a source of erotic pleasure (Agnew 2000), studies by Tsagakamilis (1999) and Curtis and Biran (2001) identify body fluids as the most frequently mentioned elicitors of disgust with faeces considered the most disgusting. Potentially, IBD and related incontinence (which observers may mistakenly perceive as purposeful) could cause disgust and lead to stigma. Culturally, and globally, there are rules about containment of stool, which often include ensuring that people do not observe the excrement of others.

Smith (2007) confirms that the human behaviour of putting excrement 'outside' - separated from the living area - is universal and has been since the time of early man, as the stone-built drop-latrines preserved in the Neolithic settlement at Skara Brae in the Orkneys, demonstrates. Over time, at least in Western countries, toilet behaviours have become increasingly private (Elias 2000). The introduction of feelings of shame and repugnance are believed to have originated with Erasmus in the 1500s (cited in Elias 2000:110); the advice to keep 'private parts' hidden from view and to conduct elimination in private in order not to offend others, is demonstrated in the Brunswick (Germany) Court Regulations of 1589, quoted in Elias (2000:111-112):

Let no one, whoever he may be, before, at, or after any meals, early or late, foul the staircases, corridors or closets with urine or filth, but go to suitable, prescribed places for such relief.

By the 18th Century, privacy for conducting all natural functions was expected amongst the upper classes (Elias 2000). Shame was beginning to develop if these expectations were not met, as the language and actions of toilet behaviour became silenced. The invention in the late 1700s of the flushing toilet eventually moved urination and defecation off the streets of Europe and the USA. By the 20th Century, most Western homes had a private toilet in either home or garden (Lambert 2012). The association between excrement, dirt and disease may originate in the link between poor sanitation and illness. In early 19th Century London, three major cholera outbreaks prompted official action, and a new fully enclosed sewerage system was installed under the streets (Daunton 2004). The threat remains in modern times, as one of the biggest problems facing support agencies following a natural disaster is the potential for cholera and dysentery as human waste builds up (Morris 2011; Tappero and Tauxe 2011).

The Western expectation of privacy when passing urine and stool, and the shame, embarrassment and taboo that surround reference to such functions are addressed further in Chapter 11: Discussion. Here, this summary reveals the difficulties facing those living in the UK with disease and uncertain bowel control. Unable to guarantee keeping these functions private, they risk 'fouling the staircase, corridors or closets'

(Elias 2000). It is reasonable to suppose that they cannot ask for help, or talk to others about it because it is taboo, an unmentionable and unclean topic. The risk of stigma lies in the discreditable nature of the illness: the person is meant, due to social norms, to be continent, have control of the bowels, and deposit their excrement in the proper place. If they *do not* or *may not* have control, they risk contravening these inviolable cultural expectations.

2.6. The link between stigma and illness

Before the 1950s, illness was not seen as deviance. The term *deviance* was ‘reserved for behaviour for which individuals could be held responsible’ (Scambler 1997:171) and at that time, there was little or no understanding of any relationship between lifestyle choices and the onset of related illnesses. Illness was also a normal part of life. Childhood mortality was high, many common illnesses which now cause minimal problems were then untreatable, and people rarely survived for many years with a chronic illness. Illness was perhaps more accepted, and there was a lower standard of health particularly among the poor and working classes (Wohl 1983). Illness as deviance and as a potential source of stigma emerged following Parsons (1951) work on the sick role. Expectations to conform within expected parameters also arose from the possibility of better health, informed partly by the creation of the UK’s National Health Service in 1948. Now, those who fail to return to health due to chronic illness, or are perceived responsible for their illness (Else-Quest et al 2009; Sogolow et al. 2010; Thomas 2008) may become blameworthy, and may also be considered deviant.

There is a wealth of worldwide research evidence on health-related stigma including that linked to HIV /AIDS and accessing anti-retroviral therapies (Gilbert and Walker 2010; Nachega et al. 2006; Ware et al. 2006). Research addresses mental illness as a whole (Angermeyer 2004; Dinos et al. 2004; Link et al. 2001), specific diagnoses such as bi-polar disorder (Michalak et al. 2006; Proudfoot et al. 2009), schizophrenia (Berge and Ranney 2005; Brohan et al. 2010), or post-natal depression (Edwards and Timmons 2005), and barriers to mental health care (Gary 2005; Watson and Corrigan 2011).

Because humans are naturally suspicious of anything which is different from the majority - including illness - stigma occurs in a wide-range of health conditions including epilepsy (Dilorio et al. 2003), leprosy (Tsutsumi et al. 2007), pregnancy loss and abortion (Haws et al. 2010; Orner et al. 2010), obesity (Myers and Rosen 1999; Thomas et al. 2008), hearing loss (Wallhagen 2010), psoriasis (Uttjek et al. 2007), cancer (Else-Quest et al. 2009; Lebel and Devins 2008) and sickle cell disease (Jenerette and Brewer 2010). Stigmatising attitudes towards the ill and their concerns about being stigmatised can also affect wellbeing. Understanding these issues through exploration of the experiences of people with IBD is a further purpose of this study.

2.7. Summary

In charting the development of stigma theory, the rationale behind selecting Goffman's definition of stigma as a guiding principle in this study has been demonstrated. Stigma language has been addressed, with related concepts, before moving to a consideration of the relationship between stigma and society, culture, health and illness. A foundation for locating IBD stigma into existing stigma theory has thus been laid.

In Chapter 3, a review of inflammatory bowel disease is presented; by linking IBD to the stigma theory addressed above, the potential relationship between the illness and stigma is evidenced. The chapter ends with confirmation of the research aims and questions. A critical review of the relevant literature follows in Chapter 4.

3. Inflammatory bowel disease

Inflammatory bowel disease affects millions of people worldwide. It can cause faecal incontinence (FI), a common and socially devastating problem affecting over 1 in 100 adults in the general population (Norton et al. 2007; Perry et al. 2002), and impacting severely on self esteem, confidence and quality of life. FI often limits close family, affecting social activities, travel, work and intimacy. It is a likely symptom during IBD relapse but experiences and perceptions of IBD-related faecal incontinence have only recently been explored (Dibley and Norton 2013). Bowel diseases and poor bowel control challenge social rules and expectations of personal control and hygiene. There is potential for IBD, with or without incontinence, to attract responses of disgust and disapproval in others, leading to feelings of stigma in those with the illness. This chapter illustrates the potential link between IBD and stigma by:

- presenting inflammatory bowel disease (history, prevalence, aetiology, symptoms, management, complications and concerns)
- addressing the potential connection between inflammatory bowel disease and stigma
- clarifying the aims of the research
- confirming the research questions

3.1. Inflammatory bowel disease – an overview

Inflammatory bowel disease (IBD) is an umbrella term for a range of bowel conditions of which the commonest are Crohn's disease (CD), and ulcerative colitis (UC). Historical evidence documents the earliest record of symptoms suggestive of IBD from 1612, with pathology indicative of IBD also being reported throughout the 19th century. In 1913, Dalziel reported in the *British Medical Journal* on autopsy findings of now characteristic transmural gut inflammation in 13 patients, although the identification and naming of the condition as Crohn's disease is attributed to Crohn, Ginsberg and Oppenheimer who combined and published their medical and surgical observations in

the *Journal of the American Medical Association* in 1932 (Baron 2000). Historical records also describe symptoms of bloody diarrhoea retrospectively recognised as probable ulcerative colitis. The earliest evidence comes from AD 117 / AD 130, reported again in AD 300 by Aretaeus of Cappadocia, and termed 'bloody flux' by Thomas Sydenham in the late 1600s (Anon 2000; de Dombal 1968). The first modern description of ulcerative colitis, recognising it as a non-infectious disease, came from Wilks and Moxon in 1875, although Sir Samuel Wilks had in fact, described the condition in an earlier letter to *The Medical Times and Gazette* in 1859 (Anon 2000; Mulder et al. 2014). On the publication of Crohn's description in 1932, the two diseases were considered distinct from each other (Mulder et al. 2014). It is now recognised that they can overlap, when the term 'indeterminate colitis' is used.

IBD is most prevalent in Caucasian populations, affecting 1.4 million people in the United States, and 2.2 million people in Western Europe (Loftus 2004). Previously low prevalence areas such as southern Europe and Asia are showing an upward trend (Goh and Xiao 2009; Loftus 2004). Racial and ethnic differences appear to be diminishing; the emergence of the disease in previously low-incidence ethnic groups such as Indian and Asian people who migrate and settle in high prevalence countries, suggests an environmental influence (Loftus 2004; Rampton and Shanahan 2006). Onset is typically during adolescence / early adulthood, with a second peak of incidence between the 6th and 8th decades of life. CD and UC are both slightly more common amongst women. Cause remains uncertain: the disease is recognised as an abnormal inflammatory process which may be triggered by genetic predisposition in the presence of certain environmental factors (Annese et al. 2007). Current thinking suggests a strong genetic component, and factors such as excessive childhood hygiene, smoking, and some drugs such as anti-inflammatories, oral contraceptives, or antibiotics may be influential (Baumgart and Carding 2007; Cornish et al. 2008; Geary et al. 2010).

Crohn's disease can affect the intestinal system anywhere between mouth and anus but occurs most commonly in the ileocaecal region of the small bowel. It is characterised by patches of disease between areas of healthy mucosa (skip lesions). Inflammation penetrates into the gut wall, causing deep fissuring ulcers. Fibrosis (thickening),

stricturing (narrowing), and perforation of the bowel wall leading to fistulas, can occur. Ulcerative colitis is confined to the colon, typically starting in the distal section as proctitis. It can extend minimally, partially or throughout the entire colon. The disease can be cured by total resection of the colon, but extra-intestinal manifestations affecting joints, skin, eyes and liver will remain (Ardizzone et al. 2008). For both diseases, medical management with anti-inflammatories, antibiotics and biologic therapies aims to induce and maintain remission. About 30% of UC patients, and 70% of CD patients will need surgery at least once in their life (IBD Standards Group 2009).

Common symptoms of active disease in both conditions are diarrhoea, abdominal pain, anaemia and fatigue. The disease impacts on employment (Bernklev et al. 2006), quality of life (Casellas et al. 2001; Mitchell et al. 1988) and psycho-social functioning (Graff et al. 2006; Lix et al. 2008). Urgency causes difficulties with bowel control, which consistently appears as one of the main concerns of people with IBD (Casati et al. 2000; Drossman et al. 1989; Jelsness-Jorgensen et al. 2011; Moser et al. 1995; Stjernman et al. 2010). Recent findings suggest that up to 74% of people with IBD experience some degree of FI and that this is not necessarily related to active disease, with 9% reporting regular incontinence (Norton et al. 2013). The prevalence of FI in the non-IBD general community-dwelling population is reported as ranging from 1% - 15% (Bharucha et al. 2005; Macmillan et al. 2004; Perry et al. 2002; Whitehead et al. 2009). FI has a deleterious effect on quality of life in non-IBD and IBD populations (Akpan et al. 2007; Bartlett et al. 2009; Norton et al. 2013). Accurate measures of prevalence remain elusive due to probable under-reporting of the problem as a result of feelings of embarrassment and shame (Bartlett et al. 2007). Stigma is known to be associated with IBD (Taft et al. 2011), and with IBD-related FI (Dibley and Norton 2013).

3.2. Inflammatory bowel disease and stigma

IBD causes occasional, intermittent, frequent or regular difficulties with bowel control (Norton et al. 2013). Expectations relating to bowel control are deeply embedded in socio-cultural rules and norms (Norton 2004; Weinberg and Williams 2005). Control

over faeces is learned early in childhood development and only the very young, who do not yet have control, are 'permitted' to emit waste in a public setting, although this is expected to be contained (in nappies) and removed (through nappy-changing and personal cleaning) as soon as possible, and preferably out of sight. Bowel control is expected if the individual is to integrate comfortably into a wider social world. Society may view bowel control as an indication of maturity, reflecting personal control over one's own body (Weinberg and Williams 2005). Loss of the learned voluntary control of bowel function might, in the public's eyes, suggest a lack of personal control. An early paper reporting the consequences of losing anal sphincter control due to surgery concludes that:

the attainment of anal sphincter control in childhood is so fundamental in human socialization that the surgical destruction of anal sphincter control must result in severe emotional and social disruption (Orbach et al. 1957:121).

Loss of control due to IBD may have the same personal impact. Even if FI rarely or never occurs, the concern that it *might* causes sufficient anxiety to lead people to avoid situations or limit preferred activities (Dibley and Norton 2013). People with IBD can look well, but their hidden illness and the risk of associated incontinence make them discreditable. If they are incontinent in a public place, they become discredited. Those with IBD are subject to the same social rules about control of body functions as the rest of the population, creating potential for anticipated, self or enacted stigma. Stigma is associated with other conditions where there is poor control of body functions or actions including urinary incontinence (Garcia et al. 2005), obesity (Puhl and Heuer 2009) and epilepsy (Iphofen 1990), regardless of whether these are beyond personal control or not. Incontinence evidences loss of control, generating disgust and disapproval in others despite the loss being accidental, and discrediting those responsible.

With reference to Goffman's stigma framework [Chapter 2: Table 2-1, p. 17] IBD and the FI that can occur are physical, (because IBD is a bodily, bowel-focussed disease), conduct (because of the inability to control bowel actions), and tribal (because of the cultural expectation to manage excretory functions in private) discreditable features.

Comparison with Jones et al's six dimensions of stigma [Chapter 2: Table 2-2, p. 19] reveals the ways in which IBD and FI might be stigmatising. FI might be concealable from sight, but its particular odour will expose it. The course of IBD is unpredictable, and associated incontinence causes considerable disruption to social, personal and private interactions and communications (Dibley and Norton 2013). Aesthetically, disease and symptom are unappealing – messy, smelly, and dirty, and whilst the individual is not responsible for illness (it is not their 'fault' that they have IBD), social expectations about bowel control may lead others to perceive that the person *is* responsible for remaining continent. Peril is presented by the frequently perceived association with dirt, contamination and risk of infection arising from faeces. Odour may additionally play a role in perceived peril, since unpleasant odours are frequently linked to events which suggest biological danger - vomit, rotting food, stool (Low 2005). In contrast, pleasant aromas usually represent aesthetically pleasing events - a bunch of flowers, a perfume, or a culinary dish - which offer no threat and are pleasurable. Miller (1997:66) explains:

Smells are pervasive and invisible, capable of threatening like poison; smells are the very vehicles of contagion. Odors [sic] are thus especially contaminating and much more dangerous than localized substances one may or may not put in the mouth. Before germ theory existed, nauseating smells bore the burden of carrying disease, while good smells were curative.

The individual with IBD, with or without FI, may self-stigmatise because they know that society treats bowel issues as taboo (Smith 2007). They may anticipate stigma because others in their social world have the same rules about bowels, so they expect the subject to be considered distasteful. Negative responses from others, when queue-jumping or using toilets for the disabled when apparently able-bodied in an attempt to gain urgent access to toilet facilities for example, can lead to enacted stigma. Because of the underlying social rules and behaviours about bowel control, people with IBD may perceive stigma in a range of other settings - anything negative or discomforting that happens may become attributed to the illness, rather than being independent of it.

Stigma can be associated with illness, or with the behaviours attached to symptom management (Elstad et al. 2010). Frequent toilet trips, social disruption or interruption, and speculation from others over ‘what’s wrong’ create stigma through fear of discovery and discredit. Expectation of disapproval has been shown to affect help-seeking for other health problems (Vogel and Wade 2009) including eating disorders (Hackler et al. 2010), epilepsy (Dilorio et al. 2003), mental illness (Barney et al. 2009; Corrigan 2004), irritable bowel syndrome (Dancey et al. 2002), obesity (Drury and Louis 2002), and gay and lesbian health needs (Pennant et al. 2009; Reed et al. 2010). FI-related stigma may cause people with IBD to deny their difficulties, or avoid seeking help. Although FI can be a major problem in IBD, very few IBD patients are referred to specialist continence clinics. Patients resist complaining about the problem, and clinicians do not ask (Bartlett et al. 2007; Duncan et al. 2013; Leigh and Turnberg 1982). Embarrassment, not knowing who, or how, to ask for help, and limited awareness of available help, limits help-seeking (Norton and Dibley 2013). Specialist nurse-led clinics for management of FI in adults in the general population do exist (Ness 2008), but there are currently no specific support services for people with IBD-related FI, who face additional issues due to the underlying illness pathology.

Understanding the role of stigma in IBD, with or without FI is a necessary step towards designing specialist continence support services which meet the needs of this patient group. Exploring the experiences of those who do not feel stigmatised, regardless of incontinence status, alongside those who do, may inform understanding of stigma resistance and resilience - the ways in which people actively or passively reduce the potential for, or impact of, stigma on themselves (Miller and Kaiser 2001). Recognising how stigma is created and resisted can inform the design and delivery of specialist services (Beals 2009), including those provided by IBD specialist nurses, to address practical and emotional aspects of FI, and promote stigma resistance and resilience. Enabling people with IBD-related FI to self-manage the physical, emotional and psychological effects of their condition potentially increases their quality of life, reduces isolation and withdrawal, maintains employment and sustains recreation activities.

3.3. The aims of the study

Stigma would seem to be likely in some of those living with IBD. In working towards the ongoing development of specialist IBD nurse and continence services for people with IBD, the role of stigma in illness experience and help-seeking must be understood, and findings incorporated into service design and delivery. The research aims are therefore to:

3. explore the experience of stigma in IBD, with and without faecal incontinence, and the impact this has on wellbeing
4. generate findings to inform future studies into patient experience and management of the social aspects of IBD.

3.4. Research questions

My original (erroneous) assumption was that FI *would* lead to stigma since I imagined this would be my response if I were in that situation. However, some respondents in the *Continence in IBD* study reported being unconcerned since each was the only person who knew of their problem. This consideration, combined with existing evidence, the research aims, and the hermeneutic nature of the study, resulted in two research questions:

- What is the experience of stigma in people with inflammatory bowel disease with or without FI?
- In what ways does stigma affect the social, emotional and personal wellbeing of people with inflammatory bowel disease, and how do they manage these issues?

3.5. Summary

Inflammatory bowel disease and related faecal incontinence are significant health issues which challenge the implicit socio-cultural rules about silence and privacy regarding bowels, excretory functions and associated behaviours. The six dimensions of stigma, which help gauge how stigmatising a feature may be, can readily be applied to both IBD and FI, suggesting that illness and symptom may both be stigmatising. Dibley and Norton (2013) have shown preliminary evidence of stigma linked to IBD-related FI, but the need for detailed exploration of the phenomena remains. Through consideration of IBD information and evidence of stigma in other conditions, an argument has been developed for the likely presence of stigma in IBD with or without associated incontinence, informing the formulation of research aims and questions.

In Chapter 4, the literature search strategy is evidenced and a critical review of the relevant stigma and excretory issues literature which supports the study rationale is presented. A similar review of the relevant philosophical and methodological literature which informs the choice of underpinning philosophy (methodology) is addressed in Chapter 5, whilst papers informing study design (method) are considered in Chapter 6.

4. Literature search and review

The main purposes of the literature search and review in qualitative research are to prove the need for study based on existing evidence (Creswell 2007) and to inform study design (Hart 1998). Advice ranges from conducting a full systematic review (Burton 2000; Hart 1998; Randolph 2009), an initial review and overview with a detailed return to the literature later (Holloway and Wheeler 2010; Wolcott 2001), a review after data analysis regardless of methodology (Silverman 2000a), to undertaking no review at all (Glaser 1998). The latter stance avoids contaminating the researcher's ideas and knowledge so that they enter the research field and develop emerging theory without pre-formed ideas and expectations, but challenges the ability to prove the need for the study. A full systematic review in advance of data collection is best suited to quantitative inquiry or to extract qualitative findings which may, for example, be used to inform practice, rather than evidence the need for further research. For qualitative approaches when there is a relationship between researcher, subject and participants (Maso 2003), the researcher is advised to avoid being over-informed in advance, remaining receptive to what is seen, heard and felt during data collection and analysis (Holloway and Wheeler 2010; Wolcott 2001). A skilful qualitative researcher is disciplined, self-aware and reflexive (Finlay and Gough 2003), controlling their pre-existing knowledge to use it appropriately within the study. In this way, prior knowledge is used for interpretation, understanding and co-constitution, rather than for pre-supposing findings in the data.

Through the literature search, selection and review process (Hart 1998; Randolph 2009), the researcher reveals an evidence gap which proves the need for the proposed study (Cormack 2000; Hart 1998; Holloway and Wheeler 2010). Exploring the methodological and method (design) techniques previously used to research similar topics also guides the researcher in refining and developing their own study design. After data collection and analysis, when developing the discussion around the research findings, the literature is re-visited. Utilising data in this way helps demonstrate trustworthiness: that study findings have genuinely come from the data and not been influenced or pre-informed by the literature. Although presented here as part of the

review process, detailed immersion in findings from the literature was avoided until data collection and analysis was complete. This chapter locates the study within current research evidence by:

- describing the literature review strategy
- reviewing literature on bladder and bowel-related stigma
- discussing the relevance of findings of previous studies to the present study
- demonstrating a gap in the literature reporting IBD-related stigma

4.1. The literature search strategy

In January 2011 (updated November 2013) two sets of searches were run in the British Nursing Index database, and via Ovid© gateway (accessing AGRIS, Embase, HMC Health Management Information Consortium, International Pharmaceutical Abstracts, Maternity and Infant Care, Ovid Medline®, PsycInfo, Journals@Ovid Full Text, Your Journals@Ovid, Books@Ovid, PsycARTICLES, GLOBAL HEALTH, and Social Policy and Practice databases). The first set of searches used the terms *stigma* (with truncation symbol \$), *health*, *incontinen/ce*, *bowel/s*, *inflammatory bowel disease*, *Crohn's disease*, and *ulcerative colitis* in combinations as keywords and title words, to locate papers informing the evidence base on stigma in IBD. The search terms *stigma*, *incontinent/ce* and *bowels* also located papers addressing urinary problems, bowel cancer or other colorectal concerns. These were retained where they met the inclusion criteria in order to provide context for stigma in IBD.

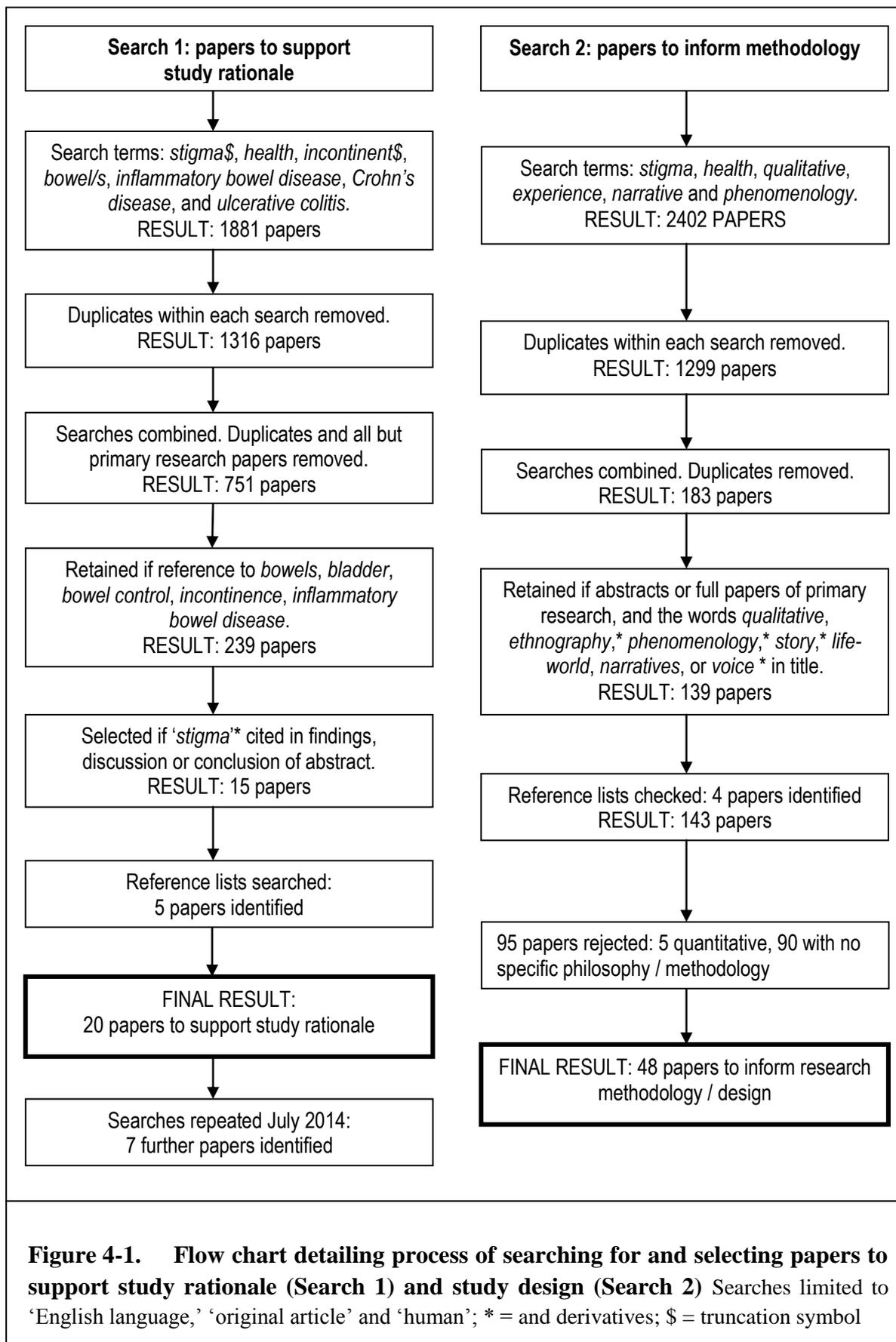
Searches were limited to 'English language', 'original article' and 'human'. 1881 papers were retrieved, and duplicates in each search were removed, leaving 1316 papers. Duplicates arising when searches were combined were also removed, and all but full reports of primary research papers were discarded, leaving 751 papers. Those referring to *bowels* (including terms such as *colorectal*, *rectal*, *rectum* or *anterior resection*), *bladder* (including *urine* or *urinary*), or *bowel control*, *incontinence* or *inflammatory bowel disease* (including *Crohn's disease*, or *ulcerative colitis*) in the title were retained

(239 papers). Of these, only those with reference to *stigma* (including variations such as *stigmatising / stigmatizing*, and *stigmatised / stigmatised*) in the results, discussion or conclusion sections of the abstract, and which were full reports of original research were retained (15 papers). Hand-searching the reference lists of these papers located a further five papers meeting the same criteria, resulting in a total of 20 papers for the review [Figure 4-1; Search 1].

The second set of original searches used the words *stigma*, *health*, *qualitative*, *experience*, *narrative* and *phenomenology* (since the intention was to explore the lived experience of stigma in IBD) in combinations as keywords and title words, to locate papers which would inform the methodological decisions for the study. 2402 papers were retrieved and duplicates within each search removed (1299 papers). Searches were combined, and again, duplicates removed (183 papers remaining), retaining only research abstracts, and full research reports addressing stigma with any of the words *qualitative*, *phenomenology*, *ethnography*, *story*, *life-world*, *narratives*, or *voice* (including derivatives) in the article title (139 papers). A further four papers were located through hand-searching the reference lists of these 139 papers. Of the resulting 143 papers, 95 were rejected - five were quantitative, 90 had no clear methodological or philosophical foundation. 48 papers were retained [Figure 4-1; Search 2].

This chapter focuses on the 20 papers arising from the first set of searches which report primary research on bladder and bowel-related stigma and inform the rationale for the study; characteristics and design quality of these papers are detailed in Appendixes 1 and 2 [pp. 319 & 326]. The papers identified in the second set of searches inform methodological and philosophical decision in Chapter 5, and study methods (design) in Chapter 6; detailed characteristics are provided in Appendix 3 [p. 332].

Search 1 was updated in July 2014 to capture full-text original research articles published either in print or online since November 2013. The additional seven articles are reviewed in Appendix 4 [p. 340] and are used to support the discussion of findings in Chapter 11.



4.1.1. The literature review process

A systematic process for critiquing literature encourages focus and ensures consistency (Hart 1998; Silverman 2000a). For this review of qualitative and quantitative papers, a combined analysis framework was developed based on the Critical Appraisal Skills Programme (CASP) guidelines (www.casp-uk.net), enabling standardised assessment of the 20 selected papers [Table 4-1].

Are the following points addressed?	Sub-questions
Purpose of the study	Is the purpose of, and rationale for the study clearly stated?
Methodology / philosophy	Does the chosen approach fit with the purpose of the study?
Sample	Does sampling method fit with methodology; is sampling method described; is sample described?
Data collection	Does data collection method fit with methodology; is process described; are any tools (interview / focus group guides) provided; are validated measures explained; is management of data (method of data capture, transcription) described and appropriate?
Data analysis	Does data analysis method fit with methodology; is process described?
Findings	How are findings presented; is this consistent with the methodology; are findings a likely product of the study?
Ethics	Are ethical assurances, including evidence of participant consent, given?
Rigour	Is the study credible and trustworthy (qualitative); valid and reliable (quantitative); what methods do authors use to demonstrate rigour?
Limitations	Does the study have any limitations; are these addressed by authors?
Key points	What are the key points arising from the study; is the need for further research specified?

Table 4-1. Analysis framework used to review selected papers arising from literature searches, based on CASP guidelines for reviewing qualitative and quantitative studies

4.2. Results of Search 1

Twenty papers (10 quantitative, seven qualitative, three mixed methods) were reviewed in order to support the study rationale by demonstrating a gap in current evidence.

4.2.1. Characteristics of included studies

The 20 studies addressed urinary incontinence and catheters (Brittain and Shaw 2013; Elstad et al. 2010; Paterson 2000; Wilde 2003), bowel cancer and consequences of associated surgery (Desnoo and Faithfull 2006; Goldman et al. 2009; Macdonald and Anderson, 1984), colostomy (Smith et al. 2007), bowel function following spinal cord injury (Roach et al. 2000), irritable bowel syndrome (IBS) (Dancey et al. 2002; Drossman et al. 2009; Jones et al. 2009), IBS compared with IBD (Taft et al. 2011), and IBD (de Rooy et al. 2001; Dibley and Norton 2013; Drossman et al. 1991; Stjernman et al. 2010; Taft et al. 2009; Taft et al. 2013, Thompson 2013).

5119 participants were reported across 10 quantitative, seven qualitative, and three mixed methods studies; sample sizes ranged from three to 991. Most participants (67%) were female. Paterson (2000), focusing on an exclusively male issue, had no female participants, whilst Elstad et al. (2010), Goldman et al. (2009), and Macdonald and Anderson (1984) recruited equal or near-equal numbers of each gender. Thompson (2013) provided neither sample size nor participant demographic data.

Thirteen studies reported age ranges between 35.5 and 68.5 years, with the remaining papers omitting this detail. In 11 studies, participants were recruited from specific aetiology groups, such as history of bowel cancer and related surgery (Macdonald and Anderson 1984; Desnoo and Faithfull 2006), or diagnosis of IBD (Dibley and Norton 2013; Stjernman et al. 2010; Taft et al. 2009) for example. In the remaining nine studies, participants had mixed aetiology or functional syndromes, for which diagnosis cannot be confirmed with screening tests such as blood tests or biopsy sampling. Detailed characteristics of each paper are provided in Appendix 1 [p. 319].

4.2.2. Quality of included studies

Quantitative, qualitative and mixed methods designs all have a role in research, the method adopted being dependent on the question being asked (Silverman 2000a).

Sampling, data collection and analysis, and reporting techniques should fit with the overall paradigm, so that research rigour is enhanced (Creswell 2007). The methodological (philosophical) and methods (design) quality of the 20 included studies are critiqued below, and summarised in Appendix 2 [p. 326].

4.2.2.1. Research paradigm and fit with methods

The fit between paradigm and methods was good in most of the 20 included papers. Although randomised controlled trials may be considered the gold standard in quantitative research where interventions are being tested (Polit and Beck 2006), the approach was unsuitable for the 10 quantitative studies reviewed here which aimed to measure (amongst other variables) either the presence of, amount of, or effect of, stigma. Only Dancy et al. (2002), measuring illness-intrusiveness, did not specify study design. The remaining nine studies used suitable designs for quantitative inquiry.

In qualitative studies, a philosophical framework should inform research design (Creswell 2007; Silverman 2000a). Failure to adopt or report the framework challenges the reader's ability to critically assess study quality. This can be overcome if sufficient rationale for study design decisions is provided, as in Paterson's (2000) study exploring post-prostatectomy urinary incontinence. The remaining six qualitative studies adopted suitable approaches for investigating participant experience, perceptions or beliefs, including grounded theory, ethnography and phenomenology.

Mixed methods studies provide a means of generating robust, trustworthy results through triangulation of method (qualitative / quantitative) and data collection techniques (Creswell and Plano Clark 2007). None of the three mixed methods studies specified any philosophical or theoretical framework but all display characteristics consistent with the approach, including using both qualitative and quantitative data collection methods, and collecting data in later study phases which explicates the findings from early phases.

4.2.2.2. Sampling methods

Random sampling is the benchmark sampling strategy in quantitative research where reduction of bias in selection can minimise confounding influences on study outcomes. Convenience and purposive sampling are often considered weak strategies in quantitative research, as these can reduce the generalisability of eventual findings. Of the two, convenience sampling is weakest since recruiting from, for example, a hospital cohort of patients, may result in a sample that is less representative of the overall patient population and more likely to contain a higher proportion of people with more severe disease. However, all included quantitative studies were addressing issues relevant to specific populations making these sampling approaches valid.

Five quantitative studies used convenience sampling, recruiting, for example, from available hospital records of patients meeting study criteria (Smith et al. 2007). Seven used purposive sampling, ensuring eligible participants were drawn from wider sources such as internet or disease-specific support groups. Drossman et al. (1991) increased generalisability by randomly sampling from their original purposive sample.

Purposive sampling is the method of choice in qualitative research, where it is essential to recruit a study population which has experienced the issue being explored (Creswell 2007). All seven included studies used purposive sampling. Elstad et al. (2010) also sampled randomly from their original purposive sample, whilst Goldman et al. (2009) used purposive stratified sampling to ensure equal representation of men and women from each of the two ethnic groups being researched. These strategies ensure that the results can be transferred to similar populations.

The design of mixed methods research drives the sampling strategy, and any sampling method may be appropriate depending on the intent and procedures of different mixed methods designs (Creswell and Plano-Clark 2007). All three mixed methods studies in this review used sampling strategies appropriate to the purposes of the research.

4.2.2.3. Ethical considerations

Ethical conduct of research protects participants and researchers. Published research should include a statement indicating that ethics approval has been given by an appropriate review board and that participant consent was secured prior to data collection, reassuring readers that the research is morally sound (Israel and Hay 2006). Eleven papers met these criteria, eight reported either ethics review board approval or that informed consent was obtained, while Thompson (2013) only reported informed consent for interview participants, but not for observation group participants.

4.2.2.4. Data collection, analysis, and reporting

Quantitative research measures variables. Fully-tested validated tools are considered the most reliable and, when used in conjunction with instruments being developed, enable assessment of a new tool's functionality. Data is analysed statistically, and presented numerically, often in tables. Stigma was the variable of interest in eight of the ten included quantitative papers, and emerged as one of several components of illness experience in the remaining two papers. Drossman et al. (1991) and Stjernman et al. (2010) reported development or validation of a measurement scale of IBD patient concerns. The remaining eight papers used existing validated and / or made-for-study measures to capture data on quality of life, and health-related concerns. All papers describe the measures used, and report findings statistically using tables and graphs, although there is wide variation in both the detail of description and clarity of reporting.

Qualitative research gathers written, verbal or visual material as expressed by respondents, and records these using a range of data capture techniques. The commonest method is audio recording, followed by interview transcription. Data is analysed using text manipulation, description and interpretation techniques. Findings are presented as a structured commentary supported by verbatim extracts to enhance credibility of the analysis. All qualitative studies in this review used semi- or unstructured interviews, audio recording and transcription. Elstad et al. (2010) also used focus groups, whilst Thompson (2013), consistent with ethnographic methodology, used another three

methods of qualitative data collection. Data analysis procedures were described in detail in all but two papers (Paterson 2000; Thompson 2013), and verbatim extracts were used in all seven studies.

All three mixed methods papers in this review used an appropriate mix of quantitative and qualitative data analysis methods.

4.2.2.5. Weaknesses and limitations

Study design was mostly robust and led to credible results, although six papers bore weakened design features, potentially reducing generalisability or trustworthiness of findings. Dancey et al.'s (2002) may have skewed the representativeness of their quantitative study participants by taking a convenience sample from an existing pool of research-keen participants. Acknowledging limitations related to low internet response rates and use of a non-validated made-for-study measure, Smith et al. (2007) present their results as 'first findings'. Roach et al. (2000), measuring the impact of spinal cord injury on community integration, conclude that education programmes to reduce stigma due to spinal cord injury-related bowel dysfunction are needed. The authors may have expected stigma to disrupt community integration, but with no reported evidence of this in the findings, this conclusion is not clearly linked to data.

The philosophical framework supporting Paterson's (2000) qualitative study of men with post-prostatectomy urinary incontinence is under-reported. Despite a robust description of process, the link between philosophy and design is obscure and it cannot be determined if the very small sample size ($n=3$) is appropriate for the philosophy, or not. The effect of a female investigator researching an intimate issue with male participants is not addressed - the relationship may have influenced what was shared by the men in both positive and negative ways and comment about this would have been appropriate. In Thompson's (2013) ethnographic study consent procedures are vague and lack of description of method prohibits assessment of the relationship between interview process and captured data.

Drossman et al. (2009) provide no statistical details, and no theoretical basis for qualitative data analysis in their mixed methods study. Verbatim extracts are not used to support claimed findings, casting doubt on the relationship between findings and data. The sample, which included a preponderance of women with severe symptoms, may affect representativeness and the very low turn-out for focus groups makes the reported comparison of findings across groups unreliable.

4.2.3. Findings of included studies

The papers in this review confirm that stigma has previously been linked with a range of bladder and bowel-related issues, although in IBD the evidence is predominantly quantitative. *Perceived* and *internalised* are the most commonly identified forms of stigma but in demonstrating the impact of urinary incontinence on carers, Brittain and Shaw (2007) present a profile of *courtesy stigma* – stigma experienced by those associated with someone who carries a stigmatising feature. Issues relating to containment, taboo, and illness credibility are bound up with stigma, which disrupts health management behaviours, quality of life, and help-seeking.

4.2.3.1. Containment and control

Urinary incontinence (UI) and associated symptoms of urgency, frequency and odour create stigma in carers and sufferers through actual, and risk of, incontinence. Symptoms of frequency (regular and repeated need to urinate) and urgency (needing to reach the toilet quickly to avoid incontinence) repeatedly force the person with UI to leave social situations, attracting unwanted attention and threatening exposure (Elstad et al. 2010). Those facing ‘bodywork’ and ‘dirty work’ whilst caring for a close relative with incontinence become stigmatised, amid the disruptive effort of sustaining a façade of social acceptability. As people become housebound, home becomes the container for the unbounded (incontinent) body (Brittain and Shaw 2007).

Men with UI following prostatectomy have two separate identities. Public identity is built around the need to appear continent, despite not being so. Private identity is structured on creating a new understanding of their leaking body against a background of gender, family history, body knowledge and attempts to reject their own lifelong cultural attitudes towards UI (Paterson 2000). Visibility and identity change also affect those living with an indwelling urinary catheter. The catheter is both positive when accepted as 'part of me', and negative, when its very presence signals vulnerability and creates stigma (Wilde 2003).

Faecal incontinence (FI) causes the same concerns regarding risk of, and actual incontinence. Following surgery for rectal cancer, up to 90% of patients may experience symptoms, including frequency, urgency and fragmentation (passing small amounts of stool on several occasions rather than complete defecation on a single occasion) which cause social and psychological difficulties as unpredictable bowel activity and intense focus on bowel needs create stigma (Desnoo and Faithfull 2006).

4.2.3.2. Stigma and taboo

Help-seeking for bowel problems can be affected by taboo and by cultural influences. Dominicans and Puerto Ricans in the US are diagnosed later and consequently are more likely to die from colorectal cancer. Cultural machismo drives men to avoid digital or colonoscopic rectal examination as these are seen as 'gay' activities, and poor health-literacy about colorectal cancer risk reduces the screening rate in these cultural groups (Goldman et al. 2009). Bowel surgery can result in poor bowel function and control, or formation of a permanent stoma. Macdonald and Anderson (1984) demonstrate that taboo and disgust may pre-dispose towards higher levels of stigma in those with permanent stomas than in those with anastomosis following rectal cancer surgery. Stigma is associated with the cancer diagnosis, is exaggerated by presence of a stoma, and does not decline over time.

Smith et al. (2007) show that disgust trait sensitivity (Haidt et al. 2002) can predict adjustment to stoma in patients, and a desire amongst non-patients to avoid those with

stomas. They indicate that those with high levels of sensitivity may be more stigmatising towards people with stomas, and may adjust less well and feel more stigmatised if they had to have a stoma.

Artificial bowel-emptying procedures due to bowel dysfunction, a consequence of spinal cord injury (SCI), are also stigmatising. SCI causes loss of sensory and motor function to all organs below the level of spinal cord damage, including bladder and bowel. Artificial procedures to enable bowel evacuation are time-consuming, and together with the permanent risk of incontinence impair community integration, confine the person to their home, so reducing life satisfaction by limiting social interaction (Roach et al. 2000).

4.2.3.3. Illness credibility

Stigma is linked to irritable bowel syndrome (IBS) if the disease is perceived as psychosomatic. Diagnosis cannot be confirmed and is established on the patient's self-reported symptoms. Dancey et al. (2002) demonstrate that this lack of credibility and the disruptive focus on bowels leads to illness intrusiveness which affects quality of life, but that intrusiveness is not necessarily greater in the more stigmatised. Drossman et al. (2009) later found that IBS impacts on social, physical and psychosocial dimensions of life, that stigma arises from the belief that intimate and significant others do not understand the condition, and that these effects and perceptions do not vary across stool sub-types (diarrhoea, constipated, or mixed IBS).

4.2.3.4. Measuring stigma

Stigma presence can be confirmed by measuring it. Through development and initial validation of an IBS stigma scale, Jones et al. (2009) identify that primary sources of stigma for people with IBS are co-workers, employers, healthcare providers and friends. The resulting Perceived Stigma Scale (PSS-IBS) was later tested and proven reliable for measuring stigma in IBS and IBD (Taft et al. 2011). IBS patients report significantly

more perceived stigma than IBD patients from all sources (health care providers, family members, significant other, friends, employer / supervisor, and co-worker / classmates) but in both groups, clinical outcomes (symptom severity and disease control) are negatively affected by perceived stigma.

Stigma has been consistently identified as a concern for people with IBD. Body stigma - the degree to which people with IBD feel dirty or smelly and perceive themselves to be treated differently - was one of four indices tested during validation of the Rating Form of IBD Patient Concerns (RFIPC), which compared well with other validated measures of health status (Drossman et al. 1991). In a later application of the RFIPC, de Rooy et al. (2001) demonstrate that physical IBD symptoms and disease stigma affect wellbeing, particularly in older women, those with longer disease duration or those unable to work due to illness. The Swedish version of the RFIPC (Stjernman et al. 2010) proved to be reliable and valid for measuring Crohn's disease-related issues, including body stigma, although Crohn's disease complications, rather than intimacy or stigmatisation were of greater concern to patients. Being female, or having active disease or higher body mass index predict higher degree of disease-related worry and concern.

4.2.3.5. Stigma in inflammatory bowel disease

Perceived stigma in IBD impacts negatively on quality of life and health outcomes, causing psychological distress and affecting medication adherence, self-esteem and self-efficacy (Taft et al. 2009). Repeated stigmatising episodes can cause the person to identify with and accept the negative attitudes they encounter. This internalised stigma is reported more, and stigma resistance behaviours are reported less amongst less educated, urban-living participants with IBD. Internalised stigma is a significant predictor for poorer patient outcomes, particularly decreased self-esteem (health-related quality of life, psychological distress, and self-efficacy) (Taft et al. 2013).

Measures of presence and impact of stigma in IBD, whilst undoubtedly important, do not illustrate the nature of the stigma experience for patients. Thompson's (2013) ethnographic study focuses on the way chronically ill 'IBD bodies' [sic] manage faecal

matters, and reveals that even in apparently 'safe' IBD support groups, members resist speaking openly about bowel matters, referring to these with euphemisms and polite subtexts. Openness is only 'allowed' in the presence of clinicians, or in the face of satire – otherwise direct reference to faecal matter and bowel activity is avoided to prevent the 'soiled disease' from invading the self. Dibley and Norton (2013) demonstrate that stigma is a component of the complex experience of IBD-related FI. Participants reported being concerned about what others would think of them if bowel control was lost in public, or if evidence of it (such as permanently stained laundry on the washing line) was seen, exposing their situation.

4.3. Discussion of findings from reviewed papers

The visibility or concealment of a bowel or bladder disorder may be fundamental to stigma development (Quinn 2006). Fear of being exposed, and of the social rejection this might cause, leads people to cover the truth of what discredits them (Goffman 1963a) but this carries the risk of being let down by the body, of being discredited (Joachim and Acorn 2000a). Findings from this review resonate with results from our earlier work, where those with IBD-related FI described the efforts to conceal and contain their leakage, the distress associated with bowel-related odour and noise, and the risk of becoming housebound and socially isolated as home became their safe haven (Dibley and Norton 2013). Governed by the same social rules about bowel and bladder control, and the same perceptions as the rest of the community - that urine and faeces are dirty contaminating materials (Tsgakamilis 1999) - people with bladder and bowel disorders, incontinent or not, can struggle to maintain self-esteem and resist stigma.

Being stigmatiser and stigmatised can lead people to be both perpetrator and victim of stigma within the same experience (Staples 2011). The Puerto Rican and Dominican culture reinforces stigma towards homosexuals by interpreting colorectal diagnostic tests in a sexualised manner; the same cultural groups then also become victim to the disease and the associated stigma, as the very stigma they perpetuate dissuades them from seeking cancer screening. Similar situations occur in trying to eliminate

HIV/AIDS in African gay communities, where homosexuality remains a crime (Stigma Action Network 2012) so that many of those in need of intervention do not seek help. We have also identified avoidance behaviours in people with IBD-related FI, influenced either by a desire to avoid invasive tests and procedures, or through feelings of embarrassment and shame about their condition (Norton and Dibley 2013).

Stigma, as a construct of people and place, occurs variably in different circumstances (Heatherton et al. 2000). Patients with IBS and IBD are affected by perceived stigma coming from different social sources, and when close relationships (family members, spouse or significant other) are the source, the impact on patients with IBS is greater (Jones et al. 2009; Taft et al. 2011) [See Chapter 11: Discussion, for a related consideration of kinship stigma]. In different situations, and over time, stigma and illness can take a more active or passive position in people's lives, reflecting the shifting perspectives model of chronic illness in which illness symptoms and concerns alternate between being in the foreground and background of a person's life (Paterson 2001). Stigma may feature more prominently with active disease (Taft et al. 2013).

The 'believability' of a diagnosis also influences the experience of stigma, perhaps attracting negative responses from others who consider functional illnesses such as IBS to be psychosomatic (Asbring and Narvanen 2002). Unlike IBS, IBD is not a functional disorder. Diagnosis is confirmed through detailed recording of medical history and symptoms, testing of biomarkers, and colonoscopy (Van Assche et al. 2010; Dignass et al. 2012). The social requirement to keep bowel and bladder conditions invisible may in fact compound experiences of stigma - people may not be believed if they do not 'look' ill, and they become the target of stigmatising responses. Stigma resistance behaviours enable people to resist internalised stigma (Ritsher et al. 2003), but mechanisms of stigma resistance in IBD have only recently been addressed (Taft et al. 2013) and deserve further investigation.

4.4. Conclusions drawn from reviewed papers

Stigma is associated with bladder and bowel-related conditions, driven by the socially disruptive impact each causes and by contravention of social and personal rules relating to taboo subjects (Drennan et al. 2011; Garcia et al. 2005; Norton 2004). Three quantitative papers in this review directly measured stigma in IBD and its effect on patient outcomes. These findings confirm the clinical impact of IBD-related stigma but do not reveal insights into how individuals experience, succumb to, or resist stigma. One qualitative paper reveals ways in which the language of IBD is made socially-acceptable (Thompson 2013) and our earlier mixed-methods work indicates that embarrassment (a recognised manifestation of stigma) prevents people from seeking help for their IBD-related FI (Dibley and Norton 2013). There is no robust qualitative evidence of the lived experience of IBD-related stigma occurring independently of FI, of how this is experienced and managed, the effect it has on the person's life, or whether it can be resisted or overcome.

Credible qualitative exploration of stigma in IBD will provide insights into the meaning of the experience for the individual, perhaps demonstrating the influences of stigma on social, personal, public and intimate worlds, or the changing nature of stigma as chronic illness proceeds. Exploring experiences of those who do not feel stigmatised, regardless of incontinence status, alongside those who do, may inform understanding of stigma resistance – the ways in which people actively or passively reduce the potential for, or impact of, stigma on themselves (Miller and Kaiser 2001). Appreciating that stigma is a complex experience which affects individuals in unique ways may also assist health care professionals in providing individual support for those with stigmatising chronic illnesses such as IBD, addressing practical and emotional aspects of illness and promoting stigma resistance.

4.5. Summary

Through a rigorous critique of the literature, the quality and type of evidence relating to stigma in a number of bladder and bowel-related illnesses and symptoms, including IBD and FI, has been considered. Stigma has been shown to have a complex impact on patients' and carers' lives, but there is a dearth of qualitative evidence reporting stigma in IBD, supporting the rationale for an in-depth qualitative exploration of the issue.

The papers identified through the second literature search are critiqued to guide the philosophical (methodological) decision for the study in Chapter 5, and to inform research design (method) in Chapter 6. The seven papers published since the original Search 1 (updated in November 2013) are reviewed in Appendix 4 [p. 340].

5. Research methodology

In research design, the researcher must choose the right tools for the task. The link between theory (methodology / philosophy) and method is unbreakable - one informs the other (Holdaway 2000), and methods only have meaning when 'embedded in particular theoretical perspectives' (Silverman 2000b). Designing qualitative research is akin to choreography where movement, flexibility and progress tell the story (capture the data) within the purpose of the dance (the research aims) and through a specific type of dance (research methodology) (Janesick 2000). The methodological / philosophical framework for the study must be selected in light of the unique challenges posed by the proposed research before methods can be clarified.

Stigma is a complex phenomenon, and since the main aim of this study is to understand and interpret stigma *experience*, a qualitative methodology is required. Stigma can be viewed from social, cultural, behavioural, psychological, environmental, political and geographical perspectives, and qualitative research can address one, some or all of these factors. For example, if the focus was on cultural aspects of stigma, ethnography might be the preferred option. If gender aspects of culture were the focus, feminist research could be more appropriate. Addressing cultural stigma in minority groups might require critical social theory.

A working definition of stigma can also inform philosophical choice. Several are available [Chapter 2], each casting a different perspective. For example, Link and Phelan's (2001: p. 382) definition of stigma as 'the co-occurrence of labelling, stereotyping, separation, status loss and discrimination in a power situation that allows these components to unfold' could direct the researcher towards ethnographic, feminist or critical social theory approaches in order to focus on the influence of power on stigma creation. Goffman's much more open definition of stigma as 'an attribute that is deeply discrediting' has been adopted for this study, providing a broad canvas on which the complex picture of stigma from any perspective, experience or situation, can be painted. A philosophy which supports this broad approach is essential.

The role of the researcher in the study must also be addressed. Following Goffman, most stigma theorists agree that in various circumstances, everyone can be viewed

negatively by another person and so all can be actually or potentially stigmatised. I have a previously stigmatising identity (although I no longer feel stigmatised by it) which potentially brings negative and positive influences to my work. I also believe that knowledge comes from understanding our interactions with our world, and that we use this knowledge to interpret new experiences. The philosophical approach to this study of stigma in IBD must embrace my role, and incorporate my pre-understandings in the capture, interpretation and presentation of data.

The literature review [Chapter 4: p. 41] demonstrates that stigma has been identified and measured in IBD, yet almost nothing is known about the *experience* of stigma for people with IBD, what exacerbates feelings of stigma in some but not others, and what helps or hinders resilience. Where little is known about a topic, the researcher should select a philosophy which enables the capture of as much information as possible about it. This can be achieved by considering the philosophical choices adopted by others when researching health-related stigma. In *Search 2: papers to inform methodology* conducted previously [Chapter 4: Fig. 4-1, p. 44] 48 research reports clearly stated the methodological / philosophical framework used. Critiquing these 48 papers, and considering other approaches not represented in these 48 papers, informed the choice of philosophy for this qualitative exploration of stigma in IBD in which the discrediting attribute was uncertain, an openness towards the experiencing person's perceptions was required, and the researcher would be 'in' the research. The capacity to provide an interpretation (rather than description) of experiences was also essential. This chapter confirms the selection of underpinning philosophy for the study by:

- critically reviewing the methodological (philosophical) choices used in previous qualitative studies of health-related stigma
- providing a rationale for rejecting other approaches not represented in the literature review
- presenting a detailed critical review of phenomenology
- confirming the decision to adopt a Heideggerian (hermeneutic) phenomenological approach

5.1. Critical review of the methodologies (philosophies) guiding previous qualitative health-related stigma studies

The second set of literature searches [Chapter 4: Fig. 4.1, p. 44] located 143 original research articles which used a qualitative approach to explore health-related stigma. The question for the following review, was ‘How well do the methodologies (philosophies) used in the reviewed papers meet the challenges identified in the current stigma study, and are any appropriate for this study?’

5.1.1. Selecting the papers for methodological review

Of the 143 papers reporting health-related stigma research, five presented as qualitative but using quantitative approaches and 90 with no specific underpinning qualitative methodology (philosophy) were excluded. The remaining 48 papers are critiqued below to determine which methodology could be adopted for this stigma study. Detailed characteristics of each paper are presented in Appendix 3 [p. 332]. Findings are not discussed here to avoid pre-conceptions ahead of data collection and analysis.

5.1.2. Miscellaneous philosophies

Nine of the 48 studies adopted miscellaneous methodological / philosophical approaches. One study each used an ethnonursing, oral history or case study approach, two used narrative research, and two stigma theory. The ninth paper, an interpretive research study (Snadden and Brown 1992) reflects the philosophical upheaval within 1990s qualitative research. It describes interpretive processes without alignment to any specific philosophy, and defends design decisions using the quantitative terms of validity and reliability which were pervasive until qualitative research developed its own language. The paper was therefore excluded from this critique.

5.1.2.1. Ethnonursing, case study and oral history research

Ethnonursing, based on Leininger's Culture Care Theory, explores nursing care delivery in the context of cultural beliefs, rules and expectations (Mixer 2008). Case study research addresses a topic through one or more cases within a specific context or setting (Creswell 2007), whilst oral history research explores changes in human lives revealed through participant's stories (Haynes 2006). As the proposed study would not exclusively investigate nursing care, focus on a single or few cases or specifically collect an oral history, these methodologies were rejected.

5.1.2.2. Narrative research

Narrative research aims to capture stories told in a logical sequential and chronological manner (Riessman 1993) and is best suited to exploring specific events or experiences. Stigma may not be a coherent issue in IBD – the fluctuating nature of IBD may vary stigma experiences which might not be considered as distinct events and, unless a single stigmatising event marked the onset of awareness of the phenomenon, participants may be less likely to describe their experience chronologically. Additionally, there are many unknown factors in the experience of stigma in IBD so a broader approach was needed. Narrative research was therefore rejected.

5.1.2.3. Stigma theory

The use of stigma theory may seem a logical way of framing stigma research, although the theory used will have an impact on the type of data gathered. For example, Roura et al. (2009) drew on Deacon's definition of stigma which links disease with sociology, presenting it as 'negative social baggage associated with a disease' (Deacon et al. 2005:19). The definition assumes, perhaps inaccurately, that stigma is a negative experience (Crocker and Major 1989; Herman and Miall 1990; Jetten et al. 2001) yet in guiding any study, this assumption could raise the profile of negative experiences of stigma and mask positive experiences which would provide balance. Balfe et al. (2010a)

used Goffman's impression management framework, and again, findings strongly aligned with the framework. A stigma framework can facilitate collection, sorting and analysis of data, but may also restrict findings: if stigma is asked about, stigma will be found, and perhaps not everyone with IBD does feel stigmatised. A stigma framework may impose preconceptions that limit the capture of a range of stigma experiences and prevent these from emerging independently from the data; the use of a stigma framework as the philosophical underpinning for the proposed study was rejected.

Additional concerns relating to the methodologies in this section were the narrow subject focus each supported, and vagueness about capacity to include the researcher as part of the research endeavour. The current study intended to address the current lack of qualitative evidence on the experience of stigma in IBD so a philosophy which would enable capture of a broad range of experiences and influences, including those as yet unidentified, was essential.

5.1.3. Grounded theory

Four of the 48 papers were grounded theory studies, which could be considered as a practical framework for managing research rather than a guiding philosophy (Creswell and Plano-Clark 2007). Ghezeljeh and Emami (2009) offer an analysis of the ontological, epistemological and methodological influences of grounded theory design, while Kushner and Morrow (2003) are critical of its lack of philosophical foundation with unconvincing links to symbolic interactionism and descriptive phenomenology.

Glaser and Strauss considered early qualitative research imprecise. To eliminate ambiguity and researcher bias, they propose a series of structured research stages (Glaser 1998) in which recruitment, interviewing and analysis take place simultaneously. Further purposive recruiting and interviewing is driven by the evolving demographics of the sample and ongoing findings. Constant comparison between findings and data collection continues until data saturation, when no new data is captured.

The data coding process identifies and categorises elements. Connections are then explored, building a volume of evidence to support theory development. The researcher is separated from the research event to avoid negative bias yet ongoing recruitment and data collection are guided by what the researcher sees in the previously captured data. Kushner and Morrow (2003) describe the process as abductive (closely linked with the process of discovery) and creative, rather than inductive.

Grounded theory is suited to research where there is little understanding of the social processes at work (Hunter et al. 2011). Although the phenomenon of stigma in IBD is not fully explored, the social processes which give rise to stigma are very well documented in sociology research (Goffman 1963a; Jones et al. 1984; Heatherton et al. 2000; Franzese 2009, for example), and in health (Ablon 1981; Cottenden et al. 2003; Heijnders and Van Der Meij 2006; Link et al. 2001; Scambler 2006, for example). The dismantling of data into abstract codes can eliminate the respondent's voice from the findings, the separation of researcher from the research event, and the indistinct philosophical foundations do not support the previously identified requirements for the study, and so grounded theory is rejected.

5.1.4. Exploratory qualitative research

Six studies used exploratory qualitative research as the guiding framework, although none provided a clear description of what was meant by 'exploratory.' Kowalczyk (2014) explains that exploratory research develops initial ideas or insights to provide direction for any future research that might be needed, or for policy development. There is no underpinning philosophy beyond a requirement to adhere to qualitative methods. Although cited in these reviewed papers as a methodology, it presents as a combination of methods used independently of any guiding theory, which may nonetheless have a role in early investigation of unexplored issues.

In exploratory qualitative research, study intention and design are both purposive and deductive, and aimed at answering a specific question rather than discovering what

might be in the data. Data may be obtained from new sources, or involve secondary analysis of existing data. Findings should clarify the course of later related research. The researcher's role in the process is indistinct.

Exploratory research is unsuited to this study which seeks to understand stigma through the ways people express, perceive and make sense of stigma experiences. Findings will emerge from the data without pre-conception of what might be there. Since the proposed study is inductive, rather than deductive, exploratory research as a methodology is rejected.

5.1.5. Ethnography

Six studies were ethnographic. Ethnography, with roots in anthropology (Hammersley and Atkinson 1983), is the study of any cultural group and may refer to race and culture (Riessman 2000), or to organisational culture (Punch 1979). No single consensual definition exists (Lambert et al. 2011), but it is a common approach within the social sciences when seeking to investigate peoples' socio-cultural world by *living among the natives* and developing an understanding of their world through direct observation and experience of it (Silverman 2000b). *Entering the field* is a fundamental requirement: ethnographers consider that a person's behaviour is linked to the meaning a situation has for them, and can only be understood by observing behaviour in the context in which it occurs rather than relying on later verbal descriptions of recalled events (Baillie 1995; Silverman 2000b). The researcher enters the field of study, often for extended periods of time, to become either a non-participant (*etic*) observer – in the group but not of it, or a participant (*emic*) observer - part of the group under study. The focus is on observation of group processes:

Ethnography is appropriate ... to describe how a cultural group works and to explore the beliefs, language, behaviours and issues such as power, resistance and dominance (Creswell 2007:70).

Ethnography appears suitable for the study of stigma since culture and social forces contribute to the construction of stigma over time. The approach includes the researcher in the research endeavour and supports capture of a wide range of data from observation of group processes. However, this study did not intend to explore group processes, nor understand the cultural construction of stigma within a group, but to investigate individual's perceptions of their experiences of stigma. It is not *how* stigma arises that is the focus, but *what it means* to the person experiencing it. Ethnographers may spend months or years in their field of study, but although stigma may build in people over a long period of time, participating in the lives of people with IBD to witness stigma development first hand is impractical. For these reasons, ethnography is rejected.

5.1.6. Mixed methods research

Five studies described a mixed methods approach. Mixed methods research uses both qualitative and quantitative approaches, creating a fuller understanding of an issue than could be achieved using either approach in isolation (Creswell and Plano Clark 2007). Though not always clearly described, studies which mix methodologies should be underpinned by structures appropriate to either quantitative or qualitative inquiry. For example, a first quantitative phase might use a case-control design, whilst the second qualitative phase might be based on descriptive phenomenology. Qualitative aspects tend to be descriptive, rather than interpretive, and are frequently transformed into quantitative form during data processing (Brannen 2005:19). The decision to use mixed methodologies must be guided by the researcher's philosophical position and the pragmatic requirements of the study (Brannen 2005; Creswell and Plano Clark 2007).

As a research associate, I have a working knowledge of a range of approaches to research, and can employ these according to the requirements of any particular study. My absolute belief about the nature of knowledge and how we come to know what we know is, however, rooted in the interpretive tradition which holds that knowledge comes from interpretation of experience, and I bring this to my PhD study. A design utilising both quantitative and qualitative methodologies is unsuitable for the proposed stigma

study since quantitative approaches gather vast amounts of shallow data from large numbers of participants, and represent the findings statistically. Whilst the qualitative arm of a mixed methods study would facilitate interpretation of meaning, it is inappropriate to place a quantitative value of any sort on an individual's experiences and perceptions. For these reasons, a mixed methods approach is rejected.

5.1.7. Phenomenology

The remaining 19 papers all used a phenomenological approach. Of these, five papers which did not specify the phenomenological philosophy underpinning their studies, but used data collection and analysis techniques aligned with descriptive phenomenology, or combined with interpretive and located in the Dutch School (Dowling 2007), are not considered further here.

5.1.7.1. Interpretative phenomenological analysis (IPA)

Four papers used IPA (Smith 1996). The theoretical foundations lie in symbolic interactionism and phenomenology, although IPA resists alignment with either the descriptive or interpretive school by embracing aspects of each (Smith et al. 2009). The researcher creates a double hermeneutic as they try to make sense of the participant, who tries to make sense of the issue being researched (Smith et al. 2009). Data collection is via semi-structured interview following a schedule of open-ended questions delivered in a non-directive style (Brocki and Wearden 2006). The method increases depth and quality of captured data, whilst avoiding the risk in unstructured interviewing of gathering surplus data. Participants are often interviewed more than once to give an insight into the phenomenon over time, as in Clare's (2002; 2003) studies on new onset Alzheimer's disease. Data analysis involves organised coding and sub-coding of the textual data to develop common themes, as well as creation of an interpretive commentary (Reid et al. 2005).

IPA could have guided this study, but although it is underpinned by phenomenology and involves a hermeneutic / interpretive process, the phenomenological positioning is indistinct. The researcher's role in interviewing and interpretation can be seen as interpretative, but the use of a formal interview guide and highly structured analysis framework and method seem to bracket the researcher and obscure their influence on the analysis process (Brocki and Wearden 2006). The data analysis method and presentation of findings also appear to fragment participants' individual accounts (Collins and Nicolson 2002), challenging the demonstration of theoretical intersections between participants through development of within-transcript and across-transcript themes. IPA as a potential guiding framework is therefore rejected.

5.1.7.2. Descriptive phenomenology

Six papers used descriptive phenomenology. The relationship between methodology and method in these papers is often obscure. For example, Proudfoot et al. (2009) describe their study as descriptive yet use an analysis process which includes interpretation. Phenomenologies can be combined but appropriate methods should be employed (Van Manen 1990). A key aspect of descriptive phenomenology is that the researcher must *bracket out* their prior knowledge and understanding to avoid contaminating the analysis process. This *bracketing* of the researcher precludes the use of descriptive phenomenology for the current study.

5.1.7.3. Interpretive (hermeneutic) phenomenology

The final four papers report interpretive (hermeneutic) phenomenological studies. Apart from Raingruber et al. (2010), where design weaknesses are evident, the remaining authors demonstrate a rigorous fit between philosophy and methods, presenting designs which reflect essential requirements for the current study. Data collection via in-depth semi-structured interviews enables capture of a wide range of issues, explained by the experiencing person in their own words. Data analysis and interpretation is hermeneutic; the researcher moves back and forth between transcripts and consulting with other

experts to establish rigour in interpretation, and findings are developed inductively from the text. The researcher is embedded in the research process as their *pre-understanding* (experience of the world) assists data collection, co-constitution (generating new understanding together with the interviewee) and interpretation. Researcher position is managed through journaling, field notes, supervision and reflexivity.

Interpretive (hermeneutic) phenomenology appears to meet the philosophical requirements for this qualitative exploration of stigma in IBD where the discrediting attribute is uncertain, an accepting openness towards the experiencing person's perceptions is required, the researcher's role in the study is embraced and there is capacity to provide an interpretation (rather than description) of experiences.

5.1.8. Methodologies not represented in stigma research

The majority of familiar methodologies are represented across these 48 reviewed papers. Critical social theory and feminist methodology are absent, but are considered here to avoid an error of omission. In a specific search of the literature, few critical social theory papers, and only two feminist methodology papers reporting health-focussed research projects were located (Craig and Scambler 2006; Nosek et al. 2008).

5.1.8.1. Critical Social Theory

Critical social theory (CST) addresses power relationships which affect the oppressed, marginalised and under-served in society (Manias and Street 2000). Familiar in sociological research, Browne (2000) argues for the potential for critical social theory to drive exploration of the sociology of health and illness. Since CST aims to illuminate inequalities, research focuses on minority groups and issues, and the way members of such groups are treated by the majority. As discussed earlier [Chapter 2: Stigma, p. 7] minority status and stigma often co-exist, since the majority group creates the social rules and has the larger share of any power. Superficially, CST would seem suited to the

current study. However, CST assumes that social reality is shared, is the same for everyone, and that individual experiences and perceptions can be unified into a single collective purpose (Browne 2000). This undermines the intention in health-care to provide individualised care responses tailored to each person's unique needs rather than adopt a 'one size fits all' approach, which perhaps explains why CST has only rarely been used for any health-related stigma research (Bevin et al. 2012; Warin and Gunson 2013, for example). The focus on minority groups and on producing a universal answer makes CST unsuitable for the current study. Individual nuances of experience, the influence of personal background and history, and issues which promote or damage resilience to stigma would be lost, though these are the edges which illustrate the range and variation of human experience. These aspects are sufficient to reject CST as a philosophical foundation for this study.

5.1.8.2. Feminist methodology

Feminist theory is rooted in the feminist movement which traditionally and currently works to represent and promote the rights of women in society (Traulsen et al. 2003), emphasising 'emancipatory action to promote social justice in the context of women's issues' (Kushner and Morrow 2003). Further consideration of the appropriateness of feminist theory for the current stigma study is unnecessary. This primary requirement, to address women's issues and advance women's political and justice-based rights, rules it out. If the current study was focused on the socio-political aspects of stigma in women, perhaps exploring whether being female and stigmatised creates a unique disadvantage, this approach might be suitable. The aim, however, is for a non-political broad understanding of the experience of stigma in IBD for both women and men.

5.1.9. Outcome of critique

This critique has considered a range of research methodologies and compared them with the aims of the current study. Due to inconsistencies between philosophical stance and associated methods which would support the research aims, all except phenomenology

are rejected. A detailed exploration of phenomenology theory would now confirm the relationship between the philosophy, my epistemological position and the study aims.

5.2. Critical review of phenomenology

Phenomenology was developed as a philosophy in the 1800s, originally by Brentano but later through the work of Husserl (descriptive phenomenology) and Heidegger (interpretive phenomenology). Deciphering the philosophical underpinnings of phenomenology is challenging: Knafl (1994:134) comments that ‘this is tough stuff, very abstract, very conceptual.’ The abundance of information available to the budding phenomenologist is immense (Caelli 2001), disparate and frequently confusing, and finding one’s way through the maze of information is a considerable challenge. Moran (2000:65) identifies that Husserl was chaotic in his writing and thinking, often failing to date his work. Consequently, there is no simple story of progress but frequent examples of Husserl using words in ways alien to our current usage, making the reading of his work even more difficult. For example, Husserl uses *presentations*, which modern biographers now take to represent ideas ... ‘there can be no mental act without a presentation’ ... meaning that one cannot think, without an idea coming to you to be thought about. Currently, *presentation* means an offering of some sort made to others. Additionally, these original German writings may have lost some of their primary intended meaning in translation (Corben 1999). Paley (1997: 188) explains that:

Husserl’s terminology, as translated into English, makes considerable use of ordinary words that have had unusual meanings conferred upon them, for example ‘object’, ‘intuition’, ‘real’ and ‘act’, none of which mean what a casual reader would expect them to mean.

Brentano and Husserl use the word *objects* to describe the focus of a person’s experience. We now interpret *object* to mean a solid, tangible item, but these early phenomenologists used the term to describe any intangible thought or idea that consciousness could be directed towards.

The very nature of phenomenology means that it has no absolute theory to give it a finite structure. Heidegger declared that ‘there is no such thing as **one** [sic] phenomenology’ (Heidegger 1927, transl. Hofstadter 1982: 328), which is problematic when explanation of the philosophy is required, yet there are many varied interpretations of it. This fluidity reflects not only the point of phenomenology, but also human experience - that experience is different to each person who experiences it because they themselves are different through their own unique interaction with their world.

Phenomenology is used widely in health research as it promises a philosophical framework for researching the *lived experience*, particularly subjective and immeasurable issues, such as pain, experiencing a miscarriage, or living with chronic illness. Norlyk and Harder (2010) claim that phenomenology is poorly understood and inconsistently described, and Paley (1997; 1998) argues that nurses misunderstand and misuse Husserl, and that investigating *lived experience* is alien to Heideggerian theory. Paley defends this first claim well but the second with less conviction (Paley 1998) as he dwells on the more abstract aspects of Heidegger’s work. He appears scornful of nurse academics’ and health researchers’ efforts to translate Heidegger’s main concepts into an approachable research philosophy even though these concepts are recognised as complex, abstract and challenging. Koch (1995), Gearing (2004) and de Witt and Ploeg (2006) demonstrate that health and social science researchers frequently claim to be using a phenomenological approach but equally as often fail to make the philosophical underpinnings of their research explicit, challenging the reader’s ability to assess the trustworthiness of the work if they cannot trace the relationship between philosophy and methods.

Although phenomenology is not a rigid philosophy, researchers should not hide behind the structural freedom this suggests but make explicit the branch of phenomenology and the key related principles that inform study design. This requires an appreciation of the historical development of phenomenology as a philosophy, beginning with Brentano. Throughout the following section, original terms attributed to the major phenomenology theorists are italicised.

5.2.1. Franz Brentano

Phenomenology originates in the European Psychology of the 1800s. Edmund Husserl (1859 -1938) is considered the founding father of phenomenology, but his ideas built on the work of his mentor, Franz Brentano (1838-1917), who had been attempting to rethink psychology as a science. Brentano wanted to make psychology a rigorous science, enhanced by *exactitude* and developing what he called *descriptive psychology* (Moran 2000). To make the truth of psychology unquestionable, Brentano led its development from the theoretical knowledge of previous generations, towards becoming a science whose knowledge-base was built on understanding things as they are for those who experience them. The aim was to recognise that peoples' experiences of the world are guided by the way they *bring the world to consciousness* – how they perceive their world and how they come to know what they know. This difference between perceiving (an awareness of an event) and noticing (bringing to consciousness, thinking about and therefore knowing) was later developed further by Husserl.

Brentano's ideas centred around three main tenets – that description held primacy over explanation, that we can never truly 'know' something ...only our present understanding of it, and that the aim was to describe the *life-world* (the lived experience) of others. For Brentano, empirical knowledge depended on accepting another's description of a given experience. The aim was not to make any interpretation of such descriptions, since this would place an alternative understanding on the event. Brentano originally proposed that every experience happened in isolation to time and context: that it was the ability to draw on memory which added meaning to a person's experience. He later amended this position, accepting that inner perception had to be extensively present in time, since otherwise, descriptive psychology would become restricted to the moment in which the experience occurred. Husserl disagreed with Brentano over the temporal nature of experiences, insisting that time was irrelevant in our ability to understand experience.

Brentano was adamant that we cannot truly 'know' something, we can only know our own attempt to understand something – what it truly 'is' remains unreachable:

We have no experience of what truly exists, in and of itself, and that which we do experience is not true - the truth of a physical phenomenon is only relative truth.
(cited in Moran 2000:42)

Brentano also believed that psychology should be underpinned by empirical knowledge, drawn from actual experience - from the *life-world* of others - what is now referred to as the *lived experience*. To understand what a lived experience is like, one must listen to the descriptions given by people who have had that experience.

5.2.2. Edmund Husserl

Husserl (1859-1938) was Brentano's student. In 1900-1901 he presented *descriptive phenomenology*, developed from his mentor's *descriptive psychology*, as a new way of understanding psychology. Husserl agreed with Brentano on two points – that psychology should be founded on empirical evidence drawn from descriptions of peoples' experiences of their life-world (the lived experience) and that one cannot 'know' the true nature of anything – only one's own perception or understanding of it. But Husserl also disagreed on two points. Firstly, Brentano proposed that in attempting to reach another's understanding of an object the investigator should influence the description of the event, while Husserl countered that any description should not be influenced by the investigator. Secondly, where Brentano proposed time (temporality) as being an important component of experience, Husserl argued the opposite.

Husserl's descriptive phenomenology focused on three themes: that the phenomenon under review cannot be understood if clouded by one's own knowledge, that the difference between *perceiving* and *noticing* enables humans to bring things to consciousness, and that description demands a return to the *essential essence* of how we understand.

5.2.2.1. Phenomenological epoché, reduction, or bracketing

Husserl introduced the notion of the *phenomenological epoché*, or *suspension of the natural attitude*. The aim is to suspend preformed notions, beliefs or ideas so that one's own thinking does not contaminate understanding of another person's experience as they describe it, and to remain objective by controlling one's own influence. Since knowledge cannot be un-known, Husserl proposed *bracketing* – consciously separating off or suspending conscious knowing to allow the investigator to get *back to the things themselves*. They can then describe for others what the object was, and how it was experienced, as faithfully as possible (Paley 1997; Wojnar and Swanson 2007). Husserl's quest led him to pursue *transcendental phenomenology* in which everything – presuppositions, knowledge, and own perceptions - are stripped away or reduced (*bracketed*) to arrive at the purest essence of how something is experienced. Knowing is thus transcended to reach a higher place of understanding. Husserl eventually conceded that this level of complete reduction was, in fact, unobtainable (Moran 2000).

5.2.2.2. Bringing to consciousness

Brentano had laboured inconclusively over the point of how we bring things to consciousness. He posited the notion that we see with our eyes, but do not necessarily see with our minds, and tried to determine what makes the difference between these two states that he described as *perceiving* and *noticing*. Husserl thought of *perceiving* and *noticing* as being separate elements within a greater whole, thus reflecting Cartesian dualism: reality consists of two basic and separate parts, usually taken to be mind (mental) and body (physical), and these are causally related (one happens because the other exists) (Withers 2008).

Husserl claimed that the difference between perceiving (seeing with the eyes) and noticing (seeing with the mind) is that perceiving refers to the whole, the general of something, whilst noticing refers to the specific, and that this latter *seeing* brings things to consciousness. Moran (2000) gives examples of a flock of sheep and a music chord as being perceived, but it is only when we notice the individual sheep, or the separate

notes that make up the chord, that we become conscious of (we really start thinking about) what we are *seeing* (experiencing). This *bringing to consciousness* is, according to Husserl, able to occur because of *intentionality* – the mind’s ability to direct itself towards objects (ideas), to think.

5.2.2.3. The essence of conscious thought

Husserl intended that through the *phenomenological epoché* it would be possible to reach the *essences* (the fundamental ways) in which we understand (Dowling 2004). This makes Husserlian phenomenology objective – the desire to reach the absolute structures of conscious thought and understanding, free of any external influence, and the belief that these structures (*essences*) can be isolated and studied. Koch (1995) confirms that the three governing concepts in Husserlian phenomenology are *phenomenological reduction* (bracketing), *essences*, and *intentionality*. The aim of the Husserlian researcher is to explore the meaning of experience for a mind-body person who lives in a world of objects, and to describe (not interpret) this experience for others.

5.2.2.4. Temporality

Husserl also disagreed with Brentano over the influence of time in humans’ perception and understanding of the world. Husserl was certain that events had to be understood in isolation, and that context, specifically time, was unimportant to our understanding. It is difficult to accept this view. Using the example of an unmarried pregnant woman, for Husserl the issue is purely the physical experience of being pregnant. Yet the experience of being pregnant is physical, social and temporal - an unmarried pregnant woman in 1950s England would have had a very different experience than a similar woman in the 2000s, precisely *because* of changes in social attitudes over time (Kiernan et al. 1998; Thane 2008). The physical nature of pregnancy remains unchanged, but that is only part of the experience. By insisting that time is unimportant in our understanding of events, Husserlian phenomenologists may capture just part of the experience, which is then only relevant in the moment in which it occurred.

5.2.3. Martin Heidegger

Heidegger (1889-1976), a pupil of Husserl, challenged the descriptive phenomenology favoured by his teacher, eventually developing interpretive (hermeneutic) phenomenology. Hermeneutic phenomenology is ontological – it focuses on understanding what it is to be human, and gets this understanding from exploring humans' *lived experiences*. Heidegger agreed with Husserl on the importance of understanding being human, but disagreed with him on how this should be achieved. Heidegger argued that all understanding precedes knowledge – understanding the world is what makes knowledge possible. Our understandings and interpretations reveal the world we live in and are the fundamental features of what Heidegger terms as *Dasein*, our *being in the world* - so our experiences must be addressed through interpretation (hermeneutics) (Mackey 2005). Stewart and Mickanus (1990:69) explain that:

[Dasein] emphasises the situatedness of human reality in the world; being there (the literal meaning of the term) stresses the fact that human existence is always existence in the world.

Dasein means that as humans, we are *always-already* 'in the midst of what is, always listening and [already] responding' (Smythe et al. 2008). Heidegger therefore rejected the Cartesian view that reality (truth) existed in two separate parts, arguing that not only are mental and physical understandings of the world mutually dependent, but that they are also conjoined. Humans are not objects isolated from the world around them - their understanding of events develops from complex interactions with their existing world (*background*). Contextual structures such as culture, language and time exist in the individual's world before they come to understand these in relation to new experiences (*pre-understanding*). Interaction with the world and others leads to co-creation of new interpretations or understanding (*co-constitution*) (Koch 1999; Dowling 2004). These three principles inform Heidegger's hermeneutic circle which guides the interpretation that demonstrates what it is *to be* - in the case of this study - stigmatised. Heideggerian researchers aim to interpret understanding of lived experience in the context in which that experience takes place (Dowling 2004).

5.2.3.1. Background

Background refers to the world into which a person is born, a world which shapes and is shaped by their *being*. Heidegger argues that through *being in the world*, humans gather new understandings and interpretations of what already exists. They do this repeatedly through their lives, using their *background* knowledge to constantly modify, update and amend their understanding. The *background* (the world in which they live) already exists before they come to understand it, and understandings develop through interpretation of their world (Stewart and Mickanus 1990), not as an intentional act but as a natural consequence of *being in the world*.

5.2.3.2. Pre-understanding (fore-structure of understanding)

Pre-understanding does not mean ‘before there is any understanding’ but refers to ‘previous understanding’ – what humans already know about their world and how this shapes their interpretation of new events and experiences. *Pre-understanding* is informed by *background* and consists of three sub-sections: *fore-having* - pre-existing knowledge, skills or practices which make interpretation possible; *fore-sight* - an existing point of view, based on background, which informs interpretation; and *fore-conception* - an idea already formed, based on background, enabling anticipation of new situations or experiences (Benner 1994; Wojnar and Swanson 2007). The interaction of these three components was fundamental to Heidegger’s development of interpretive (hermeneutic) phenomenology, informing his claim that our past is always in our future - meaning that past experiences inform and guide our interpretation of future ones, and in this way we are *thrown* into our future because of our past. Heidegger disagreed with Husserl over the influence of time (temporality, historicity) on experience. His major work *Being and Time* (Heidegger 1962) addresses in typically complex, obscure and dense language, the nature of human *Being* and the influence of *Time* on experience. Heidegger argued that human experiences of phenomena do not exist in isolation, but become what they are through relationships with the social, cultural and historical (time) context in which they occur. For Heidegger, the experience of the unmarried pregnant woman will be as it is *because* of the time in which the experience occurred,

not despite it. These experiences result in *thrownness* – being propelled, without one's choosing or control (since we cannot know which experiences we are yet to have) into a future with new experiences which we then interpret on the basis of our past.

5.2.3.4. Co-constitution

Co-constitution has two meanings in Heideggerian phenomenology. It refers to an inseparable bond between the person and their world with each being constructed by and constructing the other - they are what they are because of the world they live in, and their world is what it is because of the way it is interpreted and understood (Koch 1995). *Co-constitution* also refers to an inseparable bond of interpretation between people: humans understand an experience due to an unavoidable combination of the *background* and *pre-understanding* of each person with the other in the same event. This stance led Heidegger to reject Husserl's notion of the *phenomenological epoché* (bracketing), arguing that background and pre-understanding are essential parts of how humans interpret and make sense of their experiences in the world, so everyone – including the researcher - must participate in the interpretation of the event:

... an interpretation of human existence cannot be neutral, dispassionate, theoretical contemplation, but must take into account the involvement of the enquirer him- or herself in the undertaking. Human beings are involved with their existence in such a way that hermeneutics must be able to accomplish this movement backwards and forwards between the existence to be examined and the nature of the examining enquirer (Moran 2000:197).

For the Heideggerian researcher, how a participant understands an experience and the context in which it is understood, helps create their interpretation of what the experience is. What is shown to the researcher at interview is taken as the participant's reality. The researcher blends their own background and pre-understandings with those of the participant so that the eventual representation of the experience is a *co-constitution* of the understandings and experiences of both parties. The Heideggerian researcher presents this interpretation to a critical audience not as a 'truthful' explanation of what

the phenomenon is universally understood to be, but as a representation, a *showing / revealing* (Ironsides 2014, pers. comm., 9th July) of what the phenomenon means to those experiencing it. Hermeneutic phenomenologists:

‘put aside any claim that our research will produce objective, simplified, scientific concepts of truth our quest is not to prove or disprove, not to provide irrefutable evidence but rather to provoke thinking towards the mystery of what [a phenomenon] ‘is’ (Smythe et al. 2008:1391).

The preconceptions that the researcher brings to interview and analysis are essential to the interpretive / hermeneutic process, and any attempts to stand outside of one’s own pre-understanding is considered ‘absurd’ (Lavery 2003). Smythe et al. (2008) confirm that ‘who one is as-researcher is fundamental to the thinking of research, for thinking does not happen as a mechanistic process divorced from being in the world.’

Paley (1988) criticises Heideggerian researchers who amalgamate several individual stories of experience into core themes, so risking separation of experience from context, but there are pragmatic issues to consider; qualitative health and social science research is often criticised for the very uniqueness it celebrates, and researchers have to prove value for money by demonstrating that findings are transferable to other populations. This tension may create phenomenological research which, by combining experiences, separates the uniqueness of each original experience from its contextual world and risks introducing the Cartesian dualism which Heidegger stringently rejected. The criticism can be overcome by presenting findings which display the range of an experience occurring within a phenomenon, and by presenting findings as common, shared experiences rather than descriptions of the totality or essence of the phenomenon.

5.3. The methodological decision

Husserl’s phenomenology does not fit with my epistemological position. I disagree with his central principles - I cannot separate myself from my background, experiences, or

pre-understanding (prejudice). I believe that knowledge and experience enable us to make sense of new experiences and lead to new knowledge. I cannot suspend my pre-existing awareness and do not believe these 'prejudices' to be a negative influence, and so Husserl's descriptive phenomenology is rejected as an underpinning philosophy for this research. Conversely, Heidegger's interpretive phenomenology offers a philosophy aligned with my own perspective on the role of human interaction in developing knowledge. Interpretive phenomenology views human interaction as necessary in understanding and interpreting experiences, and accepts that my connectedness as a person who understands what it feels like to have an invisible but discreditable identity is a positive prejudice which facilitates interpretation of others' experiences.

Heideggerian interpretive phenomenology offers a means of understanding the lived experience of IBD-related stigma as expressed by those who have had the experience. Since it provides the best fit with the aims of the study and has robust philosophical foundations, it is adopted as the guiding theoretical framework.

5.4. Summary

This chapter has offered a critique of the methodological / philosophical approaches that can guide qualitative health research. Comparison of each with the aims of the proposed study has informed the rationale for rejecting all but interpretive phenomenology. The decision to adopt Heideggerian interpretive phenomenology has been made after detailed consideration of its philosophical provenance, revealing its alignment with the aims of the study and with my position in it. The terms *hermeneutic* and *interpretive* will now be used interchangeably in this thesis when referring to Heidegger's phenomenology.

Chapter 6 presents the research design detailing the methods used to conduct the study, which also align with the same philosophical principles. The data analysis method is explored in detail in Chapter 7.

6. Research Methods

Research methods are the practical tools selected from all those available which, when combined, provide the blueprint for conducting the study. Guided by the philosophy and aims of the research, methods ensure the researcher uses strategies most likely to capture data that will answer the research questions (Cormack 2000) whilst acknowledging time and resource constraints (Cormack 2000; Lewis 2003).

Interpretive phenomenology aims to understanding people's lived experiences as they themselves interpret, understand and express those experiences (Flood 2010). Phenomenological research uses data collection methods which capture the richness of experience in the person's own words, and analysis strategies which retain their voice. The aim is to avoid breaking data down into unrelated chunks, retain the context of the story, and show the relationship between individual participants' experiences. The researcher and the reader both make their own interpretation of findings. Typically, sampling is purposive, with smaller sample sizes than in some other forms of qualitative research (Higginbottom 2004) such as ethnography, which often samples large cultural groups. Data is often collected by semi-structured or unstructured interview, and analysed using strategies which encompass the whole data (Creswell 2007).

The challenges of researching stigma in IBD have previously been identified: there is a need to take a broad approach with no pre-suppositions of what the experience of stigma might be, and to include the researcher in the endeavour. The methods chosen must address these challenges whilst staying true to Heideggerian hermeneutic principles. Reviewing the methods selected by other researchers using the same philosophical approach can guide design. This chapter details the design decisions for the study by:

- critiquing and rationalising the selection of methods, with reference to design decisions in Search 2 papers
- explaining co-constitution and introducing the data analysis method
- presenting ethical considerations and issues of rigour

6.1. The population and the sampling frame

In research, *population* refers to all those who have or are likely to have the feature of interest from whom the sample can be drawn. For focussed exploration of experiences, *purposive sampling* is recommended (Creswell 2007) as it ensures participants will have experienced the issue being researched. Of the 48 qualitative methodology papers reviewed above [Chapter 5], 44 used purposive sampling; the remaining 4 used either snowball (chain-referral) and / or convenience sampling. One paper did not specify sampling technique. Snowball sampling is commonly used when the target population is difficult to locate. Since it requires onwards referral from those meeting the study criteria, it is a form of purposive sampling (Holloway and Wheeler 2010). Convenience sampling is also purposive as participants are drawn from a readily available population which suits the study's purpose. All 19 phenomenological papers in the Chapter 5 review used purposive sampling, suitable for exploring lived experience, making it the sampling method of choice for this study.

6.1.1. Sampling, inclusion and exclusion criteria

6.1.1.1. Sampling

Denscombe (2003) explains that the sampling frame is a complete list of members of a researchable population from whom the researcher can select the sample. The sampling frame for this study drew on the population of respondents to an earlier Continence in IBD Study (Dibley and Norton 2013; Norton et al. 2013), which recruited from the membership database of the IBD charity Crohn's and Colitis UK (C&CUK). 10,000 members were randomly selected for the Continence Study by the charity's database manager, enabling the recruitment of those with and without incontinence. Study invitations and documents were addressed and mailed out on behalf of the study team by the charity's usual distributors, to ensure anonymity. 230 of the C&CUK members who participated in the Continence Study gave permission for their contact details to be kept, and for us to approach them if we needed participants for any future studies.

These 230 original respondents were approached for this study because they were a community-based population with IBD, some of whom reported incontinence and some of whom did not. They were all invited by letter or email to visit an online recruitment page where we were attempting to identify participants for three different projects, including this stigma study. A short description of the study, and a definition of stigma was provided. Respondents registered their interest in participating and indicated which of the following four categories they felt they belonged to:

1. Experience faecal incontinence and DO feel stigmatised
2. Experience faecal incontinence and DO NOT feel stigmatised
3. DO NOT experience faecal incontinence and DO feel stigmatised
4. DO NOT experience faecal incontinence and DO NOT feel stigmatised

These four categories would later enable respondents' stories to be compared, highlighting a range of experiences and revealing whether stigma is related only to having FI or if IBD itself is stigmatising. Those who registered interest subsequently received, according to their preference, a hard copy by post or electronic version by email, of the study information leaflet, enabling them to make a fully informed decision regarding participation, or not.

6.1.1.2. Inclusion criteria

Inclusion criteria are guided by the aims of the research and ensure that the people most likely to provide data which answers the research question(s) are selected (Ritchie et al. 2003). Having registered, eligible participants were required to:

- be aged over 18 years (no upper age limit)
- have a confirmed (self-reported) diagnosis of inflammatory bowel disease (Crohn's Disease, Ulcerative Colitis, Crohn's Colitis or Indeterminate Colitis, or Proctitis)
- live anywhere within the United Kingdom or any of its outlying islands
- experience or not experience faecal incontinence

- feel or not feel stigmatised by their incontinence or bowel disease
- have or not have a current stoma
- be able to read, write and express themselves in basic English

Participants had to be able to read and understand the study information leaflet, sign the consent form, and explain their experiences. Despite having no capacity for translation, recruitment was not discriminatory. IBD is a predominantly Caucasian disease affecting Americans, Europeans and Scandinavians (Rampton and Shanahan 2006). It is largely unknown in Arabic and Eastern peoples, although incidence has been recently been increasing in Asia (Goh and Xiao 2009). Interestingly, IBD has been seen to develop in non-Caucasians following migration to America, Europe or Scandinavia. Since many second and third generation immigrants speak good English, non-Caucasian populations could still be represented in this research. Recruitment was, however, selective – potential participants had to be able to respond to a question about feeling stigmatised and assign themselves to one of the previously mentioned groups. To reduce as far as possible the effect of self-selection on bias, no assumption was made that respondents would understand or identify with the term *stigma*. The recruitment information [Appendix 5: p. 353] also included an explanation of stigma as:

being, or feeling that you are being treated differently, feeling ashamed or guilty, worrying that others will find out about your illness, worrying that others will think badly of you because of your illness.

This increased the likelihood of people who had not linked their feelings to the label of *stigma* being able to contribute to the study.

6.1.1.3. Exclusion criteria

Exclusion criteria help to reduce the likelihood of selecting those less able to answer the research question, and limit confounding influences. One example is to exclude anyone who has significant co-morbidities so that the key issue of interest can be isolated. This particular excluder was inappropriate for this study because stigma, if it exists, does not

exist without the context of a person's life. Heideggerian phenomenology holds that all aspects have influence on the way humans understand their world, so the experience of stigma must be explored in full context. No exclusion criteria were applied.

No sampling frame is perfect. It is accepted that some who might have been eligible did not have the opportunity to participate. Since this sampling frame was drawn from a database of previous responders, any member of C&CUK who did not, or was not invited to respond to the original Continence Study, had no opportunity to participate in the current study. There are pragmatic, and ethical, reasons for not addressing this. With over 160 people in the sampling frame who represented the C&CUK demographics, there were sufficient numbers to draw the sample from, and it is ethically unsound to recruit people to a study who are not needed. Extending recruitment would have been appropriate had it been impossible to create a sampling frame from existing contacts.

6.1.2. Sample size

In quantitative research, large sample sizes are needed to evidence that the conclusion reached is accurate, significant and beyond reasonable doubt. Data is described as being thin or shallow, but plentiful. In contrast, qualitative enquiry generates thick, deep, rich data (Geertz 1973) which reveals meaning. There is no formula for calculation of an appropriate qualitative sample size, the general principle being that smaller numbers are needed than for quantitative methods. Sample size depends on what the research(er) is trying to achieve (Baker and Edwards 2012). Whilst some qualitative researchers aim for a sufficient sample size to achieve data saturation (the point where nothing new is collected), the principle is anathema to interpretive (hermeneutic) phenomenologists who assert that data saturation is impossible because there is always unheard, unknown experience that exists beyond the reach of the study: 'new possibilities for understanding are limitless' (Ironsides 2006: 480). Typically, small samples reflect the underpinning philosophies of qualitative research: it is about discovery and interpretation rather than proof. In grounded theory studies, however, further members of the sample are identified as the study progresses, continuing until data saturation is achieved (Creswell 2007; Tuckett 2004).

From the sampling frame, participants were purposively selected to create a homogenous sample (all have a diagnosis of IBD) with equal numbers of men and women, and diagnoses broadly reflecting the demographics of Crohn's and Colitis UK (49% Crohn's Disease, 45.5% Ulcerative Colitis, 4.5% Crohn's Colitis, 1% Proctitis) across the four categories of 1) FI, stigma; 2) FI, no stigma; 3) No FI, stigma; 4) No FI, no stigma. The aim was to capture 10 interviews in each category, but as the numbers eligible for categories 3 and 4 were low, the final numbers were 1) FI, stigma, n=12; 2) FI, no stigma, n=16; 3) No FI, stigma, n=4, and 4) No FI, no stigma, n= 8. These figures meant that 70% of the sample had FI. An attempt to redress the balance was not made as the figure for FI was similar to the prevalence rate identified in our earlier study, demonstrating that 74% of people with IBD have some experience of FI (Norton et al. 2013). It is acknowledged that the previous study may have had a sample bias towards people with IBD-related FI.

6.1.3. Data Collection

Seventeen of the 19 phenomenology papers reviewed above collected data via in-depth (semi- or unstructured) interviews. One study used email dialogue (Proudfoot et al. 2009), and the remaining paper failed to describe the data collection method (Grofik 2008). Interviews are common in qualitative research, enabling people to use language to express their understanding of experience. This study did not focus on the structural elements of language, as in conversation or discourse analysis, nor on the chronological process of narrative inquiry, but hermeneutic phenomenology emphasises the use of language as the means by which people learn, make sense of, and share understanding (Gadamer 2004). Holroyd (2007:5) explains:

... language [is] integral to hermeneutic understanding. It is in language that our world is disclosed to us. The world that is spoken of here is not the environmental scientific world, but the lifeworld.

Whilst methodologically appropriate to capture participants' contextual stories with interviews, the risk of an unstructured approach is that dialogue can go wherever

participants' choose, capturing an excess of unrelated data (Holloway and Wheeler 2010). The benefit is that unexpected issues, which may seem irrelevant yet become apparent during analysis, can be revealed. Ideally, the respondent is encouraged to focus on the phenomenon of interest, expressing their experiences in their own words (Legard et al. 2003). The researcher then probes further to get to the heart of an issue. Legard et al. 2003:141) explain that *unstructured* does not mean *without purpose*: 'the first key purpose of the in-depth interview is that it is intended to combine structure with flexibility.' In this context, *structure* means an open framework of topics to be addressed, whilst *flexibility* permits the researcher to probe, prompt and encourage the respondent to explore issues in greater depth. Reflexivity is also needed – the researcher can introduce both positive (helpful) and negative (unhelpful) bias as their own pre-understanding of the phenomenon influences the interview process. To enable capture of a broad range of experience whilst retaining focus, semi-structured interviews with a schedule were selected as the data collection method.

6.1.3.1. Developing the interview schedule

To minimise bias, interview schedules should be based on available evidence and expert opinion, rather than researcher preference. The evidence for this interview schedule came from the Contingence in IBD Study, where stigma emerged as one of seven themes contributing to the experience of living with IBD-related FI (Dibley and Norton 2013). Respondents made direct or subtle reference to their experiences of stigma, either using the word '*stigma*' or referring more indirectly to concerns that '*others will know what I've done,*' or '*what will people think of me?*' An interview schedule with a focussed opening prompt and a question linked to each of the study subgroups was developed. The Six Dimensions of Stigma (Jones et al. 1984) were included as an aide- memoire. This focus on stigma would enable respondents to express their experiences in their own words, and retain flexibility to follow-up issues of interest with probes and scoping questions (Legard et al. 2003). Each interview was terminated after recapping and closing prompts, and after ensuring the interviewee's emotional safety [Table 6-1].

<p>Opening prompt <i>Safe opener to enable the person to feel comfortable talking with me. They may mention something that I can pick up on to pursue the stigma angle</i></p>	<p>Thinking about social and psychological or emotional aspects, rather than medical aspects, can you tell me the story of what life is like for you with IBD? How does it affect you?</p>
<p>No FI, no stigma <i>Questions enabling me to check where the person places themselves, and how it relates to what they say about stigma</i></p>	<p>You have told me that you <i>do not</i> experience incontinence and <i>do not</i> feel stigmatised. Can you tell me a little more about that?</p>
<p>No FI, stigma</p>	<p>You have told me that you <i>do not</i> experience incontinence and <i>do</i> feel stigmatised. Can you tell me a little more about that?</p>
<p>FI, no stigma</p>	<p>You have told me that you <i>do</i> experience incontinence and <i>do not</i> feel stigmatised. Can you tell me a little more about that?</p>
<p>FI, stigma</p>	<p>You have told me that you <i>do</i> experience incontinence and <i>do</i> feel stigmatised. Can you tell me a little more about that?</p>
<p>Consider issues of:</p>	
<p>Concealability</p>	<p>Is the condition hidden or obvious? To what extent is its visibility controllable?</p>
<p>Course</p>	<p>What pattern of change is shown over time by the condition? What is the ultimate outcome?</p>
<p>Disruptiveness</p>	<p>Does it block or hamper interaction and communication?</p>
<p>Aesthetic qualities</p>	<p>To what extent does the mark make the possessor repellent, ugly or upsetting?</p>
<p>Origin</p>	<p>Under what circumstances did the condition originate? Was anyone responsible for it?</p>
<p>Peril</p>	<p>What kind of danger is posed by the mark and how imminent or serious is it?</p>
<p>Prompts <i>Use whichever is appropriate to confirm or probe themes arising in interview</i></p>	<p>How does that make you feel? How do you feel about asking for help for your IBD / incontinence? Is it easy or difficult for you to ask for help for IBD / incontinence? What makes it easy / difficult? Some people avoid asking for help for incontinence due to feeling stigmatised. What are your thoughts about this?</p>
<p>Drawing to close</p>	<p>Recap on story, check / create new understanding together (co-constitution). Offer chance to share / tell/ explain anything else. Inform them of next stages (analysis, writing up, submission, sharing findings). Advise re time scale.</p>
<p>Before leaving</p>	<p>Ensure participant feels emotionally safe. Provide any necessary support.</p>
<p>Table 6-1. Original interview schedule, with opening and closing prompts, and probes regarding potential issues of interest FI = faecal incontinence; blue shading indicates the aspects utilised following amendment of the interview schedule (see page 90)</p>	

Careful management of researcher influence on interview schedule development reaps rewards during data analysis. If negative bias arising from schedule development and implementation is minimised, later analysis is more likely to show / reveal the participants' meaning, thereby increasing confidence in findings. Had the interview guide been based on my own knowledge, understanding and presuppositions it would be likely, at analysis, that I would find what *I* expected, rather than being fully open to what was actually there. An interview schedule is also required for ethical approval, to demonstrate that (as far as can be predicted), it will give the best chance of capturing the intended data and that the participants are not being misled, or exposed to unnecessary emotional distress.

However, although semi-structured, the guide proved too limiting and narrow. Despite assigning themselves to one of the four subgroups, participants' experience of stigma fluctuated so that they were rarely either never or always stigmatised. By adhering to the interview guide and assuming that respondents belonged unquestionably to their chosen category, I did not have the sense of reaching the heart of the phenomenon, particularly with the non-stigmatised participants. Rubin and Rubin (2012:73) advise:

If you find that what you are doing isn't working, change a little ... if you are getting too many superficial answers, force yourself to ask more follow-up questions ... if you find yourself asking only the questions you wrote in advance, limit yourself to writing out only a few questions, so you force yourself to listen more intently and work out additional questions on the spot.

I realised the problem within the first few interviews [see Appendix 6: Field notes]: *it is much, much harder to interview for non-stigma without introducing the perception that people OUGHT to feel stigmatised by IBD* [Interview 8, Vivienne, 52, UC, NO FI, no stigma], so I partially revised the approach, retaining the blue highlighted sections in Table 6-1. Still dissatisfied with the results, and following further reflexive thinking, I made further amendments. Following introductions, re-iteration of study information and securing consent [Appendix 6: p. 363], I opened each interview with the trigger prompt: *Tell me how your IBD makes you feel* and followed up with spontaneous probes according to participants' responses, enabling more information-gathering or reflections

to confirm issues or reach joint understanding. By taking this more indirect approach, yet with participants knowing the study was about stigma, the phenomenon emerged much more naturally and subtle yet rich representations of stigma were revealed.

The researcher can also enhance qualitative inquiry by exerting positive bias during this type of interview. In this study, my prior knowledge and understanding assisted interpretation of meaning during the interview, enhanced further probing and exploration of issues that arose, and facilitated co-constitution which was woven into the interview process. To recognise and manage bias appropriately, a reflexive stance [Chapter 6: p. 103] was taken through the use of field notes / journaling [Appendix 6] and supervision, ensuring I addressed my own pre-suppositions, perceptions and beliefs, and the influence of these factors on the research.

6.1.3.2. The interview in sensitive research

Sensitive research includes that in which the subject is personal, private or taboo (Lee and Renzetti 1990). It often involves hidden or hard to find groups; the nature of the subject means that potential participants are unlikely to advertise their eligibility, or the issue of interest may be rare. The sensitive topic in this research was one reason for selecting in-depth, one to one interviews for data collection, conducted in participant's own homes. People are more likely to participate in an interview about a potentially or actually stigmatising experience if they feel safe, emotionally and physically (McCosker et al. 2001), although faceless strategies such as email, telephone or social networking forums may provide a welcome anonymity (Elmir et al. 2011). The advantage of face to face interviewing is that both parties are able to read body language and tonal cues which contribute to participation in, and conduct of, the interview:

Qualitative interviews are almost always conducted face-to-face. It would be extremely difficult to conduct really detailed in-depth interviewing over the telephone. The interview is an intense experience for both parties involved, and a physical encounter is essential context for an interview which is flexible,

interactive and generative, and in which meaning and language is explored in depth. (Legard et al. 2003:142).

People with IBD often have urgent and frequent need for toilet facilities, making travelling difficult and stressful. Home interviewing provides a physically safe place for participants with access to their own facilities and the interview arranged to suit their needs. Many report excess and discomforting bowel activity in the morning, for example, so an afternoon or evening interview was often helpful. Home interviewing also places participants in an emotionally safe place where they have the power and the researcher is the guest (Elwood and Martin 2000), and provides a private space where it is safer to talk about a taboo topic with less risk of being overheard or of offending others. Together, these aspects increase the likelihood of capturing powerful data.

6.1.3.3. Data capture and transcription

The goal in qualitative interviewing is to capture data in its original form. Note-taking is slow and inaccurate and has been superseded by electronic recording methods. Data recording needs to involve the researcher minimally, enabling her to listen actively and give full attention to detecting clues and hints that can then be explored further (Legard et al. 2003). For this study, interviews were recorded using an Olympus digital voice recorder. With 2GB capacity, historical concerns about running out of, or having to turn tape over midway through the interview so disrupting the interview event, are avoided (Walker 2011). Recording quality is excellent, with minimal risk of capturing inaudible data. Files can be easily saved, copied and shared (with due regard to confidentiality).

It is often advised that the researcher carries out transcription to achieve thorough immersion in the data through close and detailed contact with it (Holloway and Wheeler 2010), but this is an arduous process for anyone without competent touch-typing skills. A professional transcriber can complete the task in a fraction of the time although this option must be balanced against cost, quality of transcriptions, and connection that the researcher consequently has (or doesn't have) with the data. Of the four hermeneutic studies reviewed in Chapter 5 [Research methodology], three transcribed for themselves

(Pejlert 2001; Chang and Horrocks 2006; Raingruber 2010) and one employed a professional transcriber. In-depth research interviews are rarely short and can be time-consuming for the inexperienced transcriber. Using a professional transcriber was fundamental in keeping this study schedule on track.

The quality of transcription is important. The transcript should be produced in the format and with the level of detail required by the researcher, whilst respecting confidentiality. Audio files were sent via a secure web-link with instructions for verbatim transcription, my voice to be emboldened, and to include in brackets any specific events such as interruptions or participant's expression of emotion. Once I received each transcript, the transcriber deleted her copy of the digital audio file.

Lack of immersion was addressed through repeated reading of each transcript whilst listening to the related audio file of the original interview (Silverman 2000b). The audio file provided the tones, nuances and variations not represented in the two-dimensional printed transcript and, combined with field notes, recreated the context, feel and experience of each interview. Immersion was later enhanced through repeated exposure to the full transcripts and to individual data extracts during data analysis [Chapter 7].

6.2. Co-constitution and data analysis

Heideggerian phenomenology involves shared hermeneutics (interpretation) between participant and researcher to reach a new joint understanding of what the experience means (Dowling 2004). Gadamer calls this joint understanding the *fusion of horizons* and explains that 'the text brings a subject matter into language, but that it does so ultimately the achievement of the interpreter. Both have a share in it' (Gadamer 2004:390). Shared understanding comes about initially during the interview through in situ co-constitution, aided by the researcher's positive influence on the interview process. During analysis, the researcher seeks to make meaning accessible to others, by interpreting events and re-presenting them to an audience:

The quest of Heideggerian phenomenology is not to provide answers, for that shuts down and closes thinking. It is rather to invite readers to make their own journey, to be exposed to the thinking of the authors and to listen for the call on their own thinking (Smythe et al. 2008:1393).

Social science and health researchers have for some time debated whether transcripts should be returned to interview participants for verification – a strategy that, in the historical argument between positivistic and naturalistic forms of research, was believed to enhance credibility of the findings (Lincoln and Guba 1985). Early writers on qualitative methodology argued the opposite – that sending scripts back to participants is difficult (Sandelowski 1993). Some still support member-checking (Bradbury-Jones et al. 2010) while others argue that it is redundant in phenomenological enquiry (McConnell-Henry et al. 2011). Smythe et al. (2008:1392) advise that: ‘every interview / conversation is an event that simply ‘is’ - occurring uniquely at that moment in time, the story being told in the way that it is precisely because of the unique combination of time, place, researcher and participant (Bakhtin 1987). Riessman (1993:11) advises that ‘the story is being told to particular people: it might have taken a different form if someone else were the listener.’ Czerniewska and Twite (1979) refer to this as language register - that how a story is told depends on what is being told, why it is being told, who it is being told to and what the relationship is between teller and audience. The story can never be the same beyond its original telling. It cannot be replicated, and once it has passed, the person’s understanding of the phenomenon has evolved and there is no ‘right’ interpretation (McConnell-Henry et al. 2011; Sandelowski 1993) for participant or researcher. In this study, transcripts were not returned to participants.

6.2.1. Co-constitution

In the absence of member-checking, confidence in the representation of participants’ meaning is strengthened by the use of co-constitution at interview, so that the *fusion of horizons* is partially created during the interview event. Recapping phrases such as: ‘*So are you telling me that ... ?*’ secures confirmation from interviewees about an aspect of their story. In this interview, Carl (pseudonym), a 54 year-old with Crohn’s disease is

trying to explain how his IBD makes him feel. Interested in his persistent expressions of embarrassment, I probe further. Italicised comments below explain what I am doing to achieve co-constitution:

C: in our house we only had one toilet and I was in the toilet a lot, for hours in the morning and it was a fight to get in the toilet. So that was embarrassing yes, and eventually I just couldn't go to work and I was in the house all day. The tiredness was a lot to do with it as well, just through the disease. Um, but I was a builder by trade and I gave my job up at building and I'd done taxis years ago, so I tried to do that again. But I was getting caught in the car, got caught short in the car. So I remember a couple of times I had to run into McDonald's and that and so trying to clean yourself in these places is really embarrassing. There's no bins in McDonald's to put anything in. You know, (*chuckles*), to leave stuff in. So it's really embarrassing. It's embarrassing to your friends that you knew, you know, it's not the nicest thing to talk about. So it has been embarrassing for the years I had before the stoma, a lot of times.

Right, and is that, do you know why it is that you feel so embarrassed?

[The approach is corrected to avoid making an assumption of why he is embarrassed]

C: Just because of the way I was brought up, I was always clean and my mum was, you know, I was, I had to be clean and just from the smell or something – if you've had an accident you just feel really embarrassed and it's not the way to be, you know...

No, so for you it was because it's dirty?

[The 'No' indicates agreement with him about this not being the way to be, and the question about being dirty both follows up and confirms his reference to being clean]

C: It's dirty, yes. I never looked at poo before (*laughs*), you know. You know, you never look in the toilet pan, you just do it and walk away, you know.

Yes.

[Agreement]

C: Um, so this all became a new thing, you know, you were seeing it all the time, sort of thing and running, it's in your pants or whatever if you've had an accident, it's just disgusting to me, it was. Not natural, not natural, just not meant to do it. You don't even think of it if you don't have these problems.

No.

[Agreement]

C: So um that's really, it's embarrassing.

This extract demonstrates the way in which interaction between myself and Carl creates the shared understanding and agreement about why he feels so embarrassed – because the disease is unclean.

This approach was used throughout the interviews, seeking confirmation and clarification only after topics had been introduced by participants. Achieving co-constitution at interview eliminates the need to return transcripts to participants prior to analysis. The participants' right to withdraw from the study if, following interview, they changed their mind about involvement, remained. No participants withdrew.

6.2.2. Data analysis framework

In qualitative research some methodologies such as grounded theory and IPA have in-built analysis processes, while others, including interpretative phenomenology, do not. The data analysis method may be selected only after data collection, guided by the type of data that has been captured and by the aims of the study. This section describes the selection of the data analysis method for this study - practical application of the method is described in detail in Chapter 7.

To avoid separating the researched from their data, I intended to identify themes within and across transcripts, so that both the uniqueness's and commonalities of IBD-related stigma experiences could be revealed. I had planned to use McCormack's Interpretive Lenses (McCormack 2000a; 2000b), an analysis method I had used in previous research which supported these two intentions (Dibley 2009; Dibley 2011) and works well with chronologically-sequenced stories. However, as the interviews progressed it became clear that the narratives were chaotic and disordered, and that McCormack's analysis method would not suit the data. To find a suitable replacement, I revisited the literature, seeking a method which aligned with hermeneutics, guided analysis without being too prescriptive, and addressed any negative researcher influence. Of the four interpretative phenomenological studies reviewed previously, Raingruber (2010) had used a qualitative descriptive approach guided by Sandelowski (2000), which seems a poor fit with an interpretative study; Pejler (2001) had used a combination of Ricoeur (1976) and Polkinghorne (1998), both appropriate analysis methods for this type of study. Chang and Horrocks (2006) and Alqaissi and Dickerson (2010) had used a hermeneutic phenomenological method described by Diekelmann et al. (1989).

Ricoeur and Polkinghorne offer similar data analysis processes, including naive understanding, structural analysis, comprehensive understanding, and iteration between understanding and explanation of the whole and the parts. However, both are more appropriate for narrative analysis, a method already rejected for this study. Unfamiliar with Diekelmann et al. (1989) I undertook a search of 15 nursing, medical and social science databases via the Ovid gateway, using the search term 'Diekelmann' as a key word. Following removal of duplicates, 59 primary research papers were identified, published 1995 - 2013, which had used Diekelmann's framework to analyse qualitative data in hermeneutic phenomenology studies. Four (including the two identified in the original review, above) had specifically explored health-related stigma (Alqaissi and Dickerson 2010; Chang and Horrocks 2006; Nelms 1996; Saunders 1994). Although reassured that the method had been successfully associated with and applied to hermeneutic stigma research, the descriptive detail of the process varied in each paper. Diekelmann and colleagues developed the analysis method whilst researching pedagogical nurse teaching (Diekelmann et al. 1998). Analysis involves a team of people, and although Crist and Tanner (2003) suggest the team approach to hermeneutic

data analysis is optional, they do advocate its value. Nelms (1996) and Lindsay (2006) however, explicitly report the value of a team approach in adding depth and insight, ensuring consensus agreement on emerging themes and reflexively managing the influence of the main researcher. Trustworthiness and credibility of the research is thus enhanced. Existing literature can also be brought into the team analysis process to aid understanding and interpretation of data (Diekelmann 2001). This approach differs from other interpretive methods due to the development of relational themes and constitutive patterns. Smythe et al (2008:1392) explain that:

What we call ‘themes’ are not necessarily ‘the same thing’ said again and again, but rather an understanding that we have seen something that matters significantly, something we wish to point the reader towards.

Some hermeneutic researchers are not explicit about the process of theme and pattern development (Chang and Horrocks 2006), whilst others are (Alqaissi and Dickerson (2010; Foglia and Grassley 2010). Relational themes arise within transcripts and are shared with some other transcripts, but a constitutive pattern is a shared meaning which exists across all transcripts. It is not a ‘requirement’ that constitutive patterns are there – taking this stance could lead the researcher to actively seek unifying meanings, but should a meaning emerge across all transcripts, it is then defined as a constitutive pattern. Constitutive patterns are the highest form of interpretation, linking relational themes - matters of significance to which the researcher wishes to point the reader - together (Diekelmann 2001). This supported my aim to retain themes and stories within, between and across transcripts, revealing common experiences and shared meanings (Ironside 2006). Other analysis frameworks do enable development of main and sub-themes, but the presence of constitutive patterns in all transcripts is unique to this approach, underscoring the significance of the pattern. It is rare, in exploration of a specific human experience, for there to be no shared meanings. Finally, the method is fully iterative, moving back and forth between interviews, transcripts, and emerging themes, reflecting the hermeneutic cycle of Heideggerian phenomenology (Diekelmann and Ironside 1998). The findings are a co-constitution between participant data, researcher and the analysis team. Diekelmann et al.’s (1989) hermeneutic analysis method was therefore adopted for this study.

6.3. Ethical considerations and issues of rigour

6.3.1. Ethical considerations

The 1964 Declaration of Helsinki (latest amendment October 2013) regulates research activity to prevent undue harm to study participants. The researcher must demonstrate their capability to reassure against the risk of inadvertent unethical practice. They must also show their research to be potentially beneficial, that participants have received sufficient study information to make an informed consent and contributed willingly, and that participation does not affect statutory rights including access to health care. Overt statements and practice regarding protection of identity and handling of personal data should be made, and potential risks identified with evidence provided of how such risks will be minimised (Holloway and Wheeler 2010; Lewis 2003). Full approval was awarded for the current study by the ethics committee at the host university prior to data collection (Ref: BEC17012011Stigma). Following an employment move (and with data collection incomplete) additional approval was secured from the research ethics committee at King's College, London (Ref PNM 12/13-24) [Appendix 5: p. 353].

6.3.1.1. Researcher capability

Demonstration of research capability provides reassurance that the investigator has sufficient knowledge to avoid causing undue harm, and to protect the rights of participants. Good Clinical Practice training, previous successful ethics applications, and prior experience in qualitative research activities are evidence of my capability.

6.3.1.2. Benefits of the research

Research is unethical when there is insufficient rationale for conducting it, but beneficial when it provides original or additional evidence to fill an existing knowledge gap or advance understanding (Allmark 2002; Department of Health 2010). The critical

review for this study [Chapter 4] demonstrated that only minimal qualitative data about IBD-related stigma from Thompson's (2013) ethnographic study and the preliminary findings in my own recent work existed (Dibley and Norton 2013). Subsequently, two qualitative papers addressing stigma in IBD have been published (Frohlich 2014; Saunders 2014), laying beginning foundations of a body of work which reveals the many experiences of stigma in IBD, and to which this study will add.

6.3.1.3. Informed consent

Potential participants who registered an interest in the study received a detailed study information leaflet [Appendix 5]. Interviews were subsequently arranged with those who wished to participate, and informed (signed) consent was secured prior to commencement of each interview [Appendix 5]. The interviewee kept one copy of the consent form, the second copy being retained in the research site file. Participants were advised that the recording of their interview would be transcribed by a professional and handled confidentially, and that they could withdraw from the study at any time before 31st December 2012 without having to give a reason for doing so.

6.3.1.4. Data protection

Personal details (name, postal and email address and contact telephone numbers) were stored, with the participant's permission, on a password-protected encrypted data storage facility in accordance with the Data Protection Act 1998. Confidentiality was maintained at all times. In all future representations of the data (such as at conference presentations or in academic publications), anonymity is assured and all personal identifying information such as names and locations has been removed. Pseudonyms replace actual names. Participants were informed that the transcriber of the audio file of their interview would delete her copy after transcription.

6.3.1.5. Risk to participants

The participant risked embarrassment and / or emotional distress from talking about a personal, perhaps humiliating, experience, potentially needing support. My professional nurse training, and a track record of previous successful studies exploring a range of sensitive topics, were beneficial. Interview potential was enhanced and participant risk reduced by following guidance offered by Legard et al. (2003) [Table 6-2]. Interviewees could contact me, or the Help Lines of Crohn's and Colitis UK if they later required further support. These support strategies were not accessed by any participant.

INTERVIEW STAGE	PURPOSE	ACTION TAKEN FOR THIS STUDY
1. Arrival	Establish relationship; put respondent at ease; play the role of guest initially	Initial contact via email and phone; pre-arrival phone call; factor in time for pre-interview socialisation starting with safe topics – the weather, the journey, or an interest of the participant's made obvious by clues in the house
2. Introducing the research	Focus on the task in hand; ensure comfort / privacy;	Check participant understands study purpose, and is clear about information provided; secure written consent; remind about focus of study
3. Beginning the interview	Collect contextual information; 'safe' opening questions; assess how easily respondent may talk	Confirm name, age, diagnosis and length of time with IBD; use casual info gained in stages 1 and 2 to direct focus towards stigma. Use participant's language where appropriate
4. During the interview	Guide participant through key themes; use prompts / issues as they arise	Follow schedule (interviews 1-5) or opening prompt (interviews 6-40). Stay alert to issues arising during interview. Use prompts / probes, re-introduce topics mentioned earlier by participant as appropriate.
5. Ending the interview	Wind the interview down to return participant to everyday social interaction	Sense when all avenues have been exhausted, or it is clear that nothing else is being offered. Allow interview to move towards whatever unrelated issue participant leads with, and close from there
6. After the interview	Be ready for golden moments to be revealed post interview. Explain what will happen to their data. Thank participant.	Add 'golden moments' to field notes as soon as possible after leaving venue. Explain what happens to audio file. Check participant feels okay. Leave when participant is fully out of interview and settled.

Table 6-2. Stages of the research interview detailing the purpose of each stage (Legard et al. 2003) and the actions taken by the researcher for this study

6.3.1.6. Researcher (interviewer) safety

There may also be safety risks to participants and interviewer due to conducting research interviews between strangers in private addresses throughout the UK. To reduce risk, a previously proven system based on providing an itinerary to the first supervisor, and sending text messages when entering and leaving each participant's address was followed. A pre-arrival phone call to the participant and displaying the King's College ID card on arrival, confirmed identity. Participants were aware of this process, and all itinerary records were later destroyed.

Working in the field presents additional travel risks for the researcher. Flexibility is needed during sensitive research, so independent travel is preferred over public transport since the latter can adversely affect the interview process. For example, concern about catching the next connecting train can curtail an interview, or reduce the time available to support distressed participants. Conversely, the concentration required to drive and navigate can be affected by the researcher's own emotional responses to the interview experience. I elected to drive, and reduced risks by using a sat-nav to ensure reliable navigation between interview venues, and by recording field notes immediately after departing a venue to place my thoughts in a safe place.

6.3.2. Rigour, or trustworthiness

Rigour, or trustworthiness, refers to the credibility of the study. Transparency (the explanation and defence of research design) enhances credibility by providing enough information to enable critical judgement of the quality and conduct of the study, and convince that reported findings have genuinely emerged from the raw data. The design of this study demonstrates a sound fit between philosophy and method. The data analysis method, explaining how findings were revealed, is outlined above and in full detail in Chapter 7, following. The rationale for not returning transcripts has already been defended. Proof was not sought retrospectively since experiences are unique (Ritchie et al. 2003), but co-constitution at interview confirmed understanding because uniqueness is no excuse for lack of rigour (Miles and Huberman 1994). The qualitative

researcher also aims to illustrate the breadth and variety of experience. The findings [Chapters 8, 9 and 10] report relational themes and constitutive patterns occurring within and across transcripts, but also address rarely identified issues which have nonetheless ‘caught my phenomenological gaze’ and to which I invite others to ‘come and look and think’ (Smythe et al. 2008: 1393).

6.3.2.1. Insider status and reflexivity

Qualitative researchers in social and health sciences often explore issues with which they are professionally and personally connected. By the late 1990s, qualitative research was established as a credible academic endeavour, but the problem of how to deal with the researcher’s connectedness, remained (Pellatt 2003; Pugh et al. 2000; Simmons 2007). The benefits of connectedness were accepted: access to the research field and population, inside knowledge of cultural, social and ethnic detail, familiarity with topic-specific language and terminology, and the potential to enhance the quality of collected data (Bonner and Tolhurst 2002). How to manage the personal understanding, knowledge, and perspectives of the researcher remained a theoretical challenge (Chavez 2008). Reflexivity has emerged as a way of managing this problem:

Researchers, especially within the qualitative tradition, who are keen to acknowledge the situated nature of their research and to demonstrate the trustworthiness of their findings, are seeking new tools. Using reflexivity, they find that subjectivity in research can be transformed from problem to opportunity (Finlay and Gough 2003: ix).

Reflection and reflexivity are different; reflection involves thinking retrospectively about an event in order to learn from it (Mezirow 1998), while reflexivity is an active process of dynamic self-awareness which takes place as an event is happening (Dowling 2006). The reflexive researcher constantly adjusts their influence, minimising negative and enhancing positive aspects of self to benefit the study, throughout the research process (O'Connor 2011). Journaling, diary-keeping – which were particularly helpful in enabling me to recall specific details pertinent to each interview, and as repositories

for my thinking when grappling with some of the more challenging experiences of PhD studentship, provide evidence of reflexive practise [Appendix 6]. The reader can then judge for themselves the credibility of the researcher, and the research effort.

Being an insider can mean many things, such as having a shared racial connection (Serrant-Green 2002), or mutual professional or personal experience (Chesney 2000; Dibley 2009). I was connected to this IBD research through my professional identity as a nurse, and through living in the same culture, with the same social rules, as the study participants. My nursing background gave me knowledge of IBD, familiarity with health care terminology and systems, and a professional identity which participants valued and responded positively to. Several asked me, before interview, how I came to be researching IBD. Sharing my professional information facilitated the building of rapport and trust, enabling me to set participants at their ease and potentially enhancing the interview experience. Yet although my cultural background has instilled in me the social rules about bodily functions and associated hygiene, my personal perspectives are influenced by professional clinical experience: I appreciate that illness or disability can affect control of body functions, and the ability to maintain social rules. I am also connected personally, being the owner of a discreditable (lesbian) identity (Goffman 1963a). I well recall, in my youth, the fear of being discovered to be anything other than the heterosexual single woman I appeared to be.

Reciprocity is important if the researcher is to avoid becoming ‘an emotional gatecrasher’ (Chesney 2000), and giving something of oneself avoids careless emotional poaching. My socio-cultural understanding of stigma may or may not match that of the study participants, so I managed my personal perceptions carefully, adopting as open and unconditional an attitude as I could. Any potentially stigmatising response from me could negatively influence the interaction, and stop people talking to me. I explained my professional background to participants and that I had, throughout my nursing career, been interested in how people manage chronic illness in the context of their lives. This, and an interest in marginalised groups or those with difficult or hidden conditions, had led me to the study. I also explained that through experience of interviewing people with IBD-related FI, I was familiar with a wide range of symptoms and experiences, and they were unlikely to describe anything which would shock me. Equally, I did not want

people to feel obliged to share more than they were comfortable with, so reassured them that they did not have to reveal anything that they didn't want to.

Reflexivity is not something that a researcher 'does' at specific points during a study. It is a constant process, a hermeneutic cycle in itself, in which the researcher is *always-already* critically analysing their own position, insight, and understanding in the light of ongoing research events and coming to a new horizon of understanding about themselves and their research (Laverty 2003). It is:

the process of continually reflecting upon our interpretations of both our experience and the phenomena being studied so as to move beyond the partiality of our previous understandings and our investment in particular research outcomes (Finlay 2003:108)

Reflexivity guided me to conceal my sexual identity from interviewees. Even though we potentially had a shared understanding of stigma, I perceived that interviews could be jeopardised by this information as some might receive it negatively. Even though unspoken, my stigma experiences were still present in the interview space, helping to progress the interview and guide my understanding. Reconsideration of this insider knowledge later guided me to draw on my pre-understanding of stigma at analysis.

The tasks of the qualitative interviewer are wide-ranging. There is a need to simultaneously listen, understand, assess, be alert to contradictions, decide on what to follow up and what to leave, and to take note of hesitations, descriptions, emotions, and non-verbal signals (Mason 2002; Ritchie and Lewis 2003). Reflexivity is woven in as the researcher manages these tasks, and the influence of self at interview. I was reflexive in managing professional and personal perspectives to minimise potential negative influences and enhance positive ones. For example, a female participant who experienced IBD-related FI described feeling less stigmatised since moving from a large city to a small, remote village. I recall feeling very surprised, yet controlling that inner response during the interview to avoid placing a value judgement on her. My experience is that it is easier to hide and be anonymous in a well-populated place than in a small community where, as she explained, everyone knows everyone else.

In each interview, I reflexively managed self whilst simultaneously re-iterating points, clarifying understanding, and sharing my interpretation of what had been said in order to confirm that it matched what the interviewee intended. Being reflexive also resulted in the progressive adjustment to the interview schedule when the original proved to be too structured, limiting the emergence of rich data [Chapter 6: Table 6-1, p. 88].

At analysis, reflexivity involves combining one's own knowledge and experience with what is discovered in the data to *aid* understanding, whilst avoiding the assumption that personal knowledge *is* understanding. Even though an experience might be shared, it cannot be assumed that all those sharing that experience have the same understanding of it (Platzer and James 1997). Developing a *showing / revealing* of others' experiences involves the researcher in a 'complex and intense process, inextricably linked to the acts of interpretation and reflexivity' (Holloway and Freshwater 2007). In reporting the study, reflexivity illuminates the researcher's role, explicates their thinking and decision-making, and adds to the trustworthiness of the findings (Finlay and Gough 2003; Koch 2006; Koch and Harrington 1998).

Managing insider status, and being reflexive, is demanding. It can be difficult to step away and see the world as others might, whilst controlling the influence of self yet at the same time being acutely self-aware (Clancy 2013). Reflexivity requires an honesty and emotional vulnerability which can be personally challenging (Sampson et al. 2008) as old emotional wounds are re-opened, and usually reliable self-preservation strategies are tested. A strong and supportive relationship with my supervisors provided both emotional counterbalance and the necessary challenges to personal thinking which proposed alternative interpretations, and encouraged and facilitated the thread of reflexivity which runs through the study.

6.4. Summary

The methods described above were selected either because they are a fundamental requirement of any research (such as ethical aspects), or because they offered the best fit

between interpretive phenomenology and the research questions, enhancing the likelihood of meeting the study aims. Compromises, where made, have been rationalised. Throughout, a reflexive stance has enabled transparent demonstration of how my influence on the study has been managed.

Chapter 7 presents a detailed description of the process of data analysis. Findings and analysis are presented in Chapters 8, 9 and 10. A critique of Diekmann et al.'s (1989) hermeneutic phenomenological framework is included in Chapter 11 [Discussion].

7. Method of data analysis

Qualitative data analysis is complex, challenging and time-consuming, demanding rigour, resilience and integrity from the researcher. Self-awareness, discipline and insight, intertwined with a non-linear yet progressive process reveals interpretations which are applicable to practice interventions, policymaking, philosophy, and ongoing research (Crist and Tanner 2003). The processes and complexities of qualitative analysis can be obscured in academic literature (Sandelowski and Barroso 2002), perhaps due to publication limitations, but lack of detail challenges the reader's ability to determine credibility and trustworthiness of the findings. Software programmes such as NVivo® may streamline processes but threaten other aspects of analysis. This chapter underpins the trustworthiness of the subsequently-reported findings by:

- presenting the rationale for not using NVivo® to support data analysis, and
- detailing the method of Diekelmann et al's (1989) hermeneutic phenomenological analysis.

7.1. The rationale for not using NVivo®

The manual data analysis process for this study was labour-intensive, yet very intuitive. Computer-assisted qualitative data handling software (CAQDAS) such as NVivo® streamlines and expedites the process, but can be counter-productive. NVivo® is specifically designed for qualitative data management and assisting analysis, but challenges include the time and effort associated with becoming proficient with the programme (Bergin 2011; Goble et al. 2012), and the prescriptive approaches to analysis which resist ability to later amend early categories (Robson 2002). Use of CAQDAS (such as NVivo®) can result in enhanced data sifting and retrieval, but may also lead to data 'shuffling' from which only generalised descriptive analysis emerges, and the tactile nature of data analysis can become obsolete (Goble et al. 2012). Patterns and relationships are created after text has been reduced to codes, risking loss of the

overall interpretation of meaning. Supporters of CAQDAS value the accuracy of analysis and ability to easily produce a reliable view of the data by counting who said what and when (Welsh 2002). In hermeneutics, working with data is a process of thinking deeply, of ‘trusting that understanding will come’ (Smythe et al. 2008), and of ‘hearing what the data have to say’ (Thompson & Barrett 1997). From this understanding and hearing, ideas (themes) emerge which catch the phenomenologist’s gaze, and are later interpreted to show / reveal findings. Value (how much, how often, how many) is anathema to hermeneutics, and:

CAQDAS programs can impede phenomenological analysis by creating practical conditions that are markedly *unphenomenological* (Goble et al. 2012:11, emphasis original)

Hermeneutics embraces researcher connectedness, language and uncertainty but CAQDAS can separate phenomenological researchers from their work, limit them to simple words so that they become language-less, and add certainty and order; the subtle development of hermeneutic understanding that emerges from reading, thinking and writing, re-reading, re-thinking and re-writing, gets polarised as programmes force decisions that something is *this*, or is *not that*, and analysis ‘ceases to be a hermeneutic event’ (Goble et al. 2012). NVivo® was therefore not used to aid analysis in this study.

Instead, the manual pen, paper, cut, paste, move, re-move, position and reposition, highlighted, colour-coded processes of my analysis kept me in the data. Deep thinking and reflection were prompted by each review of its tangible, visible display, and thinking, reading and writing occurred in hermeneutic cycles until meaning emerged.

7.2. The data analysis process

Diekelmann et al’s (1989) analysis framework has seven stages [Table 7-1]. During analysis, the researcher addresses each stage and in an iterative, hermeneutic process, revisits analysis of earlier stages as more themes are identified. Analysis is thus not

linear, but repeatedly cyclical: ‘the hermeneutic circle, circles’ (Ironsides 2014; pers. comm. 12th July). By stage seven, transcripts may have been visited several times.

STAGE	PROCEDURE	ACTION TAKEN FOR THIS STUDY
1	Read transcripts (individually and as a whole) to gain overall understanding	All transcripts (n=40) read and audio files listened to by LD; 10 transcripts read by CN and EW.
2	Write summary of each transcript; begin to identify themes and patterns	Summaries of each transcript written; LD, CN and EW identify early potential themes
3	Agree summaries to reach consensus. Resolve conflict by returning to original data	Early findings compared, discussed and agreed. Transcripts revisited by LD to demonstrate presence of early relational themes and constitutive patterns in data
4	Reread all texts: identify hidden meanings and relational themes	All transcripts revisited by LD; stages 3 and 4 repeated until all transcripts have been carefully reviewed for all themes and patterns
5	Describe constitutive patterns	Three constitutive patterns confirmed
6	Verify results by returning to interview transcripts / participants	Discussion with CN and EW to verify presence of themes and patterns in data; transcripts revisited by LD to verify, to manage overlap between some themes, and to confirm final relational themes
7	Integrate and synthesize findings into an interpretive structure (final report /thesis)	Findings presented in thesis

Table 7-1. The seven stages of the interpretive hermeneutic phenomenological analysis method (Diekelmann et al. 1989), with procedure of each stage and how this was actioned in the current study

CN = Professor Christine Norton (first supervisor); EW = Professor Elizabeth Whitehead (second supervisor); LD = Lesley Dibley (doctoral student)

Themes are either *relational themes*, or *constitutive patterns*. Relational themes (RTs) appear across some transcripts, whilst constitutive patterns (CPs) are present in all transcripts and link several relational themes together. Hermeneutic phenomenologists resist notions of ‘conviction’ that may be suggested through the persistent presence of a theme in the data; CPs are instead the indication that there is something meaningful here which warrants attention. Emergence of RTs and CPs requires team analysis and review

in early stages, helping to mitigate against potential negative influence of a single researcher. Ideally, findings are presented in the language of interpretive phenomenology (Nelms 1996). The methods of the first six stages of analysis are presented here. The findings, representing Stage 7, are reported in Chapters 8, 9 and 10.

7.2.1. Stage 1: Read transcripts (individually and as a whole) to gain overall understanding

Data analysis followed the stages outlined in Table 7-1, above. I read through all transcripts whilst listening to the relevant audio file, verifying transcription accuracy and noting any significant emotional aspects overlooked at transcription. Professor Chris Norton (CN), and Professor Elizabeth Whitehead (EW) (study supervisors) read through 10 transcripts each. We all worked with transcripts 25 – 29, and I worked on another five with each supervisor (30 – 34 with CN; 20-24 with EW).

7.2.2. Stage 2: Write summary of each transcript; begin to identify themes and patterns; and Stage 3: Agree summaries to reach consensus. Resolve conflict by returning to original data.

In Stage 2, I wrote summaries of all 40 transcripts. CN and EW summarised each of 10 transcripts they received. We all identified preliminary issues in five shared transcripts (25-29). In Stage 3, preliminary issues were agreed through discussion; terminology differences were resolved and meanings clarified. Flexibilities in interpretation became apparent: for example, the themes of *unpredictability* and *preparedness* could be interpreted as *control*, yet *control* could mean emotional, psychological, practical and physical control over disease and situation, or not. Entering our individual interpretations in a table revealed inherent consistencies. Table 7-2, below, shows how we each identified issues within one interview, and the early relational themes which these informed.

Prof. E. Whitehead	Prof. C. Norton	Lesley Dibley	Early relational themes
Concealing	Doesn't want grandchildren to be frightened or think her strange; pretends she needs a wee when has bowel urgency;	Doesn't want grandchildren to think badly of her; others' impressions of her new life, yet socially inactive; covering; doesn't want image of herself to be tarnished; also has coeliac – also hidden, but no risk of being exposed;	Impression management
Anticipates stigmatising situations and avoids them where possible	Worries about smell, being unclean; worries about what others think about her – risk of FI haunts her, Spare knickers	Feels others' perceptions of her would be negative; fears ruining her public image – being revealed as something other than what she claims to be – fears being discredited;	Anticipated stigma Preparedness
Trapped (not in control)	Trapped, yet only feels safe at home; Urgency and FI; feels controlled by illness	Ignores advice which might improve control (Loperamide); withholds details of problem from Consultant to avoid surgery; cannot trust body to behave; has no sense of control over body; fears surgery will put her out of control, but feels controlled by UC;	Control
Childhood 'Victorian;' inhibited and very private	Inhibited person; strict upbringing; ? wanted by father; private; self-critical I hate the colitis, I hate it (<i>so not accepted into her life</i>)	Bodily functions taboo in upbringing; no openness; I hate the colitis, I hate it (<i>non-acceptance</i>)	Childhood influence on adult behaviours Normalisation / acceptance
Disruption: illness disrupts relationships and social activities. Illness is threat to her intimate partner relationship; keeps it from husband; Selective disclosure – daughters know, husband doesn't.	Unsure if husband aware of problem; feels he wants to spare her embarrassment; feels he dislikes illness so she won't say anything; keeps concerns about her girls to herself – internalises;	Hides truth of her illness from husband; cannot be open with him; hides concerns relating to her girls from him; wants no barriers with her children but has barriers with her husband; wants open relationship with children but won't reciprocate; avoids health issues with husband;	Relationships / social support
Table 7-2. Example of identification of potential themes by each analyst (student and both supervisors) from a single transcript, and agreement of early relational themes FI = faecal incontinence; UC = ulcerative colitis			

Applying this process to the interviews we had all analysed enabled development of 21 early relational themes [Table 7-3]. The *Miscellaneous* category was added to temporarily store ideas which seemed, initially, unrelated to any existing theme.

Early relational themes		Early relational themes	
1	Unpredictable	12	Humour
2	Preparedness	13	Public knowledge / interest / expectations
3	Cause	14	Illness competence, life competence / acceptance
4	Cultural norms	15	Anticipated stigma
5	Mental health	16	Perceived stigma
6	Impression management	17	Experienced stigma
7	Personality	18	Self-stigma
8	Childhood influence on adult behaviours / attitudes	19	Felt / enacted stigma
9	Control	20	Concealability / discredit/able
10	Relationships / social support	21	Stigma fluctuates
11	Information management / 'coming out' about IBD	22	Miscellaneous

Table 7-3. Early relational themes established from comparing, discussing and agreeing independent findings across five interview transcripts

7.2.3. Stage 4: Re-read all transcripts; identify hidden meanings and relational themes

Stage 4 was repeated several times, in an iterative process which refined relational themes (RTs) and confirmed constitutive patterns. Initial analysis of all transcripts was guided by the early RTs established in the previous stage [Table 7-3]. New ideas were stored in the '*Miscellaneous*' category, and subtitled to indicate focus. Transcripts were marked in hard copy in black or red pen, with text highlighted or underlined, and an interpretive comment and relational theme added. A Microsoft Word® table was created for each transcript. Each RT was allocated a row, and interpretations of that

theme were entered in order of appearance in the transcript, later enabling easy location of the verbatim quote relevant to each interpretation. Each row was labelled with the interview number and theme name, and colour coded according to the incontinence / stigma subgroup to which the interviewee had assigned themselves (No FI, no stigma = green; FI, stigma = orange; FI, no stigma = pink; no FI, stigma = yellow) [Table 7-4], creating an audit trail of the analysis process.

Interview	Interpretation	Early Relational Theme
1	Positive attitude	Personality
1	Socialised not to stigmatise; no stigma in house about anything; parents both blind – disability doesn't mean you can't do things; doesn't see disability first in others – sees person; same attitudes passed on to her son;	Childhood influence on adult behaviours / attitudes
1	Able to control bowel problem so making it concealable; be in control (might be easier with milder disease); has proven strategy for managing toilet needs – knows it works;	Control
1	Will talk to anyone about illness; not embarrassed	Relationships / social support
1	Not embarrassed but not telling; no negative reactions from others	Information management / 'coming out' about IBD
1	Light-hearted about 'close calls' – always made it to the home;	Humour
1	Quick diagnosis; accepting of situation – get on with it, be positive;	Illness competence, life competence / acceptance

Table 7-4. Method of recording and tracking interpretive findings within a transcript (transcript / interview one exemplified here)

The Word® table for each transcript, as exemplified above [Table 7-4] was printed out, cut into strips, sprayed with a re-mountable adhesive to facilitate repositioning, and fixed to a wall display under a heading for each RT [Figure 7.1]. The display enabled visualisation of, and a physical and cognitive immersion in, the entire data set by keeping it ever-present in my thinking and re-thinking. I revisited all transcripts for a second time to attempt completeness and to confirm the RTs, this time using a green

pen to mark new occurrence of themes in the text. Word® tables were subsequently printed out, this time with a background fill colour to indicate the connection to the second (green pen) analysis [Figure 7-2] of all transcripts. Several new issues emerged which were placed in the ‘*Miscellaneous*’ category.

To ensure further potential CPs or RTs had not been overlooked, I conducted a third and final analysis of those transcripts which, as evidenced by the wall display, were so far not represented within some themes. Using an orange pen and a different background fill colour in the resulting table, the presence or absence of each theme was confirmed in each transcript.



Figure 7-1. The wall display of data, demonstrating organisation of themes and positioning of strips

Miscellaneous category	Distribution of themes from Miscellaneous category across existing relational themes (RTs)	Additional relational themes arising from Miscellaneous category
Miscellaneous category	1 Unpredictable	
	2 Preparedness	
	3 Public knowledge / interest / expectations	
	→ 4 Cause	
	→ 5 Cultural norms	
	→ 6 Impression management	
	7 Concealability / discredibility	
	8 Childhood influence on adult behaviours / attitudes	
	→ 9 Control	
	→ 10 Relationships / social support	
	→ 11 Information management / coming out about IBD	
	→ 12 Illness, competence, life competence / acceptance	
	13 Anticipated stigma	
	14 Perceived stigma	
	15 Experienced / felt stigma	
	16 Enacted stigma	
	17 Self stigma	
	18 Stigma fluctuates	
	→ 19 Personality	
	→ 20 Mental health	
	21 Humour	
		→ 22 Courtesy stigma
		→ 23 Kinship stigma
		→ 24 Perspective
		→ 25 Identity

Figure 7-3. Distribution of themes from the Miscellaneous category across existing relational themes, and creation of four new relational themes Green highlights which of the 21 existing RTs received themes from the miscellaneous category; yellow indicates four new RTs emerging from the miscellaneous category

I revisited the wall display, reviewing interpretations within each theme to remind me of the overall sense of meaning. After discussion with a colleague also experienced in phenomenological investigation, some themes were combined or re-named to more accurately reflect meaning, and three emerged as constitutive patterns [Figure 7-4].

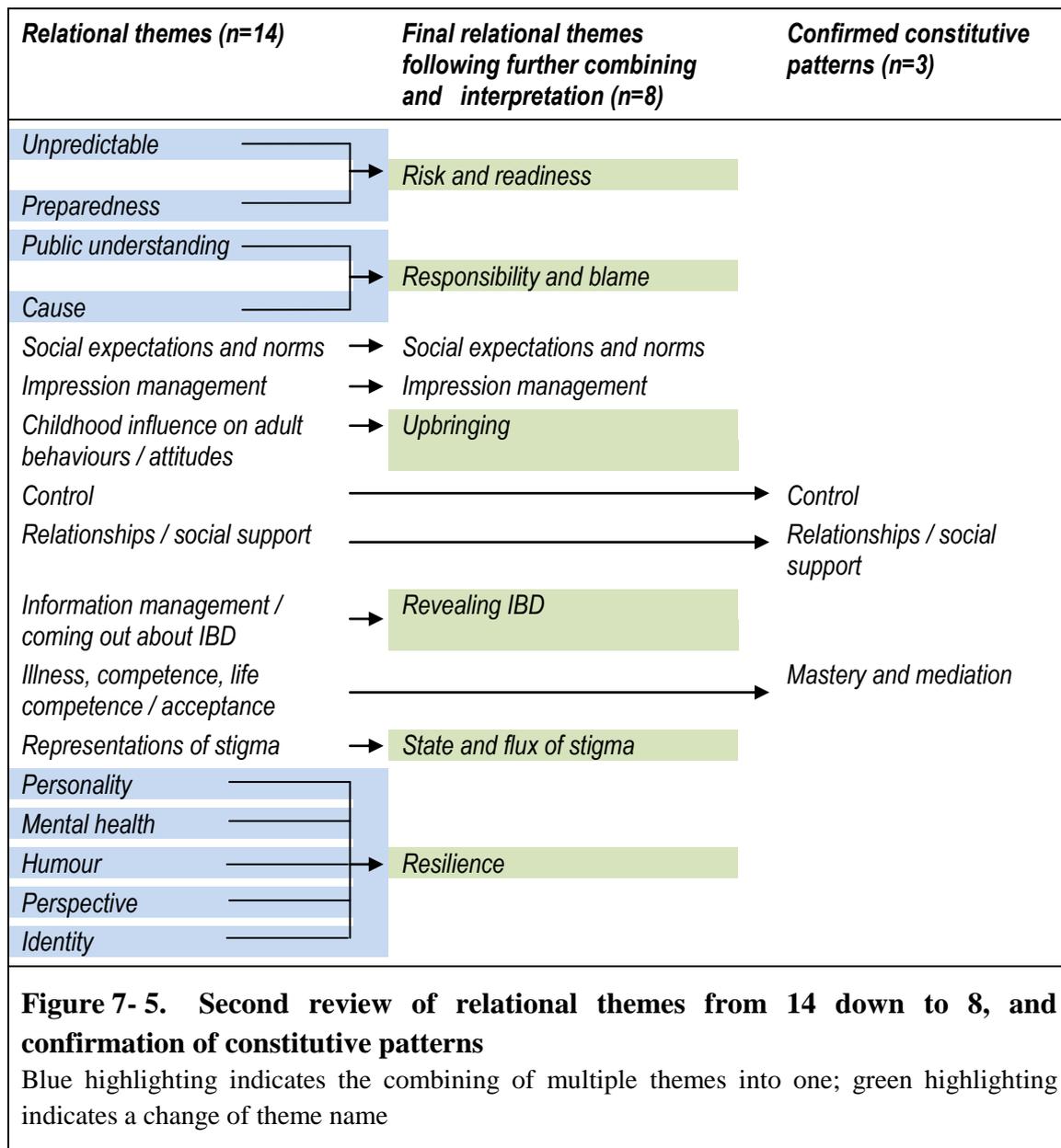
Relational themes (n=25)	Relational themes following further analysis, interpretation and discussion (n=14)	Emerging constitutive patterns (n=3)
Unpredictable	→ Unpredictable	
Preparedness	→ Preparedness	
Public knowledge / interest / expectations	→ Public understanding	
Cause	→ Cause	
Cultural norms	→ Social expectations and norms	
Impression management	→ Impression management	
Concealability / discredibility		
Childhood influence on adult behaviours / attitudes	→ Childhood influence on adult behaviours / attitudes	
Control		→ Control
Relationships / social support		→ Relationships / social support
Information management / coming out about IBD	→ Information management / coming out about IBD	
Illness, competence, life competence / acceptance		→ Mastery and mediation
Anticipated stigma	→ Representations of stigma	
Perceived stigma		
Experienced / felt stigma		
Enacted stigma		
Courtesy stigma		
Kinship stigma		
Self-stigma		
Stigma fluctuates		
Personality	→ Personality	
Mental health	→ Mental health	
Humour	→ Humour	
Perspective	→ Perspective	
Identity	→ Identity	

Figure 7-4. First review of relational themes from 24 down to 14, and emerging constitutive patterns

Blue highlighting indicates the combining of two or more themes into one; green highlighting indicates a change of theme name;

Almost all transcripts were now represented in the two newly-combined RTs of 'Impression management' and 'Representations of stigma,' making them potential constitutive patterns (CPs). Conscious of the role of CPs in revealing *significant meaning*, and aware of the challenge of personal perspectives, I worked carefully and thoughtfully through the unrepresented transcripts, bringing fully to consciousness the influences which might lead me to find evidence of these themes where none may be. Whenever I did identify a possible excerpt, I practiced reflexively, challenging myself over the degree of fit between excerpt and the meaning of the theme. I found no further representations of stigma, or of impression management, in any of the unrepresented transcripts. Consequently, no new constitutive patterns emerged. The early relational theme *Cultural norms* was renamed *Social expectations and norms*, and *Public knowledge / interest / expectations* was refined to *Public knowledge*, more accurately reflecting theme content [Fig. 7-4].

There were now 14 relational themes and three emerging constitutive patterns. The labelling of some relational themes required further revision. The original labels were functional enough but inadequately interpretive and not immediately clear to the reader. I returned to the transcripts, the summaries from Stage 2 and to my interpretations of the data in the printed strips to reaffirm the overall sense of meaning. Consequently, several themes were combined and subsequently renamed to more appropriately reflect the sense of each theme within the data. There were now eight confirmed relational themes and three emerging constitutive patterns [Figure 7-5]. Description of all relational themes, with examples, is provided in Appendix 7 [p. 379].



7.2.4. Stage 5: Describe constitutive patterns

Constitutive patterns (CPs) are themes which arise in every transcript: ‘a pattern is present in all the interviews and expresses the relationship amongst the themes’ (Diekelmann 2001). Experiences are unique and CPs are not an attempt to normalise or substantiate an experience as ‘true’ by virtue of frequent representation. CPs are a mechanism for *showing / revealing* the *shared meanings* of lived experience.

At the end of the first analysis, three themes occurred in almost every transcript. I returned to the transcripts not represented in these themes, using the same strategy as described previously when developing and confirming relational themes. 15 additional excerpts were identified, confirming that the three themes - *Control, Relationships and support*, and *Mastery and mediation* were present in all transcripts. These themes, now confirmed as constitutive patterns, are described in detail and exemplified in Appendix 7 [p. 379].

7.2.5. Stage 6: Verify results by returning to interview transcripts

With relational themes and constitutive patterns confirmed, three checks were undertaken to confirm that interpretations were representative of the raw data. 1) All interpretive strips were re-read to confirm the meaning and multidimensionality of each theme or pattern; 2) This refreshed awareness was then compared with the interview transcripts and the summaries created in Stage 2 of the analysis process, verifying the range of experiences and of meaning - that 'understanding had come' (Smythe et al. 2008). The themes and patterns seemed to meaningfully interpret participants' perceptions of their experiences; 3) Reflexive discussion with both supervisors, involving detailed consideration of the relationship between themes and patterns, provided a critical reassurance of the quality of data analysis.

7.2.6. Stage 7: Integrate and synthesize findings into an interpretive structure

A skilful qualitative researcher avoids being over-informed about published findings prior to analysis so that they are not influenced towards findings that only reflect what is already known [see Chapter 4: pp. 41 - 42]. Data analysis for this study was conducted without reference to existing literature, and as recommended, published evidence was then integrated with study findings (Diekelmann 2001; Ironside et al. 2003) to create the contextual, critical interpretations of the data.

7.3. Summary

Hermeneutic phenomenological data analysis is a complex, deep and thought-provoking process requiring diligence, self-awareness and reflexivity to both embrace and manage the influence of self on interpretation. Discussion of the data with supervisors, colleagues, and other academic peers facilitated the identification, confirmation and naming of the final eight relational themes and three constitutive patterns. The detailed description of analysis procedures here evidences the immersion in, and understanding of, the data.

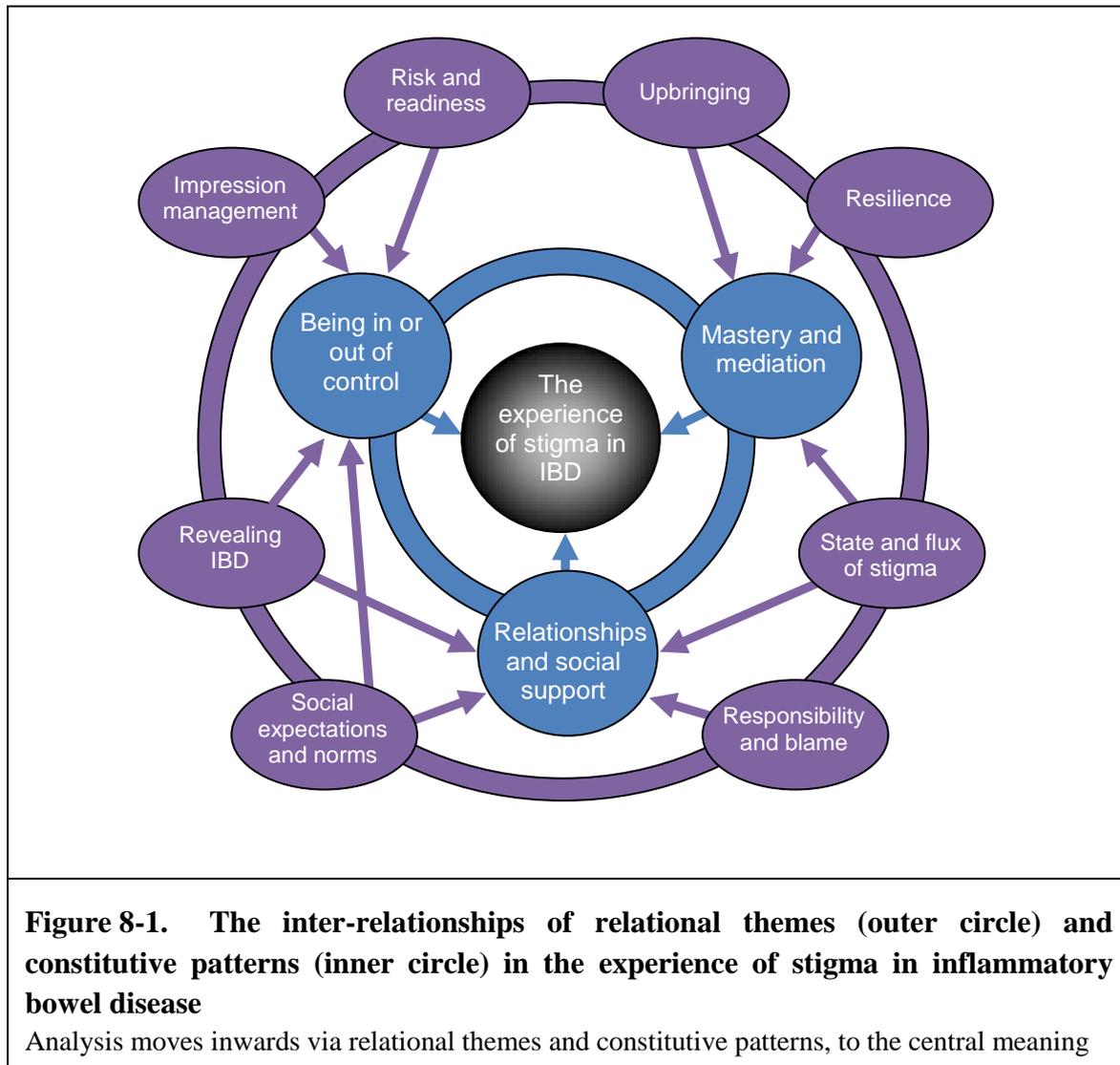
Findings and analysis of each constitutive pattern and the associated relational themes are presented in Chapters 8, 9 and 10. The analysis method is critiqued in Chapter 11, following discussion of findings.

8. Findings and analysis (i): Being in or out of control

Diekelmann et al.'s (1989) hermeneutic phenomenological analysis method enabled identification of relational themes and constitutive patterns. The requirement for constitutive patterns to be present in all transcripts can create the misconception that these are more important than relational themes. Diekelmann and Diekelmann (2009) later extended their thinking towards 'converging conversations' to explicate the ways that individual meanings can come together in a shared meaning which catches the phenomenological gaze of the research and is presented as a subject of interest to the reader, without suggestion of hierarchy.

In hermeneutic research, there is no single 'true' interpretation of the study data; what emerges is a co-constitution of the participant's, researcher's, and research team's perspectives (Wojnar and Swanson 2007). As each reader may discover a new 'truth' in an authored text (Frank 2004), each researcher may find a different 'truth' in the same data. Rigorous analysis ensures findings are firmly grounded in the data, enhancing truthfulness and increasing the potential impact of the results (Crist and Tanner 2003).

This study aimed to understand the experience of stigma in IBD, and whether stigmatisation was dependent on having faecal incontinence (FI). Three constitutive patterns and eight relational themes emerged from the data [Figure 8-1]. The relational themes represent the eight main aspects which influence participants' experiences of stigma and their ability to resist it. Some themes link to more than one constitutive pattern, indicative of the complex, interwoven nature of the stigma experience. For example, the relational theme *Revealing IBD* links to the constitutive pattern of ***Being in and out of control***, where the focus is on controlling the release of disease-related information about oneself to avoid others' misunderstanding, and to ***Relationships and social support***, where the focus is on sharing this information in order to secure support from others. The three constitutive patterns link the relational themes together, revealing an interpretation of the meaning of the lived experience of stigma in people with IBD.



IBD-related stigma will be shown to be an uncertain, inconsistent and often troublesome experience which can nonetheless be overcome. Understanding the experience can inform development of support strategies to enhance stigma resilience and resistance.

Honesty and transparency when reporting qualitative studies help create an audit trail, and enhance the credibility of findings (Crist and Tanner 2003). Use of verbatim quotes increases trustworthiness by enabling the reader to confirm the relationship between raw data and presented findings (Holloway and Wheeler 2010; Sandelowski 1994). Clustering of experience around some themes may add weight to the perceived importance of those themes within an experience, but the interpretive phenomenological researcher resists making hierarchical judgements, instead accepting unconditionally

each person's experience as they perceive it. Yet human experience perceptions inevitably reveal commonalities and uniqueness, so reporting findings which represent the range of common and infrequent human experience, also enhances credibility (Holloway and Wheeler 2010; White et al. 2003). Hermeneutic purists would resist reporting demographic detail of study participants since no relationship is being claimed between these details and the results. However, for this academic exercise, providing demographic details evidences the success or otherwise of the sampling strategy in capturing those likely to have experiences relevant to the study, and within-sample variation increases the potential transferability of the findings to a wider population (Slevin and Sines 2000). These study findings are presented over three chapters, with each chapter addressing a single constitutive pattern and the relational themes which inform it. This chapter:

- presents demographic details of the study participants
- describes the interviews
- presents the findings represented by the constitutive pattern of *Being In and Out of Control* and its four relational themes

The two remaining constitutive patterns of *Relationships and social support*, and *Mastery and mediation* are presented in Chapters 9 and 10. Study findings are discussed in the context of the wider relevant literature in Chapter 11.

8.1. Study participants

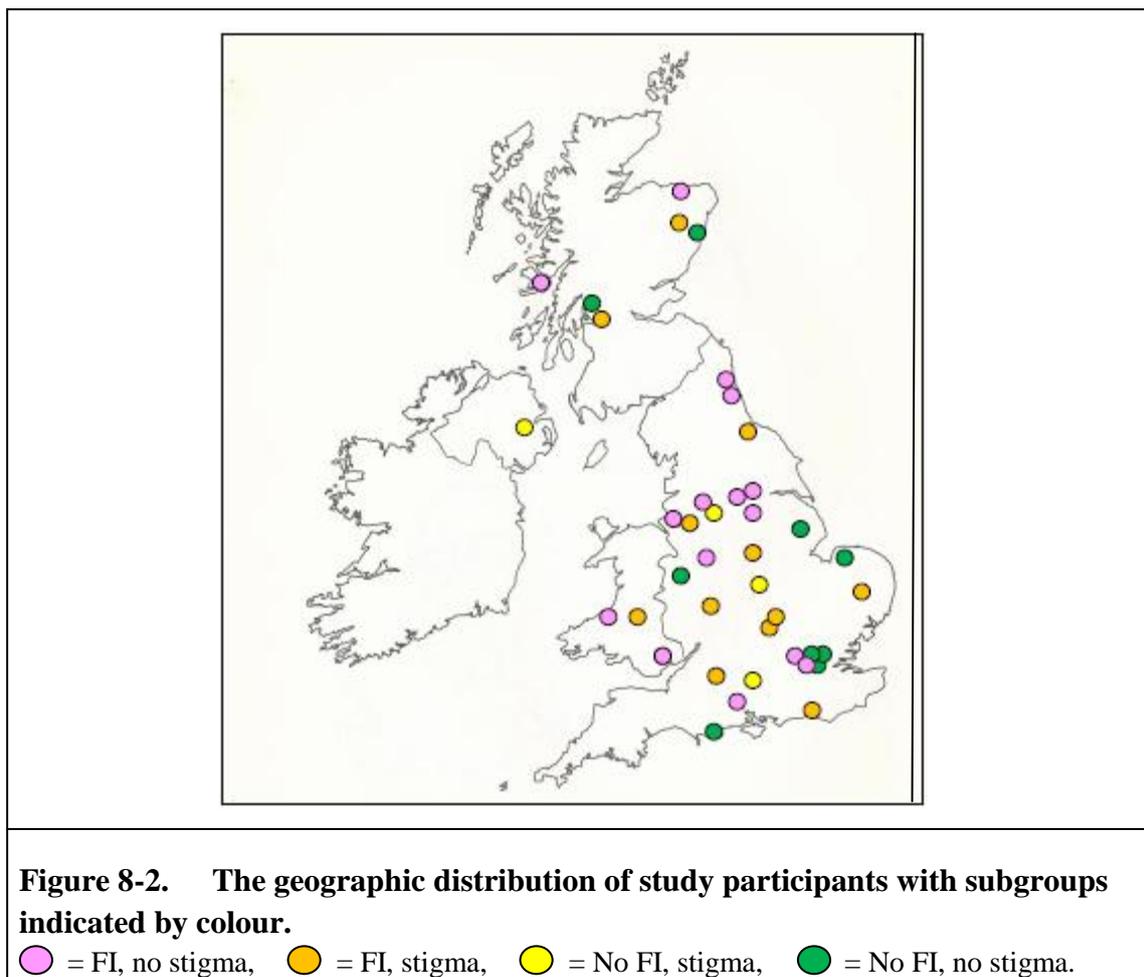
Forty participants were purposefully selected from those who volunteered to create a sample representing a range of ages, near-equal numbers of men and women, and proportionate representation of diagnosis and the four self-allocated FI and stigma subgroup [See Chapter 6.1.2, p. 86, for discussion of sampling outcome]. Participants were located throughout the United Kingdom, and data was collected between May and September 2012. Demographic details are provided in Table 8-1.

Pseudonym	Age (years)	Gender	Diagnosis	Disease duration	Study subgroup	Ethnicity
Jacob	34	M	CC	6	FI, no stigma	Caucasian
Charles	78	M	CD	30	FI, no stigma	Caucasian
Jeannie	58	F	UC	20	FI, no stigma	Caucasian
Carol	64	F	CD	14	FI, no stigma	Caucasian
Lindsey	45	F	CD	17	FI, no stigma	Caucasian
William	72	M	UC	22	FI, no stigma	Caucasian
Kevin	35	M	CD	16	FI, no stigma	Caucasian
Jason	47	M	Proctitis	5	FI, no stigma	Caucasian
Michael	47	M	CD	24	FI, no stigma	Caucasian
Rory	46	M	CD	16	FI, no stigma	Caucasian
Elsa	28	F	UC	7	FI, no stigma	Caucasian
Lily	30	F	CD	10	FI, no stigma	Caucasian
Janice	61	F	CD	30	FI, no stigma	Caucasian
Tina	44	F	UC	26	FI, no stigma	Caucasian
Juliet	52	F	CD	13	FI, no stigma	Caucasian
Rupert	68	M	UC	3	FI, stigma	Caucasian
Peter	56	M	CC	35	FI, stigma	Caucasian
Carl	54	M	CD	5	FI, stigma ^Δ	Caucasian
Lillian	61	F	CD	6	FI, stigma ^Δ	Caucasian
Sharon	61	F	CD	16	FI, stigma	Caucasian
Philip	54	M	CD	7	FI, stigma	Caucasian
Deirdre	56	F	UC	7	FI, stigma	Caucasian
Charlotte	37	F	CD	9	FI, stigma	Caucasian
Nancy	47	F	UC	4	FI, stigma	Caucasian
Reginald	61	M	UC	30	FI, stigma	Caucasian
Andrea	47	F	CD	12	FI, stigma	Caucasian
Vera	68	F	CD	10	FI, stigma	Caucasian
Andrew	69	M	UC	7	No FI, stigma	Caucasian
Marion	35	F	UC	3	No FI, stigma	Caucasian
Suzie	23	F	CC	4	No FI, stigma	Caucasian
Tamsin	38	F	CD	12	No FI, stigma	Caucasian
Katrina	48	F	CD	6	No FI, no stigma	Caucasian
Maeve	65	F	UC	25	No FI, no stigma	Caucasian
Vivienne	52	F	UC	20	No FI, no stigma	Caucasian
Caroline	34	F	CC	15	No FI, no stigma	Caucasian
Cheryl	29	F	UC	10	No FI, no stigma	Caucasian
Belinda	55	F	CD	3	No FI, no stigma	Blk Caribbean
Lawrence	52	M	CD	35	No FI, no stigma	Caucasian
Aileen	58	F	CD	7	No FI, no stigma [•]	Caucasian
Esther	27	F	CD	4	No FI, no stigma	Caucasian
	Range 23-78 Mean 51.2	Female 65%	CC* n=4;10% CD+ n=22;55% UC† n=13;32.5% Proctitis n=1;2.5%		FI, no stigma = 16 FI, stigma = 12 No FI, stigma = 4 No FI, no stigma = 8	Caucasian = 39 Black Caribbean = 1

Table 8-1. Demographic details of study participants

All names have been changed to protect identity. * = Crohn's Colitis; + = Crohn's Disease; †=Ulcerative Colitis; • = leakage per fistula rather than per rectum; Δ = has a stoma.

All but one respondent were Caucasian, reflecting the predominant distribution of IBD in Western populations (Loftus 2004). Belinda, the only non-Caucasian participant, arrived in England from Jamaica at the age of seven; IBD onset in non-Caucasians after migrating to high incidence areas supports the theory of environmental influences on disease development (Loftus 2004). The imbalance in numbers of each sub-group resulted in 70% of participants having FI, but as explained in Chapter 6.1.2 [pp. 86 - 87] this was not rectified since it reflected the 74% prevalence rate of FI demonstrated in our previous work (Norton et al. 2013). The percentage of each gender, and distribution of diagnoses in this study is similar to the membership of the charity organisation in 2010, the year from which the sampling frame was drawn: 36% were male, 64% were female; 49% had Crohn's disease, 45% had ulcerative colitis, 4.5% had Crohn's colitis, and 1% had proctitis. Study participants were located across all four countries of the UK, enabling capture of data from people living in a wide range of urban, suburban and rural locations [Figure 8-2].



8.2. Interviews

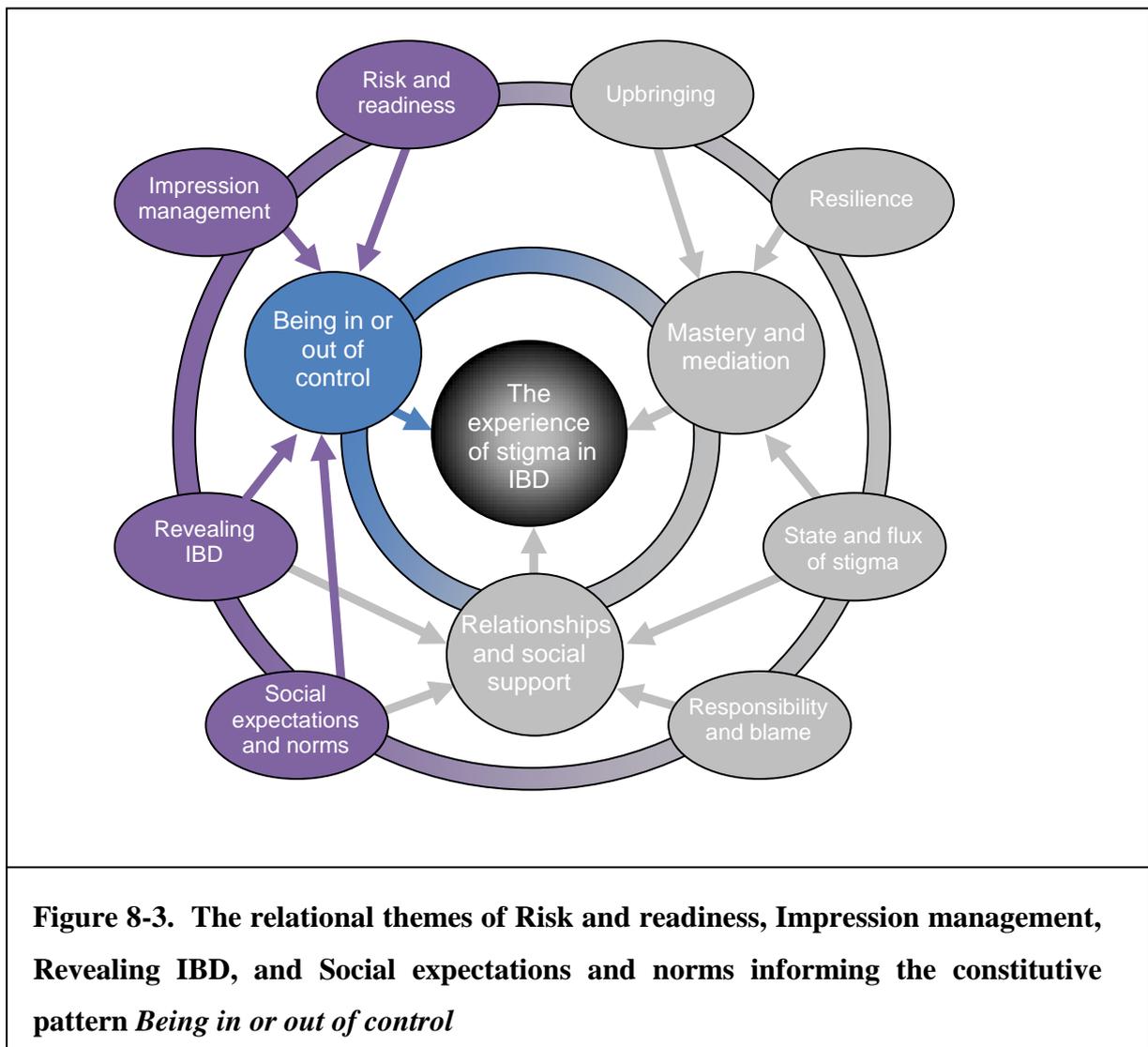
The forty interviews took between 10 and 120 minutes. Most participants spoke freely, apparently welcoming the opportunity to talk openly about their concerns. Some needed encouragement, but once reassured by verbal and non-verbal responses, seemed to relax. A minority were quite guarded and despite prompting, were not forthcoming. The most challenging interviews initially were with those who had assigned themselves to a *no stigma* sub-group. It was difficult to discern why people didn't feel stigmatised, without suggesting that they should be. The introduction of the trigger question: 'Tell me about how your IBD makes you feel' largely resolved this 'no stigma' difficulty as subtle influences on stigma resilience and resistance were revealed; the quality of all captured data also improved. 24 participants (60%) self-identified as not feeling stigmatised although interviews revealed that their stigma status was rarely static.

In reporting findings, verbatim quotes are identified by the participant's pseudonym, age and diagnosis, for example: [Katrina, 48, CD]. My voice is represented **in bold**. As recommended, existing literature is incorporated in the interpretation and representation of findings (Diekelmann 2001).

8.3. Constitutive pattern: Being in or out of control

The constitutive pattern *Being in or out of control* refers to the presence or absence of physical and emotional control of bowels, illness and life. The pattern unites the relational themes of *Risk and Readiness*, *Impression Management*, *Revealing IBD* and *Social Expectations and Norms* [Figure 8-3].

Participants described a wide range of situations and influences which contributed to or challenged their ability to be, or feel, in control of their IBD. People could have physical control of their bowels, but not feel in control of their illness: 'My whole life is controlled by it, you know, every day I'm under this control of whether [I'm near] a toilet.' [Sharon, 61, CD]



Alternatively, participants could feel in emotional control despite loss of physical bowel control leading to incontinence, when even an illusion of control was beneficial:

For me, and it always has been, the more I know, the more power I have over my disease. And even if that is purely an illusion of power, it helps. I don't care if it's an illusion or not. The more I know, the better. [Andrea, 47, CD]

Emotional control of illness and bowels, regardless of actual degree of physical control, related to how stigmatised participants felt. There was no apparent relationship between disease severity and sense of control - some with mild disease or very infrequent bowel control issues could struggle to gain emotional control of their IBD, whilst others with

severe and debilitating disease or frequent faecal incontinence could feel firmly in control. Achieving a sense of emotional control was dependent on reducing risks, preserving and presenting a positive image of self, managing the release of sensitive disease information to others, and navigating social expectations about bowel control. Positive management of these aspects, presented below in the relational themes, enabled the reduction of, and resistance to, stigma.

8.3.1. Relational theme: Risk and readiness

Unpredictability and uncertainty are well-reported concerns in IBD (de Rooy et al. 2001; Drossman 1991; Stjernman et al. 2010), the day-to-day variability of the disease making it difficult to adapt to. In chronic illness this adaptation, often termed 'transition' (Kralik and van Loon 2010), requires successful negotiation from a previous to a new identity through adjustment to a new way of living. Rather than becoming accustomed to a reliable set of consistent symptoms and developing trusted mechanisms to cope with those, people with IBD are faced with a wide range of variable symptoms, including changing rates of urgency (rapid need to empty the bowel) and frequency (frequent need to empty the bowel). These unpredictable symptoms increase the risk of being exposed, taking the individual from being discreditable (with a hidden mark), to discredited (the mark has been revealed).

Dealing with the unpredictable need for the toilet which could lead to incontinence was reflected in the theme *Risk and readiness*: participants either had a plan of action in case of a bowel accident and coped well, or did not. *Risks* were identified as potentially revealing symptoms such as foul-smelling or noisy wind or unpredictable bowel actions, whilst *readiness* was a reflection of their ability to manage that risk:

[My husband] knew immediately what had happened, but my friend had no idea. And I was thinking, 'Thank God I've got dark coloured trousers on, it's dark, or darkish, and I just hope I can walk home without going past anybody because I stink, literally,' so I could literally come home, walk straight through, go to the loo, strip myself off and clean myself up. [Juliet, 52, CD]

Juliet was able to manage the risk being exposed by her incontinence because she was able to hide the event with dark clothes, in a dark evening. Her husband provided additional cover for her by maintaining social contact with the accompanying friend, while Juliet went on ahead to their home.

The unpredictable nature of symptoms increased risk, as participants could not guarantee that their bowels would behave in a socially acceptable manner. This uncertainty either resulted in acceptance or avoidance of risk, where risk refers to the potential to be discredited in public. The disruptive effect of symptoms affected other family members when uncertainty could prevent people from leaving the house:

I do restrict [my family's] lifestyle and ability to do things, because there are certain things that I either don't do it, I resist or if I agree to do something and I'm having one of those sort of 'I don't think I've cleared my bowels this morning properly, and I'm pretty sure I'm going to have a problem,' I then become agitated and can resist doing things or being hurried up, because I'm just conscious that I'm not right. [Peter, 56, CC]

Where risk was accepted, people developed plans to address this, thus being in a state of *readiness*. Strategies included carrying a 'clean-up kit' (spare clothes, wipes and creams) with them everywhere as well as keeping these essentials in significant places (car, workplace) and wearing panty liners to catch leakage. The latter was considered less than effective as these are not designed, either in shape or function, to absorb stool. Another option was simply to stay at home until the morning cluster of bowel activity had passed: 'I know how my body works, I don't leave the house for the first couple of hours after I get up, to let everything go past. Then I'm usually okay.' [Katrina, 49, CD]

Toilet-mapping refers to the practice of plotting the location of toilet facilities in new locations, when planning journeys, or when accepting invitations. The sense of emotional control is increased when the ability to avoid loss of physical control, and therefore exposure, is enhanced:

So I get up two hours earlier before I have to set off, and then prior to setting off, the day before or whatever, I plot all the service areas. And then going through [city], I plot hypermarkets, anywhere and everywhere I can potentially stop if I have a problem. [Peter, 56, CC]

Adopting these readiness strategies created a sense of control. Having an action plan in place in case of an urgent or unpredicted bowel event reduced the risk of exposure and of being discredited. Others reduced risk by ensuring that they procured the support of people who would be able to assist should the IBD be troublesome whilst out:

If we go on holiday and for argument's sake, you are going on a day's tour, I always tell the guide or whoever it is, 'Look I've got this problem, when I've got to go, I've got to go, there's no 'well we're going to stop in 20 minutes for a toilet rest,' it's there. And I work on a similar thing – so all my friends over the years, I've made them aware of the situation. And any one, if I go anywhere who I think should know or would perhaps be able to assist me should I have that need, I tell them as well. So everyone's in the know, as it were. [William, 72, UC]

William did not feel stigmatised by his regular incontinence, and felt that that the more people knew about IBD and understood it, the less stigmatising it would become for others. Study participants thus might not have had very good physical control of their symptoms or bowel, but could feel emotionally in control of their situation. However, even diligent planning could not overcome the unreliable nature of the disease, so that the risk of being exposed, of being discredited, could be ever-present:

It's the unpredictable nature of it. If I knew that something I'd eaten was likely to cause me a problem; if I knew that whatever set of circumstances, then, you know, I would – panty liners, spare underwear carried with me, all of that no matter how awful it might be, at least I'd be prepared. But the fact that it [incontinence] can happen when I'm not going through a period of having diarrhoea, when everything is as settled as it ever is, takes you by surprise. [Andrea, 47, CD]

Where risk was not accepted, people either did not develop strategies or plans, resented having to know where toilets were and having to carry a clean-up kit all the time, or avoided actions which might help them gain control. Vera, for example, had been advised by her consultant to take Loperamide, a drug which reduces gut motility so that stool stays in the bowel longer, more water is reabsorbed, and stools are firmer. It is a common strategy used effectively by many people with IBD. Loperamide would give Vera more bowel control, reduce the risk of incontinence and enable her to leave the house with less worry. When asked if she followed her consultant's advice, she replied:

No, not very often. I don't like ... I'm on enough medication. I don't like taking them, I don't want to become constipated. I don't want to go to the other extreme either. I mean I have, I have done [in the past] – but I haven't done that probably for a year. [Vera, 68, CD]

Vera was very concerned about others' impressions of her. She worried about being 'found out' if she was incontinent in public, convinced that people would think less of her. By resisting the advice offered, her struggle to control bowel activity continued and she remained, in her own words: 'Trapped. I only feel really secure in my own home.'

8.3.2. Relational theme: Impression management

People present themselves in public situations according to what they hope to achieve by their interactions with others (Goffman 1959). Goffman described these behaviours as *impression management* - the language, props and strategies people use to give the intended impression to others. Impression management involves controlling actions, symptoms or behaviours which can discredit, acting specifically to avoid discredit, and deploying covering tactics (Goffman 1963a).

In this study, *impression management* and the representation of self that participants projected to others influenced their sense of control over their situation. Except for a very few participants who were assuredly unconcerned about what others might think of them, the desire to be perceived positively meant that maintaining a good impression of

self was important: 'I'm not saying I want to be seen as perfect but I don't want to be seen as quite imperfect' [Vera, 68, CD]. Some might hide their condition in order to avoid doubts about their competence:

I guess working in the City as I always have, there's also the desire to be seen to be capable. It's an environment where you're expected to work at high levels of performance and you don't want people to be suspicious that you might not be capable. And so if you don't have to put such suspicions in people's minds, then why bother? [Lawrence, 52, CD]

Lawrence [*No FI, no stigma*] felt firmly in control of his IBD, yet his belief that others' perceptions of him and his abilities would be adversely affected if they knew of his disease reflects his awareness of the potentially stigmatising nature of IBD. Even if colleagues were aware of illness, the need to give a good impression remained. Juliet explains:

I'm lucky because I'm the boss. But that has its own implications ... you feel when you're in a leadership role, you have to be hard on yourself in a different way than you would other people. So I might leave early but I wouldn't take it off as sick – because you're the boss, you think, 'Well, I can't let people down.' I can't be seen to be taking too much time off, you know, it's important that I set a good example. And you're seen to be in control as well, that's quite important. People feel very uncomfortable if the boss isn't in control of stuff. [Juliet, 53, CD]

Giving a good impression meant avoiding drawing attention to the illness, the symptoms, or treatments. In considering his perceptions on injury caused by his motorcycling passion, or issues relating to his IBD, Kevin explained:

[Friends would] happily come and visit us in hospital if I did break an arm or leg, but I prefer not to see people if it's something related with me stomach or Crohn's disease. Even going to hospital for outpatients appointments or going for the colonoscopy, I dread asking someone to be there ... if they do ask us, even if I've been bad, I'll say, 'Oh yes it's okay, just routine things.' [Kevin, 35, CD]

Kevin [*FI, no stigma*] adopts strategies to avoid being exposed as different. He explains that he ‘passes’ up opportunities to speak honestly about his illness even if asked directly about it, and refers to the influence of cause on perceptions of illness. The implication is that a broken limb caused by a motorcycling accident - perhaps a more macho and thrilling endeavour - is more socially acceptable and less stigmatising than any bowel-related illness. Passing means that people don’t have to reveal their condition or the incontinence or investigations that can accompany it, thereby maintaining a positive impression of self and avoiding potentially stigmatising responses:

I don’t talk about my illness to anyone. A lot of people would never know that I suffer from what I suffer, I don’t talk about it, you know. I just won’t, I don’t say anything to anybody because I just think, I don’t want to go into the bit, you know, where I have trouble with the toilet. [Sharon, 61, CD]

Passing deflects the critical gaze of others away from the secret that threatens to expose, to discredit, to show someone up as less capable, civilised or desirable than they first appear to be, but as Carlisle (2001) and Quinn and Chaudoir (2009) explain, concealing a stigmatising identity can have a negative impact on psychological well-being and health, as the fear of eventual discovery may be compounded.

Maintaining a good impression is also about ‘covering.’ Covering differs from passing in that instead of passing as normal by not taking presented opportunities, the individual purposefully offers alternative information to deflect attention from the truth:

So what I will say is I’ve got Crohn’s and they will say, ‘Well what is that?’ And I’ll say, ‘Oh it’s irritable bowel syndrome.’ And most of them go, ‘Oh yes, yes,’ as if they’ve heard of it, but they’re not really sure what it’s all about and they don’t bother to question me anymore and I don’t give any more information. [Belinda, 55, CD]

Although IBS has historically been viewed as a stigmatising condition, mainly due to its perception as a psychosomatic illness (Dancey et al. 2002; Letson and Dancey 1996), Belinda sees this explanation as more acceptable than revealing the truth about her IBD.

By describing her disease which is not well known as another which is more familiar, Belinda feels able to give an impression of self in a more acceptable light. She may also be taking advantage of knowing that others, perhaps due to embarrassment, are unlikely to reveal their ignorance by asking for more detail.

Impression management could be described as a process of ensuring that positive labels are applied to oneself – that you are seen for the person that you want to be seen as. Withholding disease information could promote positive, and avoid negative, labels:

I don't tell many people that I have Crohn's colitis – I think once you start telling people that you have something, people don't understand what it is, a lot of people don't understand what it is and they look at you like you're a sick person and I don't want to be looked at as a sick person. I don't want people to judge me or label me. [Tamsin, 38, CD]

Tamsin [*No FI, stigma*] implies that her perception of a sick label as a negative one would inevitably lead others to make negative judgements about her as she fails to meet the social expectations of what and who she should be. She is 'thus reduced in our minds from a whole and usual person to a tainted, discounted one' (Goffman 1963a:12).

Passing or covering behaviours may increase the sense of emotional control in IBD because disease information is kept hidden, but difficult symptoms of loud offensive-smelling wind and urgency can threaten the projected impression and compromise control. Charlotte has extreme urgency following a massive bowel resection that has left her with short bowel syndrome and permanent, urgent diarrhoea. She explains what happened when she had to access toilets on a local building site:

[The men] stood outside the toilet while I was in there, so they could listen to everything I was doing. And I just, I crawled out of [there], because it's noisy, it's noisy, it's loud, it's noisy and it's obvious what I'm doing. I even turned the taps on. I flushed the toilet as I'm doing it. I tried every trick but you can't [hide it]. [Charlotte, 37, CD]

Similar concerns have been demonstrated in relation to urinary symptoms of frequency and urgency (Elstad et al. 2010) or having an indwelling catheter (Wilde 2003), which do not expose the problem directly but potentially stigmatise by drawing attention to urinary control difficulties. In the same way wind, odour and noise herald bowel control problems. However, participants who viewed urine as less stigmatising than faeces, preferred to create a cover by pretending that they needed to pass urine a lot, rather than revealing that the toilet visits were for bowel needs:

I've managed to hide [my illness] for - I'd say - about three months into each relationship. Then it's obviously got to a point where I'm going to the toilet that much, but I always say it's a weak bladder. I say, 'God, I've been drinking loads of tea, I need to go to the toilet,' and I can see him looking at me, thinking, 'you've just been two minutes ago.' [Marion, 37, UC]

Projecting an acceptable impression is so compelling that some will avoid actions necessary to control the consequences of symptoms, even though inaction may risk exposing them later. Suzie explains why she doesn't queue-jump to use public toilets:

There's that fear that somebody is going to say something, or you know, if you absolutely have to go [to the toilet] right this minute, it's the fear that somebody is going to look at you as if to say, 'Well, you don't look ill enough to me to go to the toilet now, why are you, why are you not waiting in the queue like everybody else?' And I rarely do, I tend to, even if I'm bad, I will tend to try and hold on and wait in the queue like everybody else. [Suzie, 23, CC]

Suzie's comment highlights the importance of adhering to the social rules (waiting in the queue) because this prevents her from being singled out, exposed or marked as different, and reduces stigma. Yet in succumbing to the social expectation to 'wait her turn' there is an increased risk of later, perhaps more dreadful exposure if she does lose control and is incontinent, so increasing stigma.

As well as modifying behaviour in anticipation of other's responses, *readiness* actions may be adjusted as a direct result of others' attitudes:

In recent relapses I've been considering taking a change of underwear and things like that just in case, [but] I remember that a few years ago, somebody, one of the office managers was clearing out, somebody had left, I think, and they hadn't cleaned out their desk. So they cleaned out, sorted out their drawers and things. And they found a pair of pants in somebody's drawer and they were taking the Mick out of it. And that's always played on my mind a bit really. So then I think, okay if I do take underwear, where would I keep it? And how would I conceal it if I took it to the toilet? [Jacob, 34, CC]

Jacob recognises the need to be prepared to reduce risk, but feels that the strategies he wants to adopt may draw unwanted attention and be stigmatising if revealed. He ends with the question of how he would cover to protect himself against ridicule from work colleagues if he needed to use his spare underwear at work.

Regardless of the subgroup of *incontinence / no incontinence* and *stigma / no stigma* that participants had self-assigned to, many commented on concerns about giving, or needing to give a good impression by attempting to conceal symptoms or consequences of disease. Some people were happy with this and managed it in a matter of fact way. Deirdre, not bothered by her inability to prevent herself from passing wind but with a deep concern that she might smell, had found a way to cope:

I carry a little air freshener in my handbag if I'm at other people's houses, so I can spray now. But before I discovered this little spray, [wind] was a problem, yes, because it's smelly as well. [Deirdre, 57, UC]

Tina [*FI, no stigma*, 45, UC] had developed a plan for obscuring the sound of her noisy bowel actions: 'we had the builders here, so I had a radio in the toilet which I put on loud. I would switch it on so that it made loads of noise so that nothing could be heard.' The need to cover her noisy bowel actions with loud radio noise could indicate that Tina does feel the potential to be stigmatised. By masking her symptoms from others who might disapprove, Tina protects against stigma perhaps by taking the initiative to prevent a problem that could arise, rather than fearing that it may, and being happy with her plan.

Some participants were very concerned about being exposed. For example, Carl worried about people knowing or seeing that he had a stoma, so would wear extra layers of clothes to conceal it. Carl explained that he knows his stoma is not visible to others and the stoma bag he wears to go out is very reliable and does not leak, yet he still feels stigmatised, suggesting other factors may also influence stigma creation. Other participants were concerned that they would be exposed by noisy and smelly wind, or by visual evidence of incontinence - those who did not mind their friends *knowing* they had a problem with bowel control, did not want them to have *seen* evidence of it:

Thankfully, [it's] rarely that I get incontinent, but it could be that we've just gone out for a walk on the headland and I can't get back in time. So mainly, it's just been me and [husband]. It's not happened when I've been in company ... it's never been an issue when I've been in company – but everybody I know, knows. [Carol, 64, CD]

Carol's comments underline the importance of concealability. Study participants concealed on several levels – from telling no-one that they are ill with IBD, to making practical efforts to conceal symptoms of FI and of noisy odorous wind and bowel actions, to revealing information about IBD but ensuring that friends see no evidence of it. Jones et al. (1984) identify concealability as one of six dimensions of stigma which contribute to how stigmatising a mark becomes. These study findings suggest that physical control of symptoms increases concealability, and emotional control enhances a sense of psychological containment of IBD, so reducing stigmatising experiences. William [*FI, no stigma*] explains:

If it [bowel control] was something I could turn on and off, and, you know, if it was something you could control, then perhaps you might say, 'Well, I shouldn't have done it here.' But if you can't control it, there's nothing you can do about it, I don't see why you should be ashamed about it. There's nowt I can do about it, I mean it doesn't matter how good or bad you feel about it, about what I've done, I've not done it deliberately, it is just, it's a fact of life. [William, 72, UC]

William [*FI, no stigma*] does not feel responsible for his incontinence enabling him to view himself positively with his disease. In contrast Carl (see previous page) [*FI and stigma*] was struggling to adjust psychologically to his stoma, and whilst he could physically conceal it from others, he had little emotional containment of his situation.

Study participants gave no indication that it would be acceptable for others, especially social contacts or members of the public, to witness physical evidence of IBD, but not everyone was concerned about concealing information about their illness, feeling that more support is forthcoming from friends when they know:

You don't just go round talking about it willy nilly, but if you know, I've had a flare up, and I've had to say, 'Oh, I can't come because of this,' then they're fine about it, you know, they understand. [Vivienne, 52, UC]

Sharing disease information increases a sense of control by removing the risk of being unexpectedly exposed. It also increases wider public knowledge which, eventually, may lead to a greater public understanding of IBD, an issue which is addressed in greater detail in Chapter 9: Findings (ii) - ***Relationships and social support***, along with the role of partners in enabling resistance or submission to IBD stigma.

Although many participants portrayed supportive relationships, there were aspects of their illness, or incontinence, which some concealed from intimate partners and family:

Sometimes if I haven't quite made it to the toilet, I'll slip me pants off and put me trousers back on and then just kind of wrap them up and put them in me pocket until I get to the laundry basket. And that's even like at home sometimes. I don't know why I hide that little bit, but me husband knows, and the girls, I think the girls know it happens, but I don't think they know it happens quite as often as it does. [Tina, 44, UC]

Tina's [*FI, no stigma*] practise of hiding 'that little bit'- the visible evidence of her incontinence - underlines the cultural expectations to keep toilet matters private and suggests that, even in what was portrayed as a very positive, supportive family, some

things should not be revealed. For Andrea, concealment meant not only hiding evidence of incontinence, but also the truth about the extent of incontinence from her partner:

I think [my husband] had a rough idea. I think he knew without me having to tell him, more or less, probably not the extent of what happened ... he suspects it may have happened, I'm pretty certain. But if I tell him that, it's going to be more clearly in his head, and what if he thinks that it might happen at an intimate moment, and that changes everything again, you know? It's about how he views me - it feels like it knocks another edge off my attractiveness. [Andrea, 47, CD]

I probed further with Andrea to explore the likelihood of her husband really not being aware of her incontinence, if their relationship was as close as she had previously claimed. I was prompted by my experiences of openness and sharing fully within my own relationship, and not being able to imagine hiding such a difficult problem from my partner. What emerged was a sense of unspoken complicity between Andrea and her husband to avoid verbalising the extent of her incontinence, as if this in some way made it less real. By giving an impression of control, Andrea felt that she limited the impact of her condition on other family members, and reduced their worry burden about her. Andrea's interview, with my annotations, is presented in full in Appendix 8 [p. 385].

Achieving actual physical and emotional control, or projecting an image of control to maintain a good impression, can contrast with the unique challenges presented because of the invisibility of IBD. In the absence of symptoms like incontinence, the illness is often not obvious, leading others to make incorrect assumptions:

People don't, they don't understand, they don't know what Crohn's is. I've been in hospital for a month. [My daughter's] swimming coach came to see me last week, and [daughter] heard her saying to another of the coaches - 'Well, I don't know what she's in hospital for, she looks fine' ... and that is my biggest problem, is that I do look fine and especially when I've had the steroids and obviously you put weight on, and people think, 'She looks really well, she's been eating loads.' [Tamsin, 38, CD]

When illness is not immediately obvious, and the public expects to see evidence of illness or disability to prove it is there, it becomes difficult to avoid giving the wrong impression:

When I first got diagnosed, I did really struggle with what's going to happen to me, but also what are people going to say about me and think of me. I think, not in terms of the symptoms, not in terms of kind of the diarrhoea and flatulence and all the other, you know, really sexy stuff! But more kind of with me as someone who had something, had a condition that's technically a disability, but that people can't see. I was really worried that people are going to think that if I did take a day off work, I was making it up, because they couldn't see that. [Esther, 24, CD]

The mismatch between disease reality and public expectations of illness contributed to participants' perceptions that others viewed them as frauds for claiming social benefits if they were neither wheelchair-bound, nor able to demonstrate visibly why they only worked part-time or not at all. Despite not wanting to witness the grim realities of many disabling conditions, the public apparently expects to see evidence of disability in order to verify claims of incapacity. Disability tends to be interpreted somewhat narrowly as 'an inability to walk'- a status which is expected to be consistent, and is represented universally by a stylised symbol of a person in a wheelchair. Green (2009) addresses the role of technology in minimising the disability caused by HIV, mental illness and substance misuse, while the image of Oscar Pistorius (the 'Blade Runner') on the book's front cover highlights the extraordinary advances in mobility that technology has enabled. The wheelchair may become a redundant symbol of disability but currently it is the standard by which the public, and disability assessment procedures, gauge physical ability and consequently eligibility for social benefits. Poor public knowledge about disability and disabling chronic illness challenges the impressions people give of themselves and contributes to their concerns about the way they are perceived:

It's that lack of knowledge rather than anything else which makes me feel like people don't understand what it is that I'm going through. And ultimately I do look well, a lot better I'm sure than a lot of other patients with Crohn's or colitis. And so that too doesn't help. [Suzie, 23, CC]

Suzie's comment refers to the stigma that comes from others' ignorance, and arises when someone claims to be ill but looks well because the disease is hidden. For a few participants, concealability of their illness was a benefit because it meant there was nothing to explain, people didn't know about it and no-one else need know:

I don't think I show much effects [sic] for it, or it really doesn't affect my life too much. It's hidden really ... and I don't feel stigmatised because I don't think it's obvious - people don't really know about it. [Jason, 48, UC]

Jason [*FI, no stigma*] later concedes that while he can conceal his IBD and so present a positive impression of self to others because his disease is mild and well-controlled, he might well feel stigmatised if it were less predictable and more risky. Jason has more physical and emotional control than might be achievable by those with more active, troublesome symptoms. Belinda confirms the inter-relationship between concealability, impression management, and stigma:

It's not something that you can visually see. It's obviously something that I experience [but] I plan myself, I plan my routine and my schedules around my bowel habits, literally. I don't feel stigmatised about it because nobody else knows that that's what I'm doing. [Belinda, 55, CD]

Because Belinda is in control of the consequences of her IBD no-one beyond her immediate family, knows; she maintains a positive impression of self towards others and does not feel stigmatised. Choosing not to reveal disease information seems to differ fundamentally from being exposed by symptoms which take that choice away:

[Invisibility] makes it quite convenient doesn't it really? Nobody knows if you don't want them to know. If you don't want anyone to know, then they don't have to know. It's not really obvious, not like a physical disability. [Aileen, 58, CD]

Those participants who were happy with the invisible nature of their illness retained both physical and emotional control over disease and were thus in control of the impression of self they projected to others.

8.3.3. Relational theme: Revealing IBD

How people felt about the invisibility or concealability of their disease guided the decision of whether, when, how and who to talk to about IBD and the symptoms that can accompany it, and the reasons for doing so, or not. Where *Impression management* focused on containing aspects of the disease that might affect the impression of self presented to others, *Revealing IBD* addresses the controlled and purposeful choosing to reveal or conceal IBD information. *Impression management* is a defence strategy, whilst *Revealing IBD* is a proactive affirmation of self. *Revealing IBD* is akin to the ‘coming out’ of gay and lesbian people, a process perceived as necessary in developing a sense of identity, positive self-image and self-esteem (Chaudoir and Quinn 2010; Jordan and Deluty 1998; Nay et al. 2007). Comparisons between coming out about sexual identity and coming out about illness have been made in relation to mental health (Corrigan and Matthews 2003), depression (Ridge and Ziebland 2012), Alzheimer’s disease (Watkins et al. 2006), obesity (Saguy and Ward 2011) and impotence (Anon 1999), and in a single reflective case study on IBD (Myers 2004). Coming out may be beneficial to anyone with a sensitive disease identity, especially in ‘hidden’ conditions where the individual risks being unintentionally exposed by a bodily malfunction such as incontinence or an epileptic fit (Quinn 2006).

For some participants, being ‘up front’ about IBD was part of their strategy for reducing risk and being ready. Some felt it better to be open because then help could be obtained when needed thus adding to a sense of control, whilst for others, sharing information about IBD was their way of educating others:

I’ve got to the stage now where I am quite happy for people to know, because the majority of them know nothing and I want people to know because there are so many people who are hiding it and don’t seek the support and help that’s available to them. [Maeve, 65, UC]

Maeve [*no FI, no stigma*] reinforces her sense of self, and her control over her colitis, by confidently sharing information about IBD for the benefit of others. However, many people explained how they shared information selectively, when necessary, and often

for a specific purpose. Charlotte [*FI, stigma*] who was largely housebound due to the severity of her urgency and frequency, described negotiating with her daughter's school to enable her to participate in an event at the school, despite the challenges it presented:

But recently, I had to do a course, 'Stay and Learn,' you actually spend the morning with your child, the whole morning. And I had to go at quarter to nine until half past twelve. And I was like, 'What am I going to do?' But I did go and see them beforehand and explained [to the] parent liaison teacher. So I went and saw her ... She said, 'Don't worry,' and they actually changed the classroom round for me to be by the door. [School] were brilliant. But now [the liaison teacher] looks at me, it's as if, 'I know what you've got.' [Charlotte, 38, CD]

Despite her personal concerns, Charlotte chose to reveal her illness and difficulties to enable her participation in this school event with her daughter. Her final remark illustrates her belief that the liaison teacher now thinks negatively about her because of her condition, adding to her sense of perceived stigma. Revealing her IBD secured Charlotte the assistance she needed and gave her physical control in that instance (by ensuring she had ready access to a toilet), but it also undermined her emotional control since she now feels she can do nothing about the liaison teacher's perception of her.

Others, who seemed more able to resist stigma, explained how revealing IBD was sometimes necessary to avoid misconceptions: 'You make a lot of effort to explain to people what is wrong with you, um, because if you don't then you will find that people will assume other things' [Lillian, 61, CD]. Leaving people to make their own assumptions places the person at the mercy of uninformed misperceptions, and Lillian implies that 'other things' means 'something worse.' Explaining relevant details enables the revealing person to exert some control over what others know and understand about IBD. My experience is that this approach is best focused on those with whom there are meaningful personal or social relationships, or for a specific reason such as explaining family structure to school teachers so that they appreciate the context of home life for my children. In this study, although some participants had concerns about how the wider public might perceive them, efforts would be made to inform people in closer proximity, with whom there were likely to be meaningful interactions. Carl explains:

I do [tell people], depends who they are, you know? People in the flats here ... they knew I was in hospital ... and when I came out I said I had Crohn's disease, you know, they don't know what it is. And I say it's the bowel and I've got a colostomy bag on and, you know, if I was friendly enough to talk to them, so they would know. It's not as if I'm hiding it, but that's to people you can talk to about it, [the problem is with] people you don't know that's walking down the street. [Carl, 54, CD]

Carl's comment highlights the relational aspects of stigma which can arise in some interactions and not others, so he chooses who he reveals disease information to. He later confirms this when he describes the ease of interaction when he attends hospitals for appointments: 'It's different with a professional person – I know they know about it, but in general people don't even know what a stoma bag is.'

A frequent coming out technique for gay and lesbian people is to use opportunities as they arise to reveal sensitive information (Orne 2011). We also found this to be the most used technique for revealing IBD in a recent study into the needs of gay and lesbian people with IBD (Dibley et al. 2014). In the current study, participants did not often initiate conversation about IBD, but would be honest if asked directly about the illness:

I just don't feel the need to suddenly come out with the fact [that I have UC]. I have no problem in telling somebody if they asked – I have no problem in telling them because it doesn't, how can I put it? – I don't mind them asking because, in a way, it doesn't – they don't see any symptoms of it. [Cheryl, 29, UC]

People with IBD control how and when personal information is revealed, or not. The ability to comfortably conceal disease information appears to relate to the severity of symptoms, with milder symptoms being easier to manage, both physically and emotionally, and perhaps also therefore easier to talk about. Others would take opportunities as they arose to educate people. In this excerpt, Philip has been challenged by men in the pub because he's only drinking a soft drink instead of a beer, so he makes the most of the chance to educate his fellow drinkers:

And I said, 'Well I can't.' And he said, 'Why is that?' And so I told him and then I gave him a lecture on what Crohn's was. And they actually went, 'Oh right I didn't realise it was as bad.' [Philip, 55, CD]

Legate et al. (2012) explain that there is no one rule for how, when and who to come out to. In the current study, participants had learnt to amend the way they gave information about their disease to different people in different circumstances, whilst others changed the amount of information they revealed according to the setting and their role in it:

So your level of comfort with people, the extent to which you share – I never make a secret of the diseases that I've got. But I don't thrust them down people's throats, 'Oh look at me, I've got this,' that's not what it's about. It's about enough information, so hopefully people will understand. And if they need to know something, I will tell them. But generally at work it's, you know, it's, I don't hide it, but I don't talk a lot about it either, because, because that's what I'm doing now, I'm working [Juliet, 53, CD].

Those who choose, however carefully and thoughtfully to reveal information about their IBD, do so to increase their sense of control over their situation, reduce the likelihood of misperceptions, and so reduce stigma. Previous authors have demonstrated that contact with, and education about, affected individuals with other health issues are central approaches in stigma reduction strategies, reducing the mystery of difference between groups (Corrigan 2013; Heijnders and Van der Meij 2006).

In contrast, some participants would reveal no or very little IBD information because of the nature of the illness. Marion [*No FI, stigma*, 37, UC] explains:

Other than the people who need to know, like a new partner or family, it's not something that I publicise, no. It's probably kind of because it's like, it's like the worst problem to have in that area ... it's your bowels and pooing, you know?

For Marion and others in the *FI and stigma*, or *No FI and stigma* subgroups, revealing their illness would only confirm others' negative perceptions and increase feelings of stigma, reflecting concerns that coming out may not always be beneficial (King et al. 2008; Legate et al. 2012). Coming out can rarely be undone once information is disclosed. The disclosing person concedes exclusive ownership of their disease information and then has little control over what happens to it (Bansal et al. 2010). This relinquishing of control may increase feelings of stigma through concerns about what unidentified others may think.

Some participants in the *FI, no stigma* or *No FI, no stigma* subgroups withheld IBD information not through fear or concern over potential reactions, but because they never share any personal information about themselves and their IBD is no different. Rory had mentioned that he didn't tell anyone about his IBD and, prompted by an appreciation that people often withhold information because they feel others will not receive it well, I asked him to clarify why this was the case:

I don't broadcast anything about myself really. So it's not that I'm specifically not broadcasting that. But I don't go and tell people, 'I've done this, I've done that.' In conversation, if it comes up, it comes up. But I don't offer information about anything in general to people. [Rory, 46, CD]

Rory's privacy about his IBD was prompted not by a sense of shame, or expectation of disapproval from others, but from the belief that IBD is private and something that others do not need to know about, and there is no need to create a problem (the reactions of others) which need not be there. Opting to reveal IBD is, like coming out about sexual orientation, a complex choice, and one which may be guided by the sense of emotional control it gives (Taylor 1999). Repeating the process and receiving positive responses enhances self-esteem (Chaudoir and Quinn 2010) confirming ownership of disease and increasing the sense of control. In this study, those who described feeling stigmatised either by disease or incontinence, also tended to conceal disease information because of concerns about how others might respond to that information.

8.3.4. Relational theme: Social expectations and norms

Participants' concerns about revealing IBD information may be affected by awareness of *Social expectations and norms*. The aspect of this final relational theme supporting the constitutive pattern of *Being in or out of control* relates to the social expectation that biologically mature humans have physical control over excretory functions. As Deirdre [57, UC] explains: 'People don't go round pooing their pants, do they? - unless they're very little children who haven't gained control yet.'

The human infant is born with no voluntary control over bladder and bowel. The natural pattern of evacuation is governed by a reflex arc between bladder, bowel and lumbar spine. In response to stretch sensors in the bladder and bowel respectively which indicate fullness, each reflex arc relaxes the relevant sphincters and contents are expelled (Ross and Wilson 1981). The attainment of control is both physiological and social. With physical development, the infant learns to interpret the 'fullness' signals of bladder and bowel and to exert voluntary control to over-ride the reflex arc. The acts of micturition (emptying the bladder) and defaecation (emptying the bowel) become controlled by the brain, but, in Western cultures at least, it is social training and expectations which drive the selection of an appropriate time and place for these actions (Norton and Chelvanayagam 2004). Human infants learn about such appropriateness through praise and reward delivered by parents in response to successful control, usually achieved at around two years of age for bowels, and between three and eight years of age for bladder. Marion [37, UC], reflecting the thoughts of some other participants, explains: 'So from an early age you're told you're a good girl if you go to the toilet on your own and you shut the door and this kind of thing'.

Simultaneous with biological maturation, the child's world is expanding beyond the home. Opportunities for social interaction and progress increasingly require competent control of defaecation and micturition. As the child matures, control is established and social enterprise increases. Reference to these bodily functions becomes increasingly silenced so that although everyone knows that everyone else opens their bowels and passes urine, these functions (particularly defaecation) are rarely mentioned. As humans age, bodily functions can become less reliable. Bladder and bowel control may be lost

due to extreme old age, degenerative conditions such as Alzheimer's, or reduced speed and flexibility of mobility which prevents people from reaching the toilet in time to avoid incontinence (Delvaux 2003). Tolerance of incontinence at each end of the life span is addressed by Andrea, who draws on her awareness of social expectations to illustrate why her own incontinence is unacceptable:

There are two times in your life when you are likely to be incontinent – when you are very young or when you are very old. There is a general societal understanding that those happen and that's age and nature when you're very old. The fact that you are old and may be doubly incontinent, just because those people are adults, we somehow excuse that, it's not unexpected ... that as people age, their bodies let them down and it may happen. I'm 47, I'm not expected to soil myself periodically at my age. It's something people wouldn't expect. And I think would be horrified by. Would certainly not know how to react, wouldn't know what to say. And I think they would be mentally backing away even if not physically, to be honest. [Andrea, 47, CD]

The negative response to inappropriate defaecation is universal (Tsagkamilis 1999), perhaps driven by genetic inclinations amongst humans to protect against biological harm (Curtis and Biran 2001), and by early socialisation which demands control. Almost all participants regardless of study subgroup membership perceived that poor bowel control or a bowel disease would not be acceptable to the general public – only Belinda was content to let others think she has IBS. Even those with incontinence who did not feel stigmatised and were able to resist stigmatisation, believed that the general public broadly views bowel diseases and disorders negatively.

8.4. Summary

The constitutive pattern *Being in or out of control* links together the four relational themes of *Risk and readiness*, *Impression management*, *Revealing IBD*, and *Social expectations and norms*. Aspects of physical or emotional control of symptoms,

information, or self, emerged separately during analysis but ‘control’ was a central thread, creating the link between themes. Across all transcripts, all participants referred to some aspect of control, uniting the relational themes with this constitutive pattern.

Within these four relational themes, those who had a more positive outlook, who accepted risk and were ready with plans in case of unexpected events, who were not afraid of others’ finding out about their condition, and who pro-actively shared disease information, appeared to have a better sense of emotional control over their disease regardless of their degree of physical control, and seemed more able to resist stigma whether or not they also experienced faecal incontinence.

In contrast, those who avoided making plans were more fearful of being exposed and of not giving the impression of self that they preferred to give, increasing their perceptions of stigma and the potential to be stigmatised. Those who concealed information about their disease due to concerns about how others might respond were also fearful of being exposed. The inability to maintain social rules about bowel control seemed to be meaningful for many.

In Chapter 9, different aspects of the relational themes of *Revealing IBD* and *Social expectations and norms*, and the new themes *Responsibility and Blame*, and *State and flux of stigma* are presented in connection with the constitutive pattern of ***Relationships and social support***. Findings and analysis for the pattern ***Mastery and mediation*** follows in Chapter 10.

9. Findings and analysis (ii): Relationships and social support

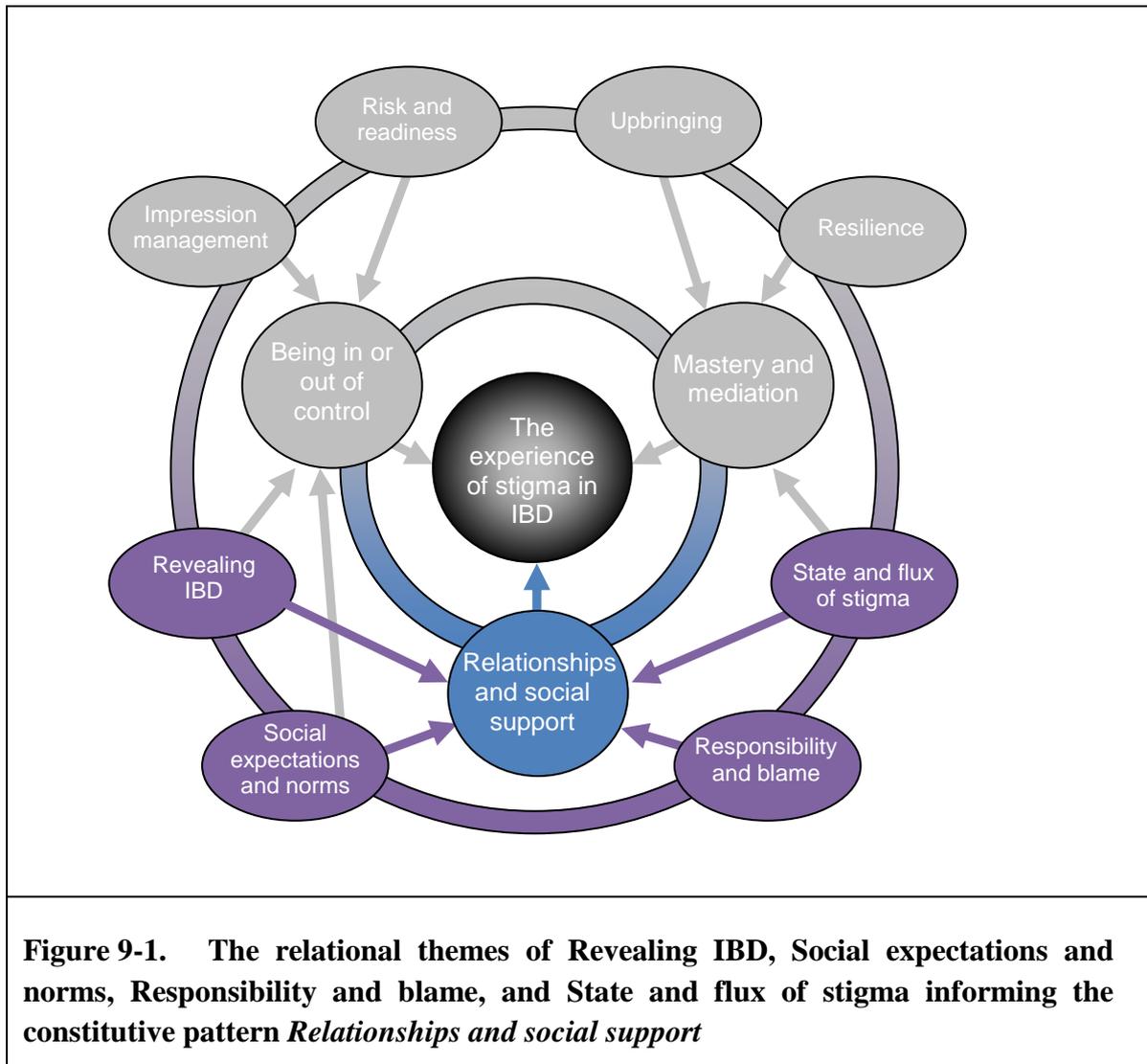
In the previous chapter, the constitutive pattern *Being in or out of control* and the four relational themes which inform it revealed the need to adhere to (or give the impression of adhering to) social rules in order to avoid discredit, emphasising the importance of interactions in stigma creation. This chapter addresses the relational aspects of stigma further. Goffman's assertion that the existence of stigma depends on the relationship between players in an interaction remains uncontested (Scambler 2009). The situation, circumstances, and personal contact in each social event are unique, often demanding different rules and expectations (Kleinman and Hall-Clifford 2009). People with a consistent stigmatising feature can therefore feel stigmatised in some situations - public or work settings, for example - and not in others, such as during hospital appointments, support group meetings, or with family members. Participants' interactions with others, the accommodation of their stigmatising identity, and the expressions of stigma they may encounter are the focus of this second constitutive pattern of *Relationships and social support*. Implicit in interpreting experiences is the understanding that what people construe as a stigmatising response or attitude towards them is perceived as such because they carry a discrediting or discreditable mark. Others viewing from a different perspective may perceive nothing extraordinary, discriminatory or stigmatising in an interaction which nonetheless generates stigma for the experiencing person.

This chapter presents the findings from analysis represented by the constitutive pattern *Relationships and social support* and its four relational themes.

9.1. Constitutive pattern: Relationships and social support

The constitutive pattern *Relationships and social support* unites the relational themes of *Revealing IBD*, *Social expectations and norms*, *Responsibility and blame*, and *State and flux of stigma* [Figure 9-1]. Participants described a range of experiences which enabled or inhibited their ability to build effective support networks, as well as

stigmatising encounters they had met with. There was no ideal type of support, but feeling supported by people able to give necessary help in a manner which met the individual's needs, appeared to result in the person feeling less stigmatised and being able to deflect stigmatising attitudes from others because they, and their condition, were accepted by those who matter most.



Relationships and social support refers to any connection the individual might have - social, intimate, with family, work colleagues or health care professionals - as well as more remote relationships with the public, and how these relationships are affected by IBD and stigma. There was no optimum type of support for people with IBD. Lindsey

verbalised the experiences of others who did not feel stigmatised, by explaining: ‘I think that does help, if you know you’ve got that network around you where people are supportive and understanding.’ What appears critical is that the person receives the support and care they need from those able to give it. Some, like Maeve, just need their immediate family and health care team:

[My] wonderful son checks on me every day to see that I’m okay. And [I have] wonderful medical people around me. My doctor said, ‘You know more than I do about your colitis, you know your body ... you [can] just ring me any time,’ he said, ‘You can have any medication that’s going to help you’... .. ‘What is it that you need, anything else?’ Absolutely fantastic. [Maeve, 65, UC]

In contrast, losing support could be the trigger for stigma to develop. Sharon [*FI, stigma*] explains what happened when her local IBD support group disbanded:

I wanted to be with other people that had got the illness and I wanted to learn more and during that time I never felt stigmatised because we had meetings where everybody had got the same thing, we were all working [together]. And then the chairman [gave] up and all the rest of us gave it up along with her. And now I don’t meet with anybody that’s got it. And I think from that point I’ve probably started to feel the stigma more. When I was with others and everybody was talking openly, I don’t know, I just felt differently. [Sharon, 61, CD]

Durkheim originally proposed that outsiders enable establishment of social norms by creating the contrast to the majority group, thus defining ‘normal’ as everything that outsiders are not (Falk 2001). People with IBD are outsiders, and their difficulties define the rules of control and containment by which insiders - everyone without bowel disease or poor bowel control - lives. When outsiders aggregate and create their own ‘normal,’ stigma can be overcome since everyone is similar and feelings of self-worth are enhanced (Crocker et al. 1998; Saylor 1990). Belonging and acceptance seemed meaningful in the relationships of these study participants.

9.1.1. Relational theme: Revealing IBD

The role of social support in reducing stigma and improving quality of life has been reported in connection with, for example, epilepsy (Whatley et al. 2010) and HIV (Colbert et al. 2010). Structural (specific sources of) social support is a key component in enabling people with chronic illnesses to make the transition to normalisation (Nicholas 2010). In the previous pattern of *Being in and out of control*, *Revealing IBD* referred to the deliberate sharing of IBD information to avoid misunderstanding. In this pattern of *Relationships and social support*, it focuses on revealing information about illness or about bowel control to help develop supportive relationships by enhancing others' awareness and understanding of the disease. Concealing information seems to restrict the development of an effective support network.

In this study, relationships with intimate partners were often crucial to coping with IBD long-term. Jacob [*FI, no stigma*] explains the need for complete openness with his wife:

My wife is my main support really, total support. I think you've just got to be up front with it really, you know ... it was, it is pointless to try and hide something like this, especially if you want to be with them, with a partner, for a long time.
[Jacob, 34, CC]

This could be interpreted simply as a strategy for coping with the illness, rather than counteracting stigma, but the point lies in the importance of having family 'on your side.' Despite identifying himself as not feeling stigmatised, Jacob had expressed concern about work colleagues discovering his clean-up kit at work, expecting this to bring a negative response [see Chapter 8.3.2, p.138]. The implication is that any stigma he might feel can be overcome because he has his wife's unconditional support.

Support from intimate partners and family cannot be taken for granted. Some participants who did not now feel stigmatised explained that it had taken time for their family to understand. Lily [*FI, no stigma*] suggests the delay may have been caused by her failing to reveal the full impact of her IBD:

I think I struggled with my close family at first because I didn't want it to look like I was making a mountain out of a molehill ... and I think they underestimated the impact Crohn's could have on your life. [Lily, 36, CD]

Lily's secrecy was perhaps influenced by an upbringing in which there was little family empathy for illness or any indication of it; she was not expected to make a fuss about what were largely believed to be minor issues. To avoid being thought less well of, she hid the truth about her IBD until she realised she needed her family's support. While others needed practical help and support to deal with incontinence, for some, the acceptance of the situation by their partner was sufficient. Lawrence [*No FI, no stigma*] had previously explained that he has not mentioned his IBD at work to ensure he gives a good impression of self. He is, however, completely open with his wife, implying that her understanding is fundamental in enabling him to avoid feeling stigmatised:

As far as my bowel habits, the only other person who 'suffers' from that is my spouse. And I've got a different, a totally different relationship with her than any other person. So it's simply not a problem. She understands. [Lawrence, 52, CD]

Partner support was not always forthcoming. Although no longer feeling stigmatised by her disease, Maeve originally struggled with the attitude of her now-deceased husband who, in refusing to recognise her IBD-related problems, silenced her and compounded her feelings of stigma:

I almost felt guilty when I couldn't do the things he wanted me to do. I couldn't go on long walks – I couldn't – and he would, 'Oh for goodness sake, do I have to go past another loo?' And when I was feeling really ill, he would say, 'Have you thought about what's for lunch?' And [I would think] I don't care what's for lunch, I don't even feel I want to see food.' [Maeve, 65, UC]

Kevin [*FI, no stigma*] sums up the interpersonal relational aspects of stigma. He was living with his brother at the time of the interview, and I asked him if he had a partner:

K: No, no, and it's something I wouldn't even have thought about back then.

Because of the Crohn's?

K: Yes, because of the Crohn's. It was, I don't know how to put it in the terms of embarrassment, but yet again it was something that – if I did have the [stoma] bag, I think it would have been a lot worse. But even though I didn't, it's something – I know it's fine to talk to doctors and nurses about it. But strangers, it was, it was a little bit more embarrassing as well speaking to people about it. You possibly would like to have a laugh and a joke about it, but it was all sort of brushed under the table really. But I wouldn't – I suppose I've never really had that many girlfriends anyway, but I wouldn't have had a girlfriend back then, definitely not. [Kevin, 34, CD]

Kevin suggests that he has felt stigmatised in some relationships. He makes it clear that speaking with doctors and nurses is not at all problematic, but 'embarrassment' resulted in him not revealing his IBD to others, and not having a girlfriend. This interaction between embarrassment and stigma has been discussed earlier [Chapter 2.4.1, p. 25]. In some relationships, concealing the realities of IBD with partners and family was presented as a means of protecting others:

There are things that I don't tell my family and my partner because I don't want them to worry more than I know they already do. They really do, you know, I mean he [husband] knew me – we'd been together barely a year when I was first diagnosed. So he's been through a lot of it. And people not knowing what to do and what to say - it's mostly about protecting myself, but yes there is an element of stopping other people [worrying]. They already have this package of worry about me that they carry. I don't want to make it any heavier. [Andrea, 47, CD]

Andrea's [*FI, stigma*] reluctance to reveal IBD is presented as a means of protecting cared-about others, but this statement suggests this is a minor element of her decision – her main intention is to protect herself from stigmatisation. Andrea viewed her husband's apparent ignorance of her situation and his compliance in not asking for more information, as supportive in itself.

Even in relationships where everything else is shared, an inability to be open with a partner about IBD is isolating. Vera [*FI, stigma*, 69, UC] hides her incontinence from her husband:

I get the impression, from the way that you said, ‘I haven’t told him about this,’ that normally you tell, you share everything otherwise?

V: Yes, yes.

Okay... so why can’t you tell him about this?

V: I don’t know, I can’t be that honest. I can’t be that honest. I don’t know whether, he may well guess, he may guess, I don’t know ... and he doesn’t want to make me feel more embarrassed than I already do. He’s not one who wants to know about health issues, I suppose, and I think well, if I can cope with it, I will. But I don’t always cope with it.

It seemed that Vera’s reluctance to admit to incontinence was what prevented her from being more open with her husband, but she excuses herself from doing so by explaining that ‘he’s not one who wants to know about health issues’.

Knowing a partner’s previous response to ‘bodily dirt’ affected concerns about what could happen due to IBD. Janice [*FI, no stigma*] describes how, during her initial hospitalisation when diagnosis of Crohn’s was made, her husband had reacted to their then young daughter’s dirty nappies:

My daughter was 18 months, and not out of nappies ... but he didn’t like dirty nappies because they made him feel ill. So he wore rubber gloves and he put baby wipes under his glasses, over his nose and God knows what ...and that horror of his and the fact that if anybody is sick he will go away and be sick, just made me think, ‘Well heavens, how would he cope with it?’ I’ve always been terrified of having a stoma and having a bag because of his reaction. [Janice, 62, CD]

Her husband’s reaction to bodily waste remained a problem for Janice years later when, at the time of interview, she gave other examples of hiding her worries from him as she

expected an unhelpful response and expressed concerns about his possible reaction should her illness take an unexpected course. Despite assigning herself to the *FI, no stigma* subgroup, Janice explained that she actually feels very stigmatised but stays at home to avoid being confronted with any situation where others may stigmatise her.

Most participants identified that family support was beneficial, but could not be achieved without first ensuring their understanding of the illness:

I think it took [my family] a bit by surprise. And then I started working with Crohn's and Colitis UK and doing a lot of volunteering with them. So I'd say to my mum, 'Oh I've arranged this adventure, want to come along?' And I'd get them involved like that. And so I have got quite a few friends now with IBD. And gradually over the years – they've become more involved with that side of things. And through that and seeing other people, I think, has helped them, see how other people live with it. And that it's not just me. [Lily, 31, CD]

Lily's final comment exposes the potential to feel stigmatised by an illness that marks her as different. Enabling her family to understand that her illness experiences were 'normal' for people with Crohn's disease helped to reduce the potential for stigma. Debilitating aspects of disease such as fatigue were better tolerated by family members when these were understood. Poorer understanding could become a source of stigma as the affected person may become labelled as lazy. Maeve interprets a recent interaction with the family member of a girl with Crohn's who would not discuss her disease:

Well, the family feeling was that 'Oh, she's not coming to this party again,' you know, 'Oh, she's in bed' so by not talking about it, she was allowing the greater family to actually think she was a bit of a shirker, just opting out, a bit of a wimp, sitting on the side, 'Oh, she's going to bed again,' not realising that real horrendous experience of fatigue ... [Maeve, 65, UC]

By choosing not to reveal the full impact of her condition, the young girl perhaps helps to fuel the negative, stigmatising attitudes developing in her family.

Telling friends about IBD, or if relevant, about incontinence, procured their understanding and enabled those with the disease and their friends to work round it. Carol [*FI, no stigma*] had earlier explained that ‘everyone I know, knows’ that she has Crohn’s disease and experiences incontinence:

Um, when I went in for the colonoscopy in March, a friend of ours phoned up and she’d made a bread pudding and she said, ‘Oh I’m going to send you some bread pudding.’ Well it was on the day that I was having the Picolax, and [I] couldn’t eat. So I had to say, ‘I’m sorry I can’t, I won’t be able to eat it until Friday,’ and, of course, I then explained to her. And she was really wonderful about it, you know, ‘Oh no, no, that’s [fine].’ In fact she brought it round that night so that I could eat it before I started [bowel prep]. [Carol, 64, CD]

The willingness of friends to accommodate changes imposed by demands of the disease helped Carol to feel accepted, promoting her self-esteem and helping to protect against stigma. The support of friends, particularly those with personal insight, provided unspoken understanding and guarded against stigma. Here, Juliet demonstrates her companion’s appreciation of the consequences of having a colonoscopy:

The particular person who offered to give me a lift yesterday has irritable bowel syndrome and she’d had a colonoscopy, so - I felt very comfortable with her because she had some understanding of what it might involve. So your level of comfort with people depends on how much they understand. And that could be because they experience something similar or the same or it could be that they’re in the medical profession. It’s like the friend who did take me is a nurse. So again, you know, like I joke with her, I say, ‘It’s alright, I’m come with plastic bags,’ you know (*laughs*) - and she knew exactly what I meant. [Juliet, 53, CD]

The support and understanding which accepts Juliet, her condition and its consequences, results in stigma reduction, though it was important that friends saw no evidence of the IBD. Juliet later explains: ‘I don’t mind them knowing, I just don’t want them seeing.’

Earnshaw and Quinn (2012) have demonstrated that when stigmatising attitudes are expressed by healthcare workers, people with chronic conditions internalise these attitudes, expect future stigmatising responses, and access healthcare less often. The effect of healthcare workers' stigmatising behaviours have also been explored in relation to clients who self-harm (McAllister et al. 2002; Urquhart Law et al. 2008), endure mental illness (Ross and Goldner 2009; Thornicroft 2007, for example) and towards those with different sexual and gender identities (Weber 2010). At the time of interview, Peter was avoiding contact with any of his medical team due to disillusionment, and Lillian felt frustrated at nurses who failed to provide her with the items she needed to self-care for her ileostomy when hospitalised, but no-one reported feeling stigmatised by medical or surgical clinicians, or nurses. They were fed up and frustrated at not receiving necessary care and support but this was not stigmatising. Sound relationships with health care professionals, particularly IBD nurses and hospital gastroenterologists, were seen as beneficial. Even where participants found it very difficult to be open about their disease to friends and family, honesty with health professionals was seen as essential to enable effective care and treatment. Participants felt at ease and less stigmatised, because the relationship between them and their health care staff normalised the disease:

Because it's a clinical appointment, you're there with the specialist, you know they've chosen that specialty, they're not embarrassed by people talking about poo either. Every three years he sticks a camera up my backside. He's not going to be embarrassed by that. [Lindsey, 47, CD]

Lindsey's observation regarding lack of embarrassment on the part of the clinician highlights the point that embarrassment can only arise in the presence of others (Edelman 1985; Tangney 1996), and the term 'embarrassment' is often used to describe stigmatising experiences. Lindsey's comment suggests that embarrassment, and perhaps stigma, are reduced when the other players in the interaction are not embarrassed. Even amongst those who were otherwise very concerned about others' perceptions of them, the relationship with hospital staff stood out as different:

It's different with a professional person, a nurse. Every time I go to hospital, I'm not embarrassed to show them it, because I know they know about it, but in general, people don't even know what a stoma bag is. [Carl, 54, CD]

Carl had previously explained that he reveals information about his IBD to neighbours and friends to avoid misunderstanding, and was concerned about the public finding out about his stoma [Chapter 8: p. 146]. Here, the relational aspects of stigma - that the ease or difficulty of an interaction depends on the players involved - are seen. Yet revealing bowel control problems to health care professionals could be difficult, despite a positive relationship. I asked Nancy, who had already described her struggle with incontinence, whether she had sought help from any professional source:

No, I haven't. The only - I have, not really help but I've told the colitis nurse that, you know, I really have to dash to a loo. I don't think I've actually said in words that I am a bit incontinent but I have sort of said, you know, 'I seem to have a bit of a problem and it seems to be like wind but ...' **So to clarify - you've mentioned to her about the dashing to the loo but not specifically said, 'And if I don't get there, this is what is going to happen? No I haven't. And do you know why you haven't said that? Well, just too embarrassed really. And she's a lovely lady. [Nancy, 48, UC]**

Nancy's final comment suggests that it is not the nurse's attitudes, but her own self-stigma which stops her being able to access help for her incontinence. Self-stigma is addressed in more detail in Chapter 10, where it informs the constitutive pattern *Mastery and mediation*. Those who found it easy to discuss IBD aspects with health care professionals indicated that this is partly to do with illness being normal within those relationships.

Being 'normal' or fitting in with the majority or default social status created additional avenues of support for participants. Referring to the social taboo surrounding bowels, Tina recounts the benefits of being part of a group where she has the same disease-related concerns as everyone else:

I think going to them group meetings has probably helped [me] a little bit more because there's been people there who, you know, you can talk about bottoms as much as you like, and nobody bats an eyelid. [Tina, 45, UC]

Discussing 'bottoms' may be considered deviant but in Tina's support group it is normal. Becker (1963:14) explains: 'Deviance is not a quality that lies in behaviour itself, but in the interaction between the person who commits an act, and those who respond to it.' Discussing bottoms is deviant according to the social rules of the majority (those without IBD) who may give stigmatising responses to any mention of intimate body parts. Yet in Tina's support group, it is a normal part of interaction devoid of negative response. Reggie [*FI, stigma*] finds support amongst his similar-aged friends who know of his IBD, and he thus finds some acceptance - although none share the same disease, they all share experiences of failing bodies due to older age:

They've all got some sort of intolerance to something or, some problems of their own. So I think they realise - because they've got a problem where, it might be an arthritis thing, they now will understand that there are certain things that they can't do. So as people get older and they have their own problems - they have a better understanding as to what is happening [with me]. [Reggie, 61, UC]

Revealing IBD to others in a wide range of relationships and interactions seems necessary to garner effective support. Achieving a sense of acceptance and belonging, within any type of relationship, enhances self-esteem and offers some protection against stigma (Crocker and Major 1989). Those less able to secure support and build helping relationships may have reduced self-esteem and feel more stigmatised.

9.1.2. Relational theme: Social expectations and norms

To function and integrate in society, people are expected to adhere to implicit social rules which guide everyday behaviour and define majority group membership (Dovidio et al. 2000). These rules are reflected in the relational theme *Social expectations and*

norms. In the previous pattern *Being in or out of control*, this theme referred to the need for physical control of bladder and bowels to enable effective social integration. In this pattern of *Relationships and social support* the associations between dirt and physiological threat, maturity, education, social position and culture are addressed.

Several respondents referred to their IBD as ‘a dirty disease’ and believed this the key challenge to interactions with the public. Antagonism towards dirt may be a genetically-driven survival strategy helping humans to avoid disease (Curtis and Biran 2001). In response to my question comparing a lorry driver peeing against the side of his truck in a lay-by, and someone being incontinent of stools in public, Peter replied:

[Urine] disappears into the ground ... it’s not quite the problem of going to the toilet and then the mess, of course, the smells that can be associated with it – either physically wherever it’s dropped or because you’ve actually made a mess of yourself and the smell that would come from it. I think that’s quite a marked difference psychologically. [Peter, 57, CC]

Evidence of bowel incontinence is harder to hide, less socially acceptable, and creates stigma by identifying those who cannot maintain social rules. The problem may be the ‘matter out of place’ (Douglas 1996) rather than the visibility and odour of stool. Dirt only becomes perilous when it occurs in the wrong place – urine and stools in the toilet pan are properly placed but on the toilet seat, floor or walls, are not (Douglas 1996). Social etiquette is disrupted and the misplaced dirt becomes a threat, an aspect Smith (2007) addresses when recounting Mead’s early 18th-century theory of a connection between poor hygiene and disease. The dirty and physiological threat of stool presents a challenge to the current society-wide obsession with hygiene and ultra-cleanliness:

I think society is moving more away from the natural things like farmers and things. It’s the whole disinfectant society. One of the things I think [is] that there’s fairly strong proof now that being too clean about everything is affecting how children’s immune system develops. People are more susceptible to some diseases where there was much stronger resistance to them before. [Rupert, 68, UC]

I later took Rupert back to the issue of cleanliness and asked him if he thought that living in a cleaner society changes people's attitudes towards disease:

I think it does, yes, especially diseases which deal with bodily functions. It's because it's classed as dirty, you know, it's filthy, it's grubby, and I think anything dirty – and I mean stools and urine are full of bacteria and horrible things, you know, and they must be full of germs and they must be wiped out. [Rupert, 68, UC]

The latter section of Rupert's comment was spoken with heavy disdain; his interview revealed his frustration at a world where everything is cleaned, sterilised, packaged and sanitised, and the difficulties this creates for those with unclean diseases. The source of Rupert's [*FI, stigma*] stigma seemed to be his inability to measure up to the socially-prevalent hygiene demands that are reinforced through pervasive media advertising.

Dirty things in clean places may be obvious, but some were concerned about doing dirty things in dirty places. Deirdre [*FI, stigma*] viewed her disease as dirty and considered the forthcoming village festival and the prospect of portable toilets for public use:

They'll bring in portaloos and they will be horrible and smelly and I will go in and use them if I need to, whereas others who don't have to, will say, 'Oh those are horrible smelly toilets, I'm not going to use them.' And I sort of feel – I don't want to use them either because I know they're smelly and horrible but actually I've got to, I don't have a choice in doing this dirty thing. [Deirdre, 57, UC]

Deirdre was not stigmatised by her disease or her occasional incontinence, but by the dirtiness associated with it. Her concerns focus on whether or not she is marked by an odour, and that her disease gives her little option but to use unpleasant facilities. Her feelings of stigma are compounded by her companions' innocent remarks which emphasize their ability to choose to avoid dirty things in dirty places.

Perilous dirt and smell usually co-exist. Rarely do beautiful things smell appalling, and for people with IBD, the foul smell that may accompany bowel actions could also reveal the dirty nature of their condition. The perception of this in others is reflected in their own responses to smell:

Even if you have had to go urgently in a public toilet ... there can also be a smell and you can be a bit, 'I really want some air freshener or something,' just because I wouldn't particularly want to go into a public toilet myself with that smell, so I don't really want to leave it. [Suzie, 23, CC]

Cultural expectations have privatised toilet behaviours so that anything, visual or olfactory, which heralds the current or recent presence of stool, is viewed negatively. Repeatedly, participants referred to bowels as an unacceptable topic of conversation:

You can't talk in detail about Crohn's disease without talking about bowels and you don't talk about bowels in polite company. So you don't talk about Crohn's disease in polite company. If it were arthritis, arthritis is a clean disease. [Lawrence, 52, CD]

Not only in private company, but in society as a whole, the message is that bowels are taboo and not to be discussed. Reluctance to address the issue may prevent people from seeking help for bowel symptoms:

I think there is a thing about bowel problems. People don't talk about it because it's not the norm to talk about it. It's not, you know, it's brushed under the carpet. And I think people don't go to the doctor's about it, because people are embarrassed about it. [Charlotte, 38, CD]

Philip [*FI, stigma*] confirms the point by considering the absence of depiction of bodily functions in films despite the often graphic representation of sexual practices, and muses that this is a reflection of the cultural perception of toilet matters as taboo. Taboo topics are socially unmentionable and unacceptable subjects. Freud (1942:29) explains:

Taboo expresses itself essentially in prohibitions and restrictions ... [these] lack all justification and are of unknown origin. Though incomprehensible to us they are taken as a matter of course by those who are under their dominance.

Since Freud's early writings, privatisation of toilet behaviours (Elias 2000) and increasingly hygienic practices (Smith 2007) have contributed to toilet-focussed taboo. Exposing the issue by verbalising or demonstrating bowel control difficulties may be the source of stigma for people with IBD and related FI – the socially-approved silence around the taboo is broken, drawing disapproval from those who adhere to the rules.

Stigma is also related to social rules about maturity. Toileting behaviours become more private as humans mature, and loss of control may be equated with loss of adulthood: 'I suppose it's the thing about babies, babyish or is it you're acting like a child,' [Jeannie, 58, UC]. The relationship between bowel control and adulthood was identified as significant over 50 years ago in a report on the psychological consequences of surgical disruption of the anal sphincter (Orbach et al. 1957). Surgeons have since developed sphincter-sparing techniques to preserve function, retaining continence and preserving control (Ludwig 2007; Tyler et al. 2007). Adulthood suggests competence and maturity, which is undermined by loss of control of bodily functions (Green 2009). For those with IBD-related incontinence, stigma may arise from the discredit associated with appearing to be adult, but behaving, as far as bowels are concerned, like a young child.

Other participants perceived a link between poor hygiene and education, implying that their own poor bowel control would lead others to view them as uneducated:

We look down on people who are not taking care of their hygiene. You know, we always assume that there's something wrong with them or they're uneducated or whatever it is. [Andrea, 47, CD]

Cleanliness and education might be seen as essential in viewing others positively. Rupert equated his self-described dirty disease with other examples of social disadvantage or compromised hygiene:

A lot of alcoholics and drug addicts mess themselves often sitting on a park bench or something, and they urinate and ... they're classed as dirty, filthy people, not somebody with a problem. You know, they're dirty, grotty, therefore if somebody does it, who isn't an alcoholic or a druggie, then they're associated with that in a way. Or, as a dirty old man. I don't mean sexually dirty old man, I mean an old man who's lost control of his bodily functions because he's old. And people who are younger with, with urinary problems or with IBD, tend to be tarred with the same brush. [Rupert, 68, UC]

Rupert continues with a comparison between society's perceptions of binge-drinkers having a good time on a night out, and the alcoholic who may consume no more than the binge-drinker in one session, but is classed as 'horrible, grubby, nasty.' He perceives that the binge-drinker is accepted, the alcoholic is not, which perhaps reflects observers' ability to empathise with the event. Most may be able to recall occasionally having had too much to drink, but few perhaps understand the events which lead to alcoholism, or incontinence. Perhaps it is that events far removed from the experience of the majority generate stigma. The relationship between behaviour and perception of cleanliness may also have influenced the response Charlotte endured, when explaining her illness to a member of staff at her daughter's school:

So I went and saw [staff member]. 'I'd never have thought that you would have got something like that,' was her first words. **What did she mean by that?** I don't know. Did I not look six stone and haggard and full of malnourished or what? [Charlotte, 38, CD]

Charlotte's sarcastic final comment indicates that, at the time of this interaction, her illness was very obvious, but the staff member seems to overlook this and link the dirty disease to her own perceptions of the person before her. Her response gave Charlotte the impression that she was now thought less well of, as if the illness was her fault.

Local cultural differences may also influence the experience of stigma. In this study, participants from the north of the country seemed generally more open, spoke more

freely about their IBD, and appeared less bothered by others' perceptions of them than those in the south, perhaps reflecting a more open, friendly attitude amongst Northerners and a more private, closed disposition in Southerners. The contrast is illustrated by Carol who had previously lived in a large city on the south coast of England, but had moved to a remote Scottish village:

What we've found since we've been up here, we've not found down South, is somebody will ask you, 'Oh where have you been?' or 'Where are you going?' And you find yourself telling them exactly what you're doing and why you're doing it. And you come away thinking, 'What did I do that for?' Down South, you never did that. They're not being nosey, you just feel that they're interested and if there was something wrong they would be quite concerned, you know, and it is genuine. If people didn't see you, it wouldn't be long before somebody would come and knock at the door and ask. [Carol, 64, CD].

Evidencing a cultural difference between northern and southern England is challenging. Demarcation began in the 1700s (Jewell 1994), and differences commonly address political, financial and health inequalities (Moller et al. 2013), rather than cultural variation. The industrial North was traditionally viewed as the 'poor relation' to the white-collar commercial endeavours of the South, and whilst anecdotal evidence suggests that Northerners are friendlier, there is no substantive proof. Despite the impression gained during interviewing, geographic distribution of study participants [Chapter 8: Fig. 8-2, p. 127] does not demonstrate a clear differentiation with non-stigmatised participants in the North, and stigmatised in the South. The North-South divide is now less pronounced than it was historically since local cultural groups are no longer confined to their regions of birth, and it may be birthright, rather than where someone settles in adulthood, which governs the development of stigmatised feelings. Participants with Northern origins, regardless of current location, and those moving into Northern areas may feel able to talk openly about their IBD, gain support, and be accepted more easily, consequently feeling less stigmatised.

9.1.3. Relational theme: Responsibility and blame

Jones et al. (1984) identified 'cause' as one of the factors which make a mark more or less stigmatising. Perceptions of cause of, or responsibility for, a mark influence observers' responses with less sympathy and more stigmatising attitudes being directed at those perceived to be responsible for their situation. The loss of limbs due to warfare is likely to be viewed sympathetically by the public who may perceive that it is not the soldier, but the politics of warring countries which bear responsibility. In contrast, those with illnesses such as HIV/AIDS (Thomas 2008) and some forms of cancer (Chapple et al. 2004; Gulyn and Youssef 2010) may be blamed for their illness when it is perceived to be caused by a chosen lifestyle. This theme of *Responsibility and blame* considers participants' perceptions of the public's understanding of IBD and of who, or what, each holds responsible for illness and symptoms.

Whilst some participants suggested that the public were becoming more knowledgeable about IBD, almost everyone had experience of, or perceived there to be, little true understanding or empathy for their disease:

[The public] don't understand the absolute urgency with which you must get to the toilet, it's not like it can be done in five minutes, it has to be now. [They] don't understand that concept. [Suzie, 23, CC]

The issue here may not be about the urgency itself, but that the urgency disrupts the waiting experience of others who have, in 'the proper British way' queued patiently for their turn to use the toilet. Another of society's unspoken and unwritten rules, this one demands that each person waits their turn, just as everyone else has done. To 'jump the queue', regardless of reason, breaks the rules and leads those with IBD-related urgency to perceive that they are misunderstood, and viewed negatively.

Jones et al. (1984) also identified peril as influential in determining the ability of a mark to stigmatise. Carol explains that public ignorance about IBD leads to misperceptions of peril:

I don't think that everybody realises what it is, that you can't catch it, you know. And if you use their toilet, they're not going to have to fumigate the place or anything afterwards. [Carol, 64, CD]

Participants felt that public knowledge was limited due to limited awareness of IBD compared to other chronic illnesses such as cancer, diabetes, and heart disease. These are the focus of targeted UK health care initiatives since they are linked to obesity, represent significant morbidity for millions of people, and cost the NHS in excess of £940 million per year (BHFNC 2013). In the UK, Parkinson's disease and multiple sclerosis affect 127,000 and 100,000 respectively, yet participants believed the public to be more aware of these diseases than of IBD which affects 250,000. Charlotte explains:

I think – right, you've got someone with breast cancer, you turn round and you say to someone, 'I've got breast cancer,' somebody knows instantly what you've got. 'I've got Crohn's disease.' 'What's that?' Nobody knows anything about it, and there's not enough information about it. [Charlotte, 38, CD]

Ignorance is recognised as a factor in the creation of stigmatising attitudes, since assumptions are made based on insufficient, inaccurate or absent information (Thorncroft et al. 2007). In this study, lack of public knowledge about IBD was considered the reason that participants were held responsible for their bowel symptoms. Education and information was seen to be the key to solving the problem:

I think [information] helps because it helps people understand. If I wasn't to say anything or talk about it then, because the majority of people don't know anything about ulcerative colitis [they wouldn't understand] – so if they know what I'm going through a little bit, I think they tend to be a bit more understanding, and a little bit more accepting. [Tina, 45, UC]

Raising awareness through education is a key strategy in health-related stigma-reduction programmes (Heijnders and Van Der Meij 2006). The need for education is reflected in the different opinions that participants had about whether the public in general do or do

not know about or understand IBD. There was a feeling that the public confuse irritable bowel syndrome (IBS) with IBD, but that despite the confusion, this understanding of IBS helped to some extent in also understanding IBD:

It is out there in the open a bit, because I think now there's a lot more causes of sort of IBS or IBD, whichever, whether it's a mild form because of an intolerance to something, or they've actually got colitis, ulcerative or Crohn's. And I think because people are suffering with some sort of irritable bowel, they're then hearing about the colitis. [Reggie, 61, UC]

This partial understanding was perceived as something of a two-edged sword; whilst some public seem aware of the impact of IBD, others believe it is caused by stress or that it is IBS, adding hints of blame as the sufferer is held responsible for their illness:

A lot of people think it's IBS – and that has only recently been accepted as a disease. Until recently it was seen as a psychosomatic problem. And people related to that and I think, when you say 'IBD,' they think 'IBS,' and still think it's psychosomatic. And both of them are proper diseases but so little is known about it by the general public. [Rupert, 68, UC]

Psychosomatic (functional) disorders, including IBS, fibromyalgia and chronic fatigue syndrome are more stigmatising than comparable medical conditions (Looper and Kirmayer 2004). With no firm diagnosis, and no established medical cause, sufferers may be perceived to be fabricating their symptoms. When poor public knowledge about IBD means that this established, diagnosable condition is incorrectly assumed to be imagined, stigma may arise. Good public knowledge about IBD increases understanding and creates support. Juliet explains the acceptance she gets from her work colleagues because they understand her illness:

A level of understanding is important because they accept it more. And then that's just, 'Oh yes, yes, she's got Crohn's disease. Oh that's why she's not here, she's not well.' [Juliet, 53, CD]

IBD is diagnosed with a series of established tests, and although pathophysiological processes arising once the disease is triggered are understood, the underlying cause of the condition remains a mystery. Although some participants described occasions where they did receive public empathy and support, they also felt that the inability to explain fully the cause of the illness made it less credible, adding to a sense of peril:

I think people are frightened of chronic illness. And I think that, until somebody comes up and says, 'Crohn's, colitis, whatever, is caused by this definition,' then there is the belief in the back of people's minds that perhaps they could catch it, which we know is not true. [Lillian, 61, CD]

Participants also described other public misperceptions, including the belief that surgery will cure disease, and a drug which is effective for one person with IBD will be equally effective for all. Almost all participants believed that the public viewed them as *responsible* for any behaviours commonly identified as anti-social – passing foul-smelling or noisy wind, being incontinent, having urgency and needing to jump the queue for public toilets, or for contracting the disease in the first place:

[People would say], 'Oh you wouldn't think it with you,' and it's more that people don't expect – they expect you to look different if you have an illness or disease. Quite a common one for me is, 'You're young,' or 'attractive,' you know, 'young pretty girl. You wouldn't think that you have those problems.' And I'm, 'Why?' **Okay, so you only have those problems if you're old and ugly?** Old and ugly people generally when they get ill. [Elsa, 29, UC]

Being held responsible and being viewed negatively for something beyond one's control and outside of the majority expectation which links illness with old age can lead people with IBD to internalise these negative perceptions, leading to self-stigma. To avoid this downward spiral, those with IBD may feel compelled to find a cause for their illness to deflect responsibility away from themselves. Participants had opinions on the cause of their disease, with *blame* being allocated in several directions, including towards specific events during which extreme emotional distress had been endured:

It started in 1981 when my daughter burst a disc in her spine, aged 13. She was in hospital then for five weeks, flat on her back. And I was, my ex-wife and I were travelling backwards and forwards to [hospital] and we were passing each other on the way. And I think the stress of that [started it] ... that's my excuse anyway. [Charles, 78, CD]

Others blamed 'rectal damage' (but did not explain how this had occurred), severe infection such as peri-tonsillar abscesses, holiday-contracted gastro-enteritis, or hormonal changes: 'It came with the menopause, really' [Deirdre, 56, UC]. Tina, referring to the auto-immune response in IBD, blames her illness on a 'wonky immune system.' For others, medications were held responsible for triggering relapse after a period of remission. 'I was so ill – then we discovered it was the contraceptive pill that was setting it off' [Charlotte, 37, CD]. Identifying a cause of IBD seems important - Lillian explains a recent discovery which, for her, makes her condition plausible:

My grandmother died of Crohn's and she was 46 - but the, the fact that we know that there was a genetic factor, I felt helped the argument for [this] being a genetic disorder. [Lillian, 61, CD]

Lack of explanation may reduce the believability of the condition, adding to feelings of *responsibility and blame*. In contrast, those able to discern a reason for their IBD which added to their sense of control and vindicated their situation, seemed more content.

9.1.4. Relational theme: State and flux of stigma

The relational theme of *State and flux of stigma* in IBD refers to the changeable, unstable and flexible nature of stigma experience, influenced by the players in each situation, and by time. Although participants' stories showed stigma to be a frequent feature of IBD they did not always feel stigmatised. Some were aware of the potential for stigma, felt they understood why it arose and often were able to resist it, whilst others were troubled by it. Participants could be stigmatised most of the time with rare

moments of relief, or experience stigma only occasionally. For example, Janice always felt stigmatised unless she stayed at home to avoid social interaction while others, like Philip, explained that stigma had reduced with increasing disease duration and he was now more able to resist rare occurrences.

Of the forty participants, only six gave no indication of any perceptions, experiences or feelings of stigma. Four had self-assigned to the *No FI, no stigma* subgroup. Good bowel control and the reliable invisibility of their disease enabled them to maintain the social rules and a good impression of self. All indicated that they would feel differently if their symptoms were worse. Of these four, Cheryl was quite stigmatising towards others with IBD who had poor bowel and symptom control, expressing the opinion that such people were weak, gave in too easily and would probably feel stigmatised by anything. It was difficult to listen to, especially following the interview with Carl who was struggling to cope with the devastating impact of Crohn's disease on his life. The two remaining participants also gave no indication of feeling or being aware of stigmatising attitudes. Rory [*FI, no stigma*] was uncertain about what protected him from feeling stigmatised, simply stating that he had never been bothered about other's perceptions of him in any aspect of his life. Although unable to pinpoint the origins of this attitude, he felt it was a core part of his identity. Reggie [*FI, stigma*] said nothing at interview to suggest he felt stigmatised. He described strategies he used to prepare for unpredictable bowel actions, and adjustments he and his wife had made to cope with his disease, but gave no impression that these led him to, or protected him from, feeling stigmatised. Whether the lack of evidence of stigma in his transcript was due to interviewing technique, whether he was reluctant to open up at interview, or whether he wasn't actually feeling stigmatised, is unclear. The remaining 34 participants, regardless of self-allocated subgroup [*FI, stigma; FI, no stigma; no FI, stigma; no FI, no stigma*] described experiences which were, or could have been stigmatising [Table 9.1]. Despite experiencing stigmatising attitudes from others not all felt stigmatised, indicating that some people recognise but resist stigma. People rarely 'belonged' permanently to their chosen subgroup but, indicative of the relational aspect of stigma, could feel stigmatised or not in different situations. Temporal changes were evident, as some in the *no stigma* groups explained that they had felt stigmatised in the past.

Participant	Age	Diagnosis	Subgroup	Anticipated stigma	Perceived stigma	Enacted stigma	Self stigma	Courtesy stigma	Kinship stigma
Jacob	34	CC	FI, no stigma	•					
Charles	78	CD	FI, no stigma			•			
Jeannie	58	UC	FI, no stigma					•	
Carol	64	CD	FI, no stigma	•					
Lindsey	45	CD	FI, no stigma	•		•			
William	72	UC	FI, no stigma					•	
Kevin	35	CD	FI, no stigma	•	•				
Jason	47	P	FI, no stigma	•					
Michael	47	CD	FI, no stigma	•					
Rory	46	CD	FI, no stigma						
Elsa	28	UC	FI, no stigma	•					
Lily	30	CD	FI, no stigma	•			•		
Janice	61	CD	FI, no stigma	•			•		•
Tina	44	UC	FI, no stigma	•		•			
Juliet	52	CD	FI, no stigma	•					
Rupert	68	UC	FI, stigma	•				•	
Peter	56	CC	FI, stigma	•	•		•		
Carl	54	CD	FI, stigma	•			•		
Lillian	61	CD	FI, stigma	•	•	•	•	•	•
Sharon	61	CD	FI, stigma	•	•		•		
Philip	54	CD	FI, stigma	•	•				
Deirdre	56	UC	FI, stigma	•	•		•		
Charlotte	37	CD	FI, stigma	•	•	•			
Nancy	47	UC	FI, stigma		•				
Reggie	61	UC	FI, stigma						
Andrea	47	CD	FI, stigma	•					
Vera	68	CD	FI, stigma	•					
Andrew	69	UC	No FI, stigma				•		
Marion	35	UC	No FI, stigma	•			•		
Suzie	23	CC	No FI, stigma	•	•				
Tamsin	38	CD	No FI, stigma	•	•				•
Katrina	48	CD	No FI, no stigma						
Maeve	65	UC	No FI, no stigma						•
Vivienne	52	UC	No FI, no stigma						
Caroline	34	CC	No FI, no stigma	•	•	•			
Cheryl	29	UC	No FI, no stigma						
Belinda	55	CD	No FI, no stigma						
Lawrence	52	CD	No FI, no stigma	•					
Aileen	58	CD	No FI, no stigma	•					
Esther	24	CD	No FI, no stigma	•	•	•	•	•	

Table 9-1. Participants, their self-assigned sub-groups, and types of stigma present in their interview transcripts

CD = Crohn's disease, UC – Ulcerative colitis, CC = Crohn's Colitis, P = proctitis. Participants not reporting stigma are highlighted in blue

Hermeneutic phenomenology purists would resist presenting participant data as a table, as it is not the intention to speculate on any kind of relationship between participants, their demographic details and findings. However, for this academic exercise, it provides a useful picture of the representations of different types of stigma across all transcripts.

This relational theme of *State and flux of stigma* is informed by several sub-themes which relate to either the current constitutive pattern of *Relationships and social support*, or to the remaining pattern of *Mastery and mediation* [See Chapter 7: Figures 7-4 & 7-5, pp. 118 & 120]. Experiences of anticipated, perceived, enacted, courtesy and kinship stigma relate to the current pattern as these arise from interactions with others. Self-stigma, the fluctuating nature of stigma, and stigma resistance are presented in Chapter 10: *Mastery and mediation*, as these hinder or help people in coming to terms with their illness situation.

9.1.4.1. Anticipated stigma

The most commonly-revealed form of stigma in this study, anticipated stigma refers to negative attitudes and responses which the experiencing person *expects* from others. It has also been reported, for example, in mental illness (Cechnicki and Bielanska 2009), where patients anticipate stigma much more often than they experience it (Angermeyer et al. 2004), a pattern repeated in this study. Participants expected others' to perceive them negatively because IBD and its consequences are anti-social: 'Obviously it [incontinence] is not nice and everyone thinks it's horrible, and I think a lot of people think it's dirty as well' [Lindsey, 46, CD]. Some experienced changes in friendships because of incontinence associated with their IBD. Lillian describes *expecting* to be treated differently once friends knew:

And also the stigma is – when you tell friends that you've had this situation, they tend to look at you in a different light. And, instead of saying 'Would you like a cup of tea?' it's, 'Well, the toilet's there.' And all the time you think they're waiting for you to have an accident. [Lillian, 61, CD]

Gilbert and Walker (2010) report similar concerns about attitude changes amongst women with HIV/ AIDS once their serostatus became known to existing acquaintances. The expectation of disapproval – interpreted by them as stigma – comes from participants' own beliefs that the disease *and* its consequences are embarrassing:

I'm embarrassed by it because it has so many embarrassing toilet connotations. And also I think it's an embarrassing disease to have because it affects so much more than your gut and going to the loo. It affects the whole of your being and the whole of your life in energy levels. [Janice, 62, CD]

Others indicated that it is not the disease but the symptoms and behaviours, including urgency and frequency, which are stigmatising. Suzie explains how she feels when urgency compels her to queue-jump at public toilets to avoid incontinence:

I suppose there's that fear that somebody is going to say something or, if you absolutely have to go right this minute, it's the fear that somebody is going to look at you as if to say, 'Well you don't look ill enough to me to go to the toilet now, why are you not waiting in the queue like everybody else?' [Suzie, 23, CC].

Behaviours which expose and bring expectations of stigmatisation have also been reported in relation to urinary incontinence (Elstad et al. 2010), and the revealing aspects of wearing a urinary catheter bag (Wilde 2003). Odour could also be stigmatising and drew concerns of being thought badly of:

There's always the worry that you might smell – I'm very conscious about that ...
Does it bother you that you might smell? Yes, I would hate people to think of me as that 'smelly person.' [Deirdre, 57, UC]

Deirdre's comment underlines the social expectation to be clean, an issue essential to Andrea's belief that anyone finding out about her incontinence would negatively alter their opinions of her:

I can't stand the idea that other people would know. It makes me feel like they would view me differently, that they would somehow think less of me or be concerned that they might be with me when it happens and they wouldn't know what to do or how to react ... if not thinking less, it changes what they think about you and to me, that change can only be worse. [Andrea, 47, CD]

Together with these symptoms of urgency, odour, and incontinence, other more subtle behaviours were also problematic. Philip described concerns about leaving video-televised conferences at work to use the bathroom:

I'm linking up with other members in the US and the rest of Europe, and it's a bit awkward to sort of just get up and walk out because you're seen by loads of people all round the world and then you come back in again. And it's quite obvious where you've been, but it's very difficult sometimes to make people understand that when you've got to go, you've got to go. [Philip, 55, CD]

There is no evidence that Philip's local and global colleagues *do* know that he's been out of the room to go to the bathroom, or that they think less of him because of it, but he expects that they do. This expectation of being viewed negatively was troublesome for Carl struggling pre-surgery with incontinence, and post-surgery with a stoma:

If you have an accident, you think everybody's watching you. They're probably not even thinking about you, but you've got this feeling that they are. And it's the same with the stoma bag. I keep thinking everybody can see it, but they probably don't even know, but it's just on your mind that it's not right. [Carl, 54, CD]

Philip and Carl make comments which emphasise the point that it is their own struggle with breaking the rules of what they believe to be acceptable public behaviour, which leads them to anticipate stigma from others. They are unable, in Goffman's terms, to 'put on' and retain a character before an audience (Goffman 1959) - to display an acceptable public image due to the threat of unpredictable symptoms. I asked Vera what would be so bad about having a bowel accident in public:

What would people think of me? It sounds awful if I say I've got an image, I do have an image, and I know people have an image of me. And I don't want to besmirch it. [Vera, 69, CD]

Vera felt strongly that others had expectations of her, placing demands on herself which she could not guarantee to meet and leading her to anticipate negative responses if her expected image was proven false. Similarly, when illness affected her ability to work, Lily's expectations of self led to anticipations of negative responses from others: 'I hate the thought of what other people think of me, that they might be judging me as some kind of bad person for not working hard' [Lily, 31, CD]. Lily's narrative described the principle in her family that one should work hard, an influence which likely informed her comment. Employment is an expectation as well as a necessity, and for most people it 'occupies a larger part of [their] lives than any one other type of activity' (Giddens 1989:481). Being employed has a functional and a social aspect, and the employment that people seek or are directed towards is largely influenced by their social class (Scambler 1997). Employment is indicative of one's social position and prospects, whilst unemployment carries connotations of failure of self, perhaps driving Lily's anticipation that people will judge her badly if she cannot match this social expectation.

Anticipated stigma influenced Peter's decision, early in his career, to conceal disease information through fear that it would affect his employment opportunities. I asked him what had driven him to keep his condition secret:

Protecting my family in a way from [loss of] income, the fear of not having a job or the advancement of it. I moved positions on a couple of occasions. I've been fortunate because I was approached, but I was also [invited] to move to the States. I declined purely [because] I didn't think I'd get through the medical and I didn't want people to know. **So keeping it secret was due to a concern about being personally stigmatised?** Yes, personally stigmatised and the potential result that might have with people that may not understand the condition. [Peter, 57, CC]

There were concerns about how people might react if they learnt about the illness:

I suppose I do have a fear of it being discovered. It is a slight worry of what people would feel or would think about someone with the condition, especially, I suppose at my age I still feel quite young and it's a sort of condition that I would normally associate with, you know, elderly people. [Jason, 48, UC].

Jason's [*FI, no stigma*] perception that bowel problems are associated with the elderly led him to be concerned that anyone discovering his diagnosis would think negatively of him because he is too young to have this kind of problem. Others, making a connection between illness and character, reflected the belief that people associate dirty things with bad people. Rupert [68, UC] explains: 'If you've messed yourself, then, you know, you're not a nice person. People don't think that it's because you have a condition.'

Anticipated stigma depends on personal experiences and perceptions, mirroring the person's own view of how the world should be and raising expectations of disapproval when they know their own rules are being broken. Yet others who anticipate stigma are able to resist it, despite knowingly breaking social rules. Mechanisms of resilience are presented in detail in Chapter 10.

9.1.4.2. Perceived stigma

Perceived stigma reflects a person's belief that they are being stigmatised when this may or may not be the case. It has been reported in irritable bowel syndrome (Dancey et al. 2002; Jones et al. 2009), cancer (Else-Quest et al. 2009), multiple sclerosis (Pedro et al. 2011), leprosy (Tsutsumi et al. 2007), and IBD (Taft et al. 2009). Twelve participants reported experiences of perceived stigma. Of these, nine were those who felt stigmatised, with or without FI [Table 9.1, p. 176]. Participants described feeling that others were talking about, or perceiving them negatively, without overt evidence of this. Examples included other women's reactions to odour in a restaurant's toilets:

I went in [to the toilet] and came out and I was washing my hands, and somebody else went in, there was a group of them and one of them made a comment [about the smell] and I thought, ‘Oh that’s me. They don’t know it’s me,’ but I felt very bad about that. [Deirdre, 57, UC]

Deirdre was particularly bothered that she might carry a bad odour, perhaps alerting her towards other’s comments about smell and perceiving them as being directed towards her. The excerpt shows the complexities of interpreting stigma: Deirdre’s comment could also indicate self-stigma – the other women do not know that she made the smell, but she does, and her own difficulties with odour cause her to feel badly about herself.

Peter believed that using facilities at a venue with no intention to actually visit the venue was viewed negatively by others. His perceptions are driven by his own values, leading him to believe that others would also think his behaviour inappropriate:

I’d parked outside a museum, so I was able to go in. But again it’s embarrassing, because you’re walking into the museum with no intention of going round it, people are looking at you and you just disappear straight into the toilet. And they probably think nothing of it, but in my head, it’s ‘Oh blimey.’ [Peter, 57, CC]

Behaviours fuelled by urgency were imagined to draw stigmatising responses from others. Caroline [*no FI, no stigma*] explains how she used to perceive that people were discomforted by her justification for needing to use a toilet frequently:

I used to think, [when people would ask], ‘Why are you running to the loo all the time?’ ‘Well I’ve got bowel disease.’ And you think, and you can see sometimes people are thinking, ‘Hmm, bloody hell,’ you know ... [Caroline, 34, CC].

Caroline’s perception that information about her bowel disease was received negatively reflected most participants’ belief that bowel-related issues are taboo. The relationship between bowels, taboo and hygiene may also have informed Sharon’s interpretation of her friend’s cleansing activity:

I went to use her toilet in her house and immediately afterwards I could smell bleach. She'd been in there and bleached everywhere, and I thought, 'Is that something she would normally do? Or has she done that because she thinks she's going – you know, there's something she can catch from me being on her toilet?' [Sharon, 61, CD]

Without any direct expression of negative attitudes towards participants, expressions of perceived stigma depend on how the individual interprets the event in relation to their pre-existing experiences and expectations.

9.1.4.3. Enacted stigma

Enacted stigma occurs when people are left in no doubt that they are being treated differently, or negatively, because of a discrediting mark. There is a fine line between perceived and enacted stigma, since interpretation of behaviours directed towards an individual will always depend on that individual's perception of events. Another person, viewing or perhaps experiencing the same event from a different perspective, background and understanding, may not see stigma in the event at all. Goffman's (1963a) definition of stigma as 'an attribute which is deeply discrediting' guides this study, where 'attribute' means any aspect of an individual which they believe causes them to be treated less well. The audio files of these interviews give evidence to the very real sense of being treated differently that some participants reported. The stigmatised 'felt' these experiences in an emotional way whilst the non-stigmatised were more matter of fact, with an attitude of 'I recognised what was happening here, but shrugged it off.' Enacted stigma has previously been reported in relation to, for example, lung cancer (Chapple et al. 2004), coeliac disease (Olsson et al. 2009), and chronic low back pain (Slade et al. 2009). In this study, examples of enacted stigma had occurred in a range of settings, including public, educational and work environments, or with colleagues, health care professionals or friends. Lillian explains the change in attitude arising, she believes, from the unpredictability her condition brings to her and her husband's social life:

We actually know friends who dropped us from their social circle, because we had to turn down so many dinner party engagements at the last minute, which inconvenienced them. In the end they just stopped asking us. [Lillian, 61, CD]

An onlooker may see no stigma here. Lillian and her husband *are* unreliable guests due to her illness, and any host, faced with a persistently unpredictable guest might reasonably stop inviting them. It is Lillian's perspective that is important - she *feels* that she is treated differently by people she formerly socialised with, *because* of her illness.

Enacted stigma may be driven by a lack of understanding of the disease. In public settings, this leads to hurtful comments and actions which impact upon the person with IBD. Tina describes an episode where she had used her 'Can't Wait' card (a credit card-sized item which explains that the holder has a medical condition and may require urgent access to toilet facilities):

I once had to use the 'Can't Wait' card. I've never used it again. I just thought, 'Well either I've got to get to the front of the queue or I just poo in me pants and I haven't got a change of clothes today, so I don't want to do that.' But I got some bitchy, bitchy comments that day. There was no understanding there. It was like, 'Well, I need the toilet as well, why should you go before me?' So that wasn't very pleasant. [Tina, 44, UC]

Ignorance can also lead to incorrect assumptions being made when people make choices based on the needs of their IBD. Alcohol is often avoided because it exacerbates bowel symptoms (Swanson et al. 2010); Philip explains what happened when another man in a bar challenged him because he wasn't drinking alcohol:

I won't have a beer and things like that. And I was in one pub where it's quite obvious I hadn't driven because it was right in the middle of [city]. And I was obviously not from [there], but the guy just sort of said, 'The poofs' bar is down the road.' I said, 'Well I can't... **Because you were having a soft drink?** Yes. [Philip, 54, CD]

The presence of a thriving local gay and lesbian sub-culture combined with the avoidance of alcohol, led the commenting customer to incorrectly label Philip as gay presumably because he believes that gay men never drink alcohol.

In educational settings, enacted stigma can have a detrimental effect. Esther, in training on a health-related programme with case-load responsibility, describes the actions of her placement supervisor:

Five months in [to the placement] I wasn't well. I had a flare up [and] I couldn't go in to work for a month. And after I came back, I felt like my supervisor – she said all the right things when I started there, like, 'Don't worry if you're off sick, we're fine, it's quality, not quantity of cases, you need to look after yourself,' blah, blah, blah. But then when I was actually off sick, that changed really quickly. So all of a sudden it was, 'Look if you're not feeling 100% you shouldn't be in work. If you can't come in for a full day, don't bother coming in.' And then she upped my caseload to more than I should have. As trainees, we were only meant to carry a certain amount of cases. And I, again I know this is my perspective, but I felt as though she was punishing me for being off sick. So I got extra cases that I shouldn't have had, most of which were home visits. And she wanted me to see them twice a week which isn't normal practice. [Esther, 27, CD]

These events may appear innocuous, but Esther later explains that she felt she was treated differently than other students because of her illness. Whether the supervisor doubted Esther's illness cannot be known, but perceptions of the 'believability' of self-reported symptoms, especially where diagnosis cannot be established, has resulted in people with other conditions feeling stigmatised (Looper and Kirmayar 2004).

It can take between a few months and several years to confirm diagnosis of IBD (Can et al. 2014; Degen et al. 2013; Vavricka et al. 2012), but early signs can be non-specific and make diagnosis difficult. Charlotte reports her experience of not being believed:

I felt an idiot really – [my] doctor was supposed to be one of the best consultants in the field. And he would not be wrong, he was right. But in my case he was

wrong. He said it was imagination, and then I was going to the GP as well and they were saying, ‘There’s nothing wrong with you,’ and I’m thinking, ‘Well why am I being sick, why have I lost this weight?’ I wasn’t at work, I couldn’t go to work. And there’s only so much that my employer was sympathetic about. And they all started to think the same as well – was it in my head? But going to [different hospital] changed my life because somebody did listen to me, because you could have drove [sic] yourself mad. [Charlotte, 38, CD]

Although now receiving good healthcare, Charlotte was originally treated negatively by several people who failed to believe her. The lengthy delays she encountered resulted in extensive surgery, leaving her with debilitating bowel symptoms and the feeling that the outcome could have been much better if people had listened to her earlier. Yet even when health care professionals did listen and were supportive, they could still inadvertently direct stigmatising responses towards patients. Frohlich (2014:129) explains that:

‘Distinguishing stigmatising experiences from supportive experiences is not as easy as calling apples red and bananas yellow. Social encounters are complex, and one conversation can be both supportive and stigmatising at the same time.’

Caroline, having identified that her diagnosis made her different from the majority, demonstrates this complexity when recounting an interaction with her then consultant which she felt separated her from the majority and labelled her as ‘other’:

I can remember my consultant who diagnosed me - he gave me a leaflet for the NACC [National Association of Crohn’s and Colitis] as it was back then, and said, ‘And you should get in touch with [them] because they’re very helpful for people like you.’ I remember walking out of the room thinking, “people like me?” What the hell is he talking about?’ **Yes, does he mean female, single, young?** Yes (*laughs*). **That’s interesting that even the consultant gastroenterologist couldn’t say...** Yes and that was the day of my diagnosis, that was, ‘You’ve got Crohn’s Colitis, we’ll put you on some medication, come back in a fortnight for a check up and here’s a leaflet *for people like you.*’ Yes, and I

thought, ‘Hmm,’ and it took me ages to work out why that rubbed me up the wrong way. **And why did it?** Because he was separating me out from the crowd and putting me in a box that went, ‘people like you over there. You’re not here, you’re over there.’ [Caroline, 34, CC]

Again, appreciation of perspective is essential. Caroline, already feeling different because of her disease, interprets the consultant’s words negatively. The consultant, dealing with IBD on a daily basis, was most probably simply directing her towards a service which he expected would help her, but his choice of words - *people like you* – is perhaps telling. Had he said ‘people with IBD’ the effect on Caroline may have been different, but in her eyes, his avoidance of the diagnostic label resulted in her feeling he was giving her another equally undesirable label as an outsider.

Enacted stigma emerges when the other players in an interaction respond negatively to anyone who transgresses social rules, customs, or agreed roles. Sometimes, as in the examples of Tina, Phillip, Esther and Charlotte above, the stigmatisation is obvious even to an observer. On other occasions, as in Caroline’s case, it requires appreciation that fundamentally all experiences of stigma are perception-driven. The receiving person’s background, culture and experience influence the way they perceive attitudes directed at them, determining whether they see those attitudes as stigmatising or not. Regardless of others’ opinions, Caroline *felt* stigmatised, and that must be respected.

9.1.4.4. Courtesy stigma

Courtesy stigma refers to the stigma that others feel due to their association with the marked person, and was described by a few participants in this study. It has been reported elsewhere for example, in families of teenagers with attention deficit hyperactivity disorder (Koro-Ljungberg and Bussing 2009), carers of Alzheimer’s disease sufferers (Blum 1991), and families of people with mental ill-health and drug dependency (Corrigan et al. 2006). In this study, courtesy stigma was evidenced in participants’ perceptions of others’ responses to their illness and its consequences, or from the association that they feel they have with other stigmatised groups.

Two participants, who did not feel stigmatised by IBD or incontinence, believed that their partners felt differently: 'I think perhaps [my wife] feels more of a sense of embarrassment about it than I do' [William, 72, UC]. Jeannie recalls her husband's insistence that she get changed having had a small bowel accident whilst playing golf with friends who knew of her disease:

I remember one time, you know, [husband] saying, 'Look come on, you have to go in,' because you'd maybe had a small accident and I thought, 'I'll just carry on, I'm okay.' But, 'Come on you have to go and get changed,' sort of thing. So that was him feeling more upset for me than I was feeling for myself. I think at that time, I think he was more embarrassed whereas I wasn't. [Jeannie, 58, UC]

Without interviewing William's wife and Jeannie's husband, it is impossible to know if they really do feel stigmatised by their association with a partner who experiences IBD-related incontinence. However, Jeannie's husband doesn't *ask* her if she needs to go and get changed, suggesting concern for her, but *tells* her that she should, indicating that the concern is all his - this is something he wants sorted out because he is bothered by it.

Aspects of disease, such as incontinence, could associate people with IBD with others who experience similar symptoms, albeit for different reasons. The following quote, used in full previously to illustrate cultural expectations of cleanliness and hygiene [Chapter 9], also shows the courtesy stigma that arises by association:

I mean a lot of alcoholics and drug addicts mess themselves often sitting on a park bench or something, and they urinate and things like this. And they're classed as dirty, filthy people, not somebody with a problem - they're associated with that in a way. Or, as a dirty old man. I don't mean sexually dirty old man, I mean an old man who's lost control of his bodily functions because he's old. And people who are younger with, with urinary problems or with IBD, tend to be tarred with the same brush. [Rupert, 68, UC]

Rupert's quote is also useful in demonstrating the complexity of stigma; the bowel condition, the issues with hygiene, perceptions of those existing on the peripheries of society, all combine to give Rupert the impression that he is stigmatised by association with these social images. Courtesy stigma, then, may arise when there is an actual or a perceived relationship between persons or groups.

Similarly, being seen as disabled (by which the broadest interpretation of physical, illness-related and mental incapacity is meant) links people to a minority social group which majority group members may perceive as fraudulent, especially if the incapacity is not apparent (Halligan, et al. 2003). IBD disrupts employment in remission and in relapse: people can frequently be very unwell, and diarrhoea and urgency may demand numerous frequent and urgent toilet visits, limiting capacity to travel to and from work and to reliably access toilets once there. Whilst some employers are supportive, many people with IBD endure financial difficulty but on seeking assistance from the social benefits system, are faced with having to prove their incapacity – perhaps having to 'out' themselves about their bowel control difficulties. The invisible and inconsistent IBD challenges eligibility for social benefit, as assessment systems cope poorly with applicants with fluctuating functional abilities. Below, Esther relays her perceptions of friends' opinions on benefit fraud which they are keen to stress do not apply to her:

But you kind of sit there and go, 'Well, yes, okay, I don't claim disability allowances, but I could try, in theory I could. So I'm not different from these people that you're kind of talking about.' So there is a bit of, I kind of feel in-between groups. And sometimes I do feel sort of stigmatised – or labelled, or associated, yes, in that way.' [Esther, 27, CD]

Esther doesn't currently claim benefits, which situates her in the majority group with her friends; but she could claim, and then would be in the minority group of which her friends have such a low opinion. Courtesy stigma, occurring by association with another marginalised group, depends on the experiencing person's perceptions of those groups. If drunks, alcoholics and people on benefits are seen negatively by the individual with IBD, then any symptoms or other IBD-related event that they experience which links them with those marginalised groups, may lead to courtesy stigma.

9.1.4.5. Kinship stigma

A unique experience emerging from this study data refers to attitudes or behaviours which come from close relatives or intimate partners, and which are directed towards the person with IBD and add to their feelings of being stigmatised. I have entitled this 'Kinship stigma' and as far as I know, it has not been previously specified as a unique form of stigma. Taft and Keefer (2009) have identified that *perceived* stigma from a significant other, spouse or close friends towards the person with IBD has a noteworthy impact on patient wellbeing as measured by the Rating Form of IBD Patient Concerns (Drossman et al. 1991). Although they conclude that stigma within a patient's social support network may be detrimental to patient outcomes and health-related quality of life, their quantitative work cannot explore the nature of this type of stigma.

Kinship stigma seems subtly different from the courtesy stigma exemplified above, where although husbands and wives may feel stigmatised by association, no negative feelings are directed towards the person with IBD. Kinship stigma reflects, instead, a deep sense of feeling let-down, not believed or treated differently by those who are expected to give unconditional support, such as intimate partners, or parents. Goffman (1963a:12) reminds that:

evidence can arise of his possessing an attribute that makes him different from others in the categories of person available for him to be, and of a less desirable kind – in the extreme, a person who is thoroughly bad, or dangerous or weak. He is thus reduced our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive.

The audio files of these interviews evidence the distress felt by participants as they recalled experiences of being stigmatised by partners or parents. Carl had been a successful self-employed builder with responsibility for several employees, and an extensive portfolio of projects. The onset and diagnosis of Crohn's disease had devastated his life, rendering him unable to work or to provide for his wife in the way she had become accustomed to. He lost his business, his home, and his wife:

[The disease] stopped me working and I had a house with a mortgage on it, and I wasn't working. And the money side of things, got into a financial mess and that's when my wife realised that it's time to go, sort of thing, and have a life. And she used to go out with pals on a Friday night and I used to sit in because I just didn't feel like going out. So that's probably a lot to do with it. It could have ended this way anyway, you know, you don't know [but] um, she wasn't really bothered after a couple of years. I'd been in hospital a few times and my daughter had to say, 'You have to see your husband.' It's quite a change - we were 28 years together. [Carl, 54, CD]

Carl felt that his illness reduced him, in his wife's eyes, to a tainted, discounted person; his discrediting mark - the Crohn's disease - had an extensive impact on their life together, rendering him financially unproductive and, it seems, less desirable to her. At the time of interview, Carl had resolved his feelings about his wife's abandonment of him to some extent, but nonetheless had found it difficult. The full transcript of Carl's interview is provided in Appendix 9 [p. 399].

Numerous self-help pages accessible via the World Wide Web advise on the potential negative impact of chronic illness on relationships, with detrimental effects also being evidenced through research (Thompson 2009). The coping ability of the well spouse is influential on the capacity of the relationship to endure (Badr and Acitelli 2005), with the ill partner receiving less support if the spouse is distressed and struggling to adapt to changes enforced by the illness. Poor coping ability may, then, lead to behaviours and attitudes which stigmatise the ill partner. Robust social and emotional support from intimate partners is a beneficial aid to self-management in other chronic conditions (Gallant 2003), and may be as influential in IBD. Tamsin, reflecting on her husband's intolerance of her foul-smelling wind, ponders her decision to get married:

I do have a lot of wind. That's my big thing. And even [my husband] will get annoyed about it. And it's just heartbreaking ... I can't help the way that it is. And I don't know, it's just, yes I think, I think had [my husband], had I known how bad this was going to be, I don't think I'd have got married. Don't get me wrong, I love my husband, but - you know. [Tamsin, 38, CC]

People living with IBD often need support from a wide network of people, including parents. Even as adults, we are always children to our parents and may need their support in times of difficulty, regardless of our age. Tamsin, already finding her husband's intolerance of her odorous wind stigmatising, also feels that her mother's lack of empathy pushes her away:

But at the time I was diagnosed I would never have told [mother] because she just wasn't close and she doesn't do sick people either. She doesn't do sick very well. When [daughter] was about five, I went through a bit of a rough patch - and she could hear on the phone that I wasn't well. But, you know, I obviously didn't tell her what it was. That's the closest, I think, I've ever come to telling her. And at that time she said, 'Oh it's the weather, you just want to pull up your socks and get on with it, it's just the weather. When the weather changes you'll be fine.' And so I've never told her. You know, I've been [to visit her] when I've been all steroided up, and she laughs and goes, 'Oh you look well,' and she almost seems to relish the fact that I've got quite big. And then obviously I go the other end of the scale and I get quite slim and she tells me I'm not eating enough and I must be anorexic. So there's no, there's no winning there. But being in hospital recently, she has sounded worried, but she seems to flip between absolutely hysterical that I'm in hospital and it must be very serious, to, 'Oh I think you're just enjoying it in there too much and you just, you know, should...' [Tamsin, 38, CC]

Tamsin passed on the early opportunity to explain her illness and now cannot bridge that emotional distance to her mother. The extract demonstrates a deep complexity of feeling with evidence of anticipated, perceived and kinship stigma. During the interview, Tamsin had previously explained her mother's reaction of disgust towards a young girl who had a stoma and was formerly employed by Tamsin's father. Knowing this, and aware of her mother's abhorrence of anything to do with stools, or illness, Tamsin *anticipates* a negative response and so will not broach the subject of her disease with her mother. Tamsin *perceives* that her mother thinks less of her because she is seen as overweight, under-nourished, or hospitalised without good reason. The kinship stigma comes from being emotionally shunned and isolated by her mother's inability to 'do sick people,' not even for her own daughter, and her expectation of who and what

Tamsin should be. How keenly Tamsin feels this may be a reflection of what she perceives a maternal role to be, based on her experience with her own children.

Not being believed by a parent may represent a fundamental form of betrayal. Prior to her illness, Lillian was fit and healthy, and working in journalism. She now has complex medical needs and is mostly bed-bound due to severe osteoporosis and the effects of a stroke during stoma-forming surgery for Crohn's disease:

My mother refuses to this day to acknowledge there is anything wrong with me, because she doesn't fully understand the illness that caused it and blamed my eating habits. She believed that something I was eating must be causing this, that I was doing it on purpose. And it came as a shock that she even said to [my husband] the other day – she said, 'If she got out of that bed and did some work,' you know. [But] I have to be very, very careful. Walking frame, wheelchair, whatever, we do it. But to my mother, who is a very fit 93 years old, it's seen as something that upsets her own image of what I should be. And so that, from family, came as a shock. We did try and explain it to her, eventually showing her my [stoma] bag, to try and really get through this brick wall that she was putting up. But she just doesn't want to know, and it's such a shame because I feel that our relationship has become so distant because of it. And there is no hope for that. It is very difficult for me to accept that stigma coming from my own parent. [Lillian, 61, CD]

The key to the kinship stigma here is that Lillian now doesn't match her mother's perceptions of what she should be. Lillian is, in Goffman's terms, 'reduced from a whole and usual person to a tainted, discounted one' (Goffman 1963:12). Her final sentence underlines the uniqueness of stigma that comes from family members.

Although Carl, Tamsin and Lillian all describe examples of being treated negatively by close family members, Lillian most notably, was more resilient against it. When I asked her about this, she explained that she completely appreciated her mother's responses. These first representations of kinship stigma suggest a unique difference between stigmatising responses that come from intimate or genetic relationships, and those that

come from other sources. Although there are only a very few examples in these interviews, this experience is no less meaningful to those affected; the finding also helps illustrate the range of stigma experience and promotes the potential for further research into a newly-emerging phenomenon.

9.2. Summary

The constitutive pattern *Relationships and social support* unites the four relational themes of *Revealing IBD*, *Social expectations and norms*, *Responsibility and blame*, and *State and flux of stigma*. Aspects of sharing disease information, the potential impact of often taboo information on social interactions, cause of disease and disease symptoms, and different forms of stigma have been shown / revealed in the data. Every participant referred to the impact of relationships and support networks on their life with IBD.

Across these four relational themes, those who purposefully revealed IBD information to create an effective support network seemed less bothered by negative or stigmatising responses from others. They appreciated the relationship between the social challenge their illness presents, and the cultural requirements regarding hygiene and cleanliness. Potentially stigmatising episodes were experienced but had little impact. In contrast, those who hid their IBD through passing or covering tactics often lacked effective support networks. An inability to uphold hygiene and cleanliness expectations troubled them more, and they were more affected by stigmatising experiences. These participants were often those who also struggled to gain a sense of control over their disease.

Stigma is shown to be a complex experience. One experience can be interpreted in a number of ways, depending on the background, pre-understanding and existing knowledge of the experiencing person. Kinship stigma has been introduced as a potentially new form of stigma, which requires further investigation.

In Chapter 10, different aspects of the relational theme of *State and flux of stigma*, and the new themes of *Resilience* and *Upbringing* are presented in connection with the final constitutive pattern of *Mastery and mediation*. All findings are discussed in Chapter 11.

10. Findings and analysis (iii): Mastery and mediation

The final findings chapter presents the third constitutive pattern of *Mastery and mediation*, addressing the role that experience and acceptance of life and illness play in perceptions of stigma in IBD.

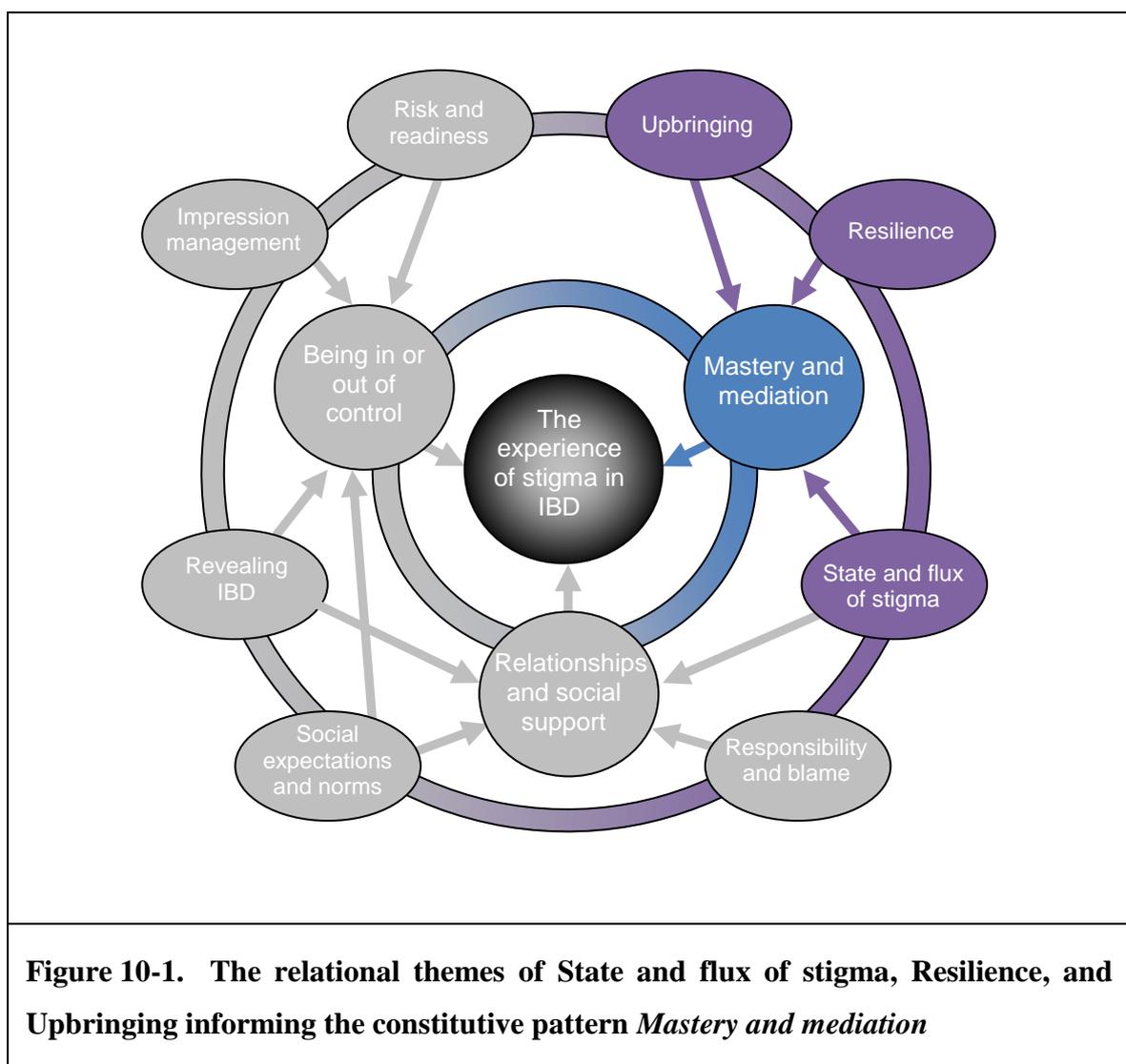
As discussed in Chapter 9, several participants reported experiences of anticipated, perceived, enacted, courtesy or kinship stigma, yet not all felt stigmatised. Often, these participants *had* felt stigmatised at diagnosis but with time and experience had learnt to overcome these feelings. Others with long illness careers remained stigmatised, and some recently diagnosed were not, while a few reported never having been stigmatised, suggesting that factors other than time contribute to stigma resistance. Joachim and Acorn (2000b) advise that stigma and normalisation - the process of adjusting to life with a chronic illness - must be addressed together to understand the full complexity of the chronic illness experience. This chapter explores how participants respond to stigma, either by *mediating* between the challenges their disease presents and drawing on other life skills to become *masters* of their situation, or by internalising stigma and succumbing to its negative effects. The idea of 'approaching mastery' has previously been reported in people with diverse causes of faecal incontinence (Wilson 2007). The participants who revealed attitudes and approaches to illness which seem to offer resistance (standing against) and resilience (hardiness) against stigma came from the *no stigma* subgroups and tended to be those who, in the previous constitutive patterns, had a firm sense of control over their disease and a strong support network.

This chapter:

- presents the findings from analysis represented by the constitutive pattern *Mastery and mediation* and its three relational themes
- draws all three findings chapters together through the use of vignettes.

10.1. Constitutive pattern: Mastery and mediation

The constitutive pattern *Mastery and mediation* unites the relational themes of *State and flux of stigma*, *Resilience* and *Upbringing* [Figure 10-1]. Stigma fluctuates over time and across social situations, and tends to decrease as the person's knowledge and understanding of their IBD increases. Some participants reported internalised negative feelings resulting in self-stigma, whilst others revealed aspects of self which seemed to protect them against stigma.



Mastery and mediation refers to the influence of life experience and illness acceptance (or not) on perceptions of stigma. Those who achieve mastery can strike a balance between the demands of life and of IBD. Maeve's [*No FI, no stigma*] example of accepting and working with disease-related fatigue explains the emotional value of this:

You do get down, there are times when you're fatigued and you think, 'Oh I know I've got to do this and I know I've got to do that,' and coming to terms and thinking, 'Okay, fine, what's vital, what is essential that [I] do?' The only thing that's essential is you maybe have to connect with an insurance company or the bank or whatever it is, everything else – life is not going to end if you don't cut the front lawn. [Maeve, 65, UC]

Maeve recognises that her IBD can overwhelm her but putting things in perspective and conserving energy for issues that really matter 'allows' her to adjust to the demands of life and illness and accept that she must do things differently. Acceptance is part of chronic illness normalisation in which people learn to function well by dealing positively with their changed situation (Thorne 1993). Normalisation enables those with chronic illness to 'fit in' with the normalness of society, thereby avoiding discredit and stigma (Joachim and Acorn 2000b). It requires the individual to make the challenging transition from their former life and self to their new, post-diagnosis identity which incorporates illness into the existing sense of self, rather than replacing it entirely (Kralik and van Loon 2010). Juliet [*FI, no stigma*] explains:

When you're in hospital and you're first diagnosed, that's always how you feel, you feel, 'I'm defined by this illness.' Somebody comes to your bed and they're looking at your [charts], you've got Crohn's disease, that's who you are. So I think as soon as you come out of hospital, you're constantly, 'No, that's not me, I am me, I just happen to have this that I deal with. [Juliet, 53, CD]

Juliet's final sentence reflects the importance of establishing and accepting the new identity and of putting the illness part of that identity into the background, so it does not become the defining aspect of self. Making this adjustment may not be straightforward -

disease demands can, particularly in a relapsing-remitting illness like IBD, repeatedly move chronic illness between the foreground and background of daily life (Paterson 2001). IBD can be more or less prominent at different times, so that support needs fluctuate between dependence and independence (Delmar et al. 2006). Learning to live with changeability seems important in enabling people to live well with IBD (Kiebles et al. 2010). Lily [*FI, no stigma*] explains the pivotal moment for her in making this adjustment:

I've come to realise that the strong thing to do isn't to pretend [the illness] is not there and carry on regardless. The strong thing to do is to accept that you have some limitations, to accept that actually life is going to have to change a bit, but that doesn't mean I can't do things, it just means I have to do things a bit differently to everyone else. And that's been a really good realisation for me.
[Lily, 31, CD]

Chapter 9 has shown that stigma is an experience of perception, and depends on the experiencing person's responses to social and cultural norms, or to another's attempts to stigmatise. How people with IBD feel about other features of difference may influence the way they respond to their own difference, or mark. Accepting the mark into one's identity both normalises and destigmatises it.

Lily and Maeve had, at the time of interview, had their diagnosis for 10 and 25 years respectively. Belinda [*No FI, no stigma*] was diagnosed only three and a half years prior to interview, yet felt she had adjusted well to IBD. Experience of life, and a strong faith, influenced Belinda's response to multiple recent diagnoses:

[It's just] another thing, because the asthma, the high blood pressure, high cholesterol, diabetes, all started after they said about the Crohn's [and] when you go to the doctor and every day there's something else, it is a thing where you could sit there and think [poor me] you know, and really start feeling sorry for yourself. And I just thought, 'Okay God, well alright, bring it on,' you know. 'What do you want me to do?' [Belinda, 55, CD]

Those with medical or nursing experience had the benefit of professional insight at an early stage of their disease. Jeannie [*FI, no stigma*] and Vivienne [*No FI, no stigma*], were able to normalise their IBD within the context of their professional knowledge:

Once I got the diagnosis, that was a lot better because then at least I said ‘Well yes that’s why I’ve got all these symptoms, you know,’ because ... **they then made sense?** Yes, so that, that helped a lot and um, and then you say, ‘Alright, I’ll deal with this now, just try and get on with it and see what [happens].’ [Jeannie, 58, UC]

Making sense of a new situation and understanding it in light of existing knowledge enabled Jeannie to work confidently with, instead of against, her illness. Normalising her situation in the context of her professional experience protects her from stigma. Knowledge and the passage of time do contribute to stigma reduction (Frohlich 2014; Millen and Walker 2000), and when professional insight facilitates social interaction, this process may be accelerated. Vivienne explains how her nursing background helps her to feel supported:

I’ve had colitis since 1992, and I think gradually, once you understand it better and you get a lot more information about it, you realise there’s more people out there. But I think, being a nurse, I’ve never had problems talking about bowels, so I’ve always been open with people. All my friends know, my colleagues know ... I think it just helps you not feel you’ve got a problem with it. [Vivienne, 52, UC]

Vivienne is able to be open about her UC due to knowledge of the topic amongst colleagues and friends – in her support network, bowels are not taboo but a normal part of conversation. The importance of a robust support network in overcoming stigma was evidenced in Chapter 9. When others already know of a mark, there is no fear of discovery, no risk of being discredited. The relief this brings, historically very well documented in relation to coming out about sexual identity (for example Hunter 2007; Jordan and Deluty 1998; Saphira and Glover 2001) and mental health (Corrigan et al. 2009; Corrigan et al. 2013) can overcome the challenges and risks of revealing sensitive information (King et al 2008).

Concerns about other's perceptions also become less bothersome with age and maturity. Hinting at the role of peer relationships in late adolescent development when 'being the same' is considered essential for an individual to feel they belong to their peer group (Smith et al. 1998), Tina [*FI, no stigma*] explains how her perceptions on 'fitting in' have changed over time since she was diagnosed:

At the beginning it was kind of quite stressful – I was only 19 and not knowing what the future held and how other people would react. I think when you're younger, you want people to like you more and you think if you're going to be different in any way, then people aren't going to like you. Whereas now, I couldn't care, they can just accept us the way I am, and if you don't like it, well you're not my friend. [Tina, 45, UC]

Tina's maturational thinking here reflects Erikson's (1968) developmental stages. In adolescence, individuals confirm their identity through primary social interactions with their peers, and anything which marks them as different threatens to isolate them from the in-group. By middle age, identity is set and the primary social concern moves towards establishing and guiding future generations. Tina also explained that she would discuss her condition with anyone, at any opportunity, feeling it important to do what she could to educate others. Confidence in her self-identity, confirmed over time, contributes to stigma resistance by promoting self-esteem. Self-esteem has been shown to affect stress and symptoms of disease: lower self-esteem correlates with higher levels of stress and worse symptoms in chronic illness (Juth et al. 2008) and in mental health (Link et al. 2001); higher self-esteem has been shown to reduce stress levels and improve symptoms in IBD (Taft et al. 2013).

In contrast Andrew [*No FI, stigma*], diagnosed in his sixties, was struggling to adjust to UC, diabetes and being wheelchair-bound due to spinal surgery. It was difficult to tease out how much of Andrew's stigma was due to his drastically-reduced mobility, and how much to his IBD: 'I think I must admit that when you combine the physical disability and the IBD, I guess I'm still struggling with that subconsciously' [Andrew, 69, UC].

Andrew's story reflects the normative crisis of integrity versus despair in Erikson's (1968) final stage of development. These illnesses have robbed Andrew of his independence and, as his interview illustrates, he is now unsure of his role and purpose in life. Andrew had a strong support network and a devoted wife, but did not feel in control of his situation, his mobility, or his IBD. His self-stigma came from no longer being the person or husband he felt he should, and wanted, to be.

For those participants who did not feel stigmatised, feelings of stigma had often diminished over time as a sense of mastery of illness had been achieved. Some who do not achieve this mastery may internalising negative feelings and stigmatise themselves:

It's because it [faecal incontinence] horrifies me so much that I project – to me it seems natural that it would horrify other people and therefore they think a bit less of you ... you know how people react. I know how I would react. It's not pleasant, it's not nice.' [Andrea, 47, CD]

Andrea's comment reflects the impact of social standards on the self – that we expect of ourselves what we expect of our particular social category (Saylor 1990), in this case, that of 'human competent adult.'

The pattern *Mastery and mediation* unites the relational themes of *State and flux of stigma*, *Resilience*, and *Upbringing*. Within these themes, participants described a wide range of events and experiences encountered throughout life which influenced their ability to gain competence in and acceptance of their IBD.

10.1.1. Relational theme: State and flux of stigma

In the previous chapter, several types of stigma within this relational theme which arise out of relationships with others have been presented. In this constitutive pattern of *Mastery and mediation*, two remaining aspects of the theme are addressed. *Self-stigma* links with this pattern because although it can arise from what Williams (2014) refers to

as ‘repeated little indignities’ emerging from interactions with others, in this study it affected the ability to gain mastery. Gaining mastery, and mediating between challenges often parallels the way that *stigma fluctuates* across relationships and over time.

10.1.1.1. Self stigma

Self, or internalised stigma, refers to the extent to which an individual adopts wider negative social attitudes towards certain features. It has previously been reported in relation to, for example, sexual minority adults (Herek et al. 2009), mental health (Brohan et al. 2010; Ritsher 2003), and IBD (Taft and Keefer 2010; Taft et al. 2013). In this study, those who *self-stigmatised* reflected the negative social perceptions of their disease as anti-social and dirty, and were unable to meet their own expectations of self. Participants often recognised that they created their own stigma. Marion [*No FI, stigma*] had intimated that she felt her disease was disgusting so I asked her where those feelings of disgust came from:

I guess the answer to the question is, it comes from me, you know, and how I feel about it and I think it’s disgusting and I think it’s horrible and smelly and going to the toilet all the time and seeing all this gunk and blood and mucus. So I think it’s disgusting, so I guess if I thought people knew the full extent of what I see every day, they would think the same ... **and does that automatically mean that if they think the condition is disgusting, that they would think that you were?** Yes.
[Marion, 37, UC]

Marion had only been diagnosed for three years, and was struggling to cope with extreme urgency and frequency that sent her ‘running to the toilet all the time.’ Her self-stigma was based on her belief that should her illness be exposed, others would find her condition disgusting, so she must be disgusting as well. The potential for discredit guides her perception.

In Chapter 8, the importance of having actual physical control or a sense of emotional control in avoiding stigma was revealed. In this example, Sharon [*FI, stigma*] suggests that her stigma comes from herself because she cannot control her IBD:

I think probably one of the reasons I feel so bad is because when I was working I had a high position and everybody looked up to me. And um, it's something to do with that – I was in control of everybody and this is because I cannot control it. It's awful that I can't control something in my life whereas before I could, you know. It's horrible. [Sharon, 61, CD]

Unable to maintain her own expectations of herself as a competent, in control person, Sharon imagines that her 'fall from grace' would be viewed negatively, and so thinks less of herself and self-stigmatises. Self-stigma could also come from having to be helped, emphasising the change from independence and autonomy to dependence and reliance on others. Andrew [*No FI, stigma*] had been a child protection social worker, but now depended on his wife for assistance with bowel care:

My wife doing what she does for me, you know, that's devotion which also gives me embarrassment. **So being helped, her devotion and care for you is difficult to accept?** It isn't now as difficult, but because I've always been an independent person by the very nature of the type of work I've done over the years, I, I was personally accountable for myself, the decisions I made – and legally I had to stand by those. When you have [had] that responsibility, and that autonomy, you – well, I personally found it quite hard to do that. [Andrew, 69, UC].

For these participants, the inability to overcome self-stigma disrupted their capacity to adjust to illness, to incorporate it into their new identity, and to gain mastery over their situation. Incorporation requires acceptance of the challenges presented by chronic illness (Stanton et al. 2007). Related emotional and psychosocial stresses which may include self-stigma, also challenge adjustment to IBD (Kiebles et al. 2010). Taft et al. (2013) suggest that the ability to offset self-stigma in IBD may be enhanced by involvement in social activities such as patient advocacy groups which reciprocate with

support. These study findings have already demonstrated the positive impact on participants of having a support network which suited their needs, be that social, family or professional support. Participants who self-stigmatised almost always reported a gap in their support network.

10.1.1.2. Stigma fluctuates

Most participants were influenced by stigma at some point during their IBD experience. Stigma *fluctuated* according to personal interactions, disease visibility, and the passage of time. Supporting the theory that stigma is relational (Goffman 1963a; Scambler 2009), Philip [*FI, stigma*] explains that whether he feels stigmatised or not depends on the relationship between him and those he is with:

That's probably the biggest thing is if you have an accident, depending on who you're with. It can be an issue. If you're with family, for example, like going with the kids and stuff, they acknowledge there's a problem. And if you're with close friends they can live with it a little bit. But if you're with extended family or with people from work, for example, who don't really appreciate what the condition is, it's, well yes, 'Can't even control himself,' sort of thing. [Philip, 55, CD]

Visibility of the mark also caused variation in stigma. Belinda [*No FI, no stigma*] explained that her very visible difference in skin colour was a problem: 'as a black person you can get stigmatised in a white environment ... people think that you are less of a person because of your colour,' whilst her invisible IBD was not: 'it's not something that you can visually see ... so I don't feel stigmatised because nobody knows.' Other participants, especially those without FI, concurred with Belinda's statement. For these respondents, invisibility and good bowel control protected against stigma as there was minimal risk of being discredited. For others with less reliable control, stigma could emerge either through fear of loss of control and potential discredit, or when poor control made their problem visible. Following Goffman's (1963a) lead, others have considered the peculiar challenges associated with marks that

are either visible or invisible (for example Joachim and Acorn 2000; Crocker et al. 1998; Smart and Wegner 2000). Due to its unpredictable pattern, IBD can be fully *invisible* if well-controlled without FI, fully *visible* if poorly controlled with occasions of FI, or oscillate between the two. Invisibility of disease and symptom can be protective but can also be stigmatising as without clear evidence of illness, some participants felt they were not believed:

People judge you ... they kind of think, ‘She must be making it up because she looks fine.’ And that is my biggest problem is that I do look fine and especially when I’ve had the steroids and you put on weight, and people think, ‘She looks really well, she’s been eating loads.’ [Tamsin, 38, CD]

IBD-related stigma fluctuates. Visible and invisible aspects of the condition can be permanently beneficial or problematic, or change with the unpredictable relapsing-remitting pattern of disease. There is no simple relationship between stigma and IBD, or stigma and IBD-related FI. If the diagnosis of IBD prompted stigma creation, everyone in the study would report stigma. Table 9.1 [Chapter 9: p. 176] illustrates that most participants have had experiences of stigma regardless of FI status. Most also refer to the antisocial, unhygienic or dirty nature of disease irrespective of FI status, suggesting that the inability to adhere to social rules about discreet bowel management, control and stool containment underpins stigma in IBD.

Socio-cultural / geographical aspects can also be influential and a mark can lead to stigma in one setting, but not in another (Watkins and Jacoby 2007). Rupert [*FI, stigma*] grew up in a rural farming community where mud and animal waste were part of everyday life. He explained his changed feelings about bodily functions when he left this community and became sensitised to majority attitudes:

I became more embarrassed when I moved away from home [and] got away from [my parents’] influence if you like. Now it’s gone again, you know ... I regained inhibitions about things ... slowly, I became more of the norm if you like, and less of the, the sort of open minded country boy kind of attitude. [Rupert, 68, UC]

The passage of time increased Rupert's stigma as he moved further away from the influences of his youth and became socialised into 'normal' responses to dirt and waste, making it harder for him to tolerate the dirty nature of his disease. Time could also reduce stigma as attitudes towards self and disease changed with maturity. Caroline [34, CC, *No FI, no stigma*] explained that she had felt stigmatised when first diagnosed 16 years previously, but did not feel so now. I asked her what had enabled this change:

I think I just got older. When you're 19 you've just got through that phase of [being] 13, 14 your periods first start and you're convinced you're walking round with a sign on your head ... but you're not and nobody cares. And then you get to 19 and discover you've got bowel disease. [My diagnosis] happened really fast. So you kind of walk out of the hospital after the diagnosis thinking, 'I've got a sign on my head.' And then as the years grind on, you realise actually nobody really cares that much. And it doesn't really matter. It's changed over the years.

Other participants also became less stigmatised over time as they became familiar with, knowledgeable about and competent in, managing their IBD. Experience and not being alone with IBD seem to help in reducing the stigma that may come from being different:

Well I think, well I've had colitis since 1992, and I think gradually, once you understand it better and you get a lot more information about it, you realise there's more people out there [with it]. [Vivienne, 52, UC]

Knowing others are in a similar situation enables people to assume membership of an actual or virtual group which contributes to their sense of identity and therefore their self-esteem. For some, like Vivienne, just knowing there are others 'out there' may be enough to overcome a sense of isolation, whilst others needed to be active in formal support groups to confirm their sense of group identity.

Caroline [34, CC, *No FI, no stigma*] also offers an example of how time, and illness events, can take the person with IBD from resisting and struggling with disease to a sense of acceptance and learning to live with the condition:

I [realised], ‘Do you know what, I have to share my body with this disease whether I like it or not. So we may as well just rub along, because it’s not getting rid of me and I’m not getting rid of it, so we may as well just co-operate.’

Her comment reminded me of Chinese handcuffs (finger traps) – the more one struggles, the tighter they bind, whilst dropping resistance releases the grip. Caroline is not describing passive acquiescence, though, but meaningful acceptance. For others, the passage of time brought better control of symptoms. As the disease became more predictable and reliable, perhaps in response to effective medications, stigma disappeared. Charles explains:

As far as stigma or anything else is concerned, no it doesn’t bother me now. I’ve got beyond that. It used to, because I had to think [about what I could do]. Before [consultant] gave me the Questran®, which literally did transform my life, I couldn’t go anywhere without being concerned and worried. [Charles, 78, CD]

Questran® binds bile salts and resolves diarrhoea that arises following certain types of bowel resection. Although as with other IBD medicines, it may not suit everybody, if it is effective it can be transformational. However, even with effective medical management, normally good control and an absence of feelings of stigmatisation, the risk of ‘breakthrough’ stigma remained:

I don’t know if it’s psychological that if you have an accident, then I’m aware of the smell, everyone else with me will be aware of the smell, of what it’s going to be. I don’t know if it’s yes, conscious of the fact that there is a smell. So people might associate me with that smell and a mess or something like that. Yes it is, that is my biggest concern when I’m in relapse. [Jacob, 34, CC]

Jacob [*FI, no stigma*] was concerned about what others would think about him in the event of a bowel accident. He doesn’t usually feel stigmatised, but this extract indicates that there are occasions when he can be, as he believes others would think of him as a smelly, dirty person if he did a smelly, dirty thing.

These findings suggest that while it does fluctuate, the overall trend is for a reduction in stigma as diagnosis duration and disease expertise increases, particularly if there is also a strong support network and a good sense of control. If any one of these three components - control, support, mastery - are absent or inadequate, then stigma is more likely to endure despite disease duration. Stigma reduction is aided by being able to conceal evidence of the disease, but can be punctuated by 'breakthrough' stigma linked to revealing symptoms such as incontinence, and odorous wind.

10.1.2. Relational theme: Resilience

Resilience refers to the ability of an individual to adapt to changing, often challenging environments, including adjusting to limitations and recovering from misfortune (Cohn et al. 2009). Stigma may thus be more likely amongst the less resilient. Health-related stigma resistance has been explored in the context of chosen and enforced (due to infertility) childlessness in India (Riessman 2000), mental health (Corrigan et al. 2013), and a quantitative IBD study (Taft et al. 2013). A core attribute amongst participants in these cited studies was the ability to view their situation positively by accepting and adjusting to any health-related limitations.

Certain characteristics of the individual with IBD appear to promote stigma resistance, resulting in *resilience* against stigma. Resilience in IBD is informed by personality, mental health, humour and perspective - aspects which emerged during early analysis [see Chapter 7: Figure 7-5, p. 120].

10.1.2.1. Personality

All members of the *No FI, no stigma* subgroup, and some others including those in the *FI, stigma* subgroup indicated at interview that they had a positive, upbeat personality with the attitude that anything could be coped with. They perceived that there are needy people and those who cope with anything, and the former may struggle more with IBD:

There are dependent personalities aren't there? - and some people who just think, 'Alright, I've got it, I'll deal with it and carry on.' [Vivienne, 52, UC]

Robertson et al. (1989) and Sajadinejad et al. (2012) suggest that patients with IBD are more likely to have high levels of neuroticism, be introverted, and perfectionist, when compared to healthy controls. Personality was not measured in this study, so it cannot be stated whether this is true or not of any of the forty study participants. Irrespective of self-assigned study sub-group (*No FI, no stigma; FI, no stigma; FI, stigma; No FI, stigma*), many participants gave the impression that they faced their disease-related challenges with a positive, pragmatic, and realistic attitude, whilst others indicated that they had a more negative outlook and tended to worry. Sajadinejad et al. (2012) also suggest that perfectionists with IBD may find the disease a particular challenge because they cannot meet their own hygiene and cleanliness standards. Several participants were concerned about their inability to meet social rules about hygiene, and stigma could come from society's expectations of them, as well as from themselves:

I'm 47. I'm not expected to soil myself periodically at my age. It's something people wouldn't expect, [Andrea, 47, CD, *FI, stigma*]

Whilst bowels were identified as a taboo topic and there were concerns about smelling and being clean, only Carl [*FI, stigma*] who stressed that he was 'brought up to be clean,' and Rupert [*FI, stigma*], who found society's excessive cleanliness and hygiene demands challenging, seemed to really struggle with a cleanliness perfection ideal. Cheryl, revealing that she has obsessive compulsive disorder, gave the only other indication of perfectionism. She expressed stigmatising attitudes towards others, describing herself as intolerant of those who complain:

Some people, I think, are weak, are weak characters, not mentally strong. And I think they wouldn't go to work because they had a bowel problem... I think if you are a sort of weaker person generally, then you would allow it to affect you perhaps. [But] none of us [family] are moaners, we're just people that get on. Whereas where [my husband] works people are the complete opposite, you know,

there's nothing diagnosed, but she has time off all the time for something that's not even there. I have no sympathy towards people like that. [Cheryl, 29, UC]

Cheryl's symptoms were mild and very well controlled, which perhaps influenced her apparent lack of awareness of the complex issues others with IBD can face. Cheryl had previously commented that she could resist feeling stigmatised because her illness is invisible so no-one need know about it, yet she is disparaging about her husband's work colleague because there is no visible reason for the person's perpetual absenteeism.

Despite being confronted with significant difficulties, participants often found ways of overcoming these. Several of the following excerpts contain no evidence of stigma but showcase the traits seen amongst those who seemed more resilient. Caroline [34, CC, *No FI, no stigma*] has found an alternative way to managing her IBD as she can no longer take any of the main IBD drugs due to side-effects:

I'm now classed as CKD [chronic kidney disease] stage 3 and there is no medication. And I can't take steroids anymore because I've got femoral osteopenia [reduced bone density, precursor to osteoporosis]. And so there is no medication apart from Infliximab and you've read the side effects of that. So I said, 'No, you're alright. I will do it purely on diet and herbs,' which is what I've done for three and a half years now.

By taking charge of her situation and being in control of her IBD symptoms, Caroline's self-esteem may be enhanced, thus enabling stigma resistance. Taft et al. (2013) have evidenced a link between self-esteem and stigma resistance in IBD, demonstrating improved resistance with improved self-esteem. Self-efficacy, the ability to use skills and knowledge in a given situation to behave optimally (Bandura 1982), may also be influential. Caroline is using knowledge of alternative medicine methods to manage her IBD effectively; she has judged herself capable and amended her disease-management behaviour, motivated by her self-perception of efficacy. Bandura (1982) explains that self-perceptions of efficacy are not simply inert estimates of future action. Instead, self-appraisals of operative capabilities help to determine how people behave, their thought

patterns, and the emotional reactions they experience in taxing situations. This may explain Juliet's tactic for working out how to cope:

I'm not pessimistic, I'm quite realistic and I like to think through all the options. [I] think 'What's the worst that can happen?' Right, now I know what the worst is, how do I deal with that? I don't think that's pessimism. I do that a lot in my life. I think, 'Well yes, okay, weigh up the options ...' and then I feel like I've made a choice and I'll deal with that. [Juliet, 53, CD]

Juliet uses the same strategy to manage her IBD as she does other life difficulties, and may be 'making a self-appraisal of operative capabilities' (Bandura 1982:123) by drawing on previous effective actions to manage new challenging situations.

Making choices about how to manage disease-related problems may bring a stronger sense of control and enhance resilience, whilst being caught up in a rollercoaster of disease-related events - such as Carl's [*FI, stigma*] emergency life-saving stoma-forming surgery - can compromise control and lead to stigmatisation:

The one thing I didn't want [was] to be left with a stoma. The last operation when they said they was putting me back on the stoma, I said I'm not signing for it, and they said, 'Well you've got about an hour to live if you don't.' [Carl, 54, CD]

Carl was left with a stoma which troubles him, because the ever-present and ever-visible dirt (the stool in the bag) compromises his ingrained expectations of cleanliness and causes feelings of stigma.

10.1.2.2. Mental health

IBD is known to affect mental health, with anxiety and depression negatively affecting patient outcomes such as symptom severity and health-related quality of life (Graff et al. 2006; Mikocka-Walus et al. 2007; Nahon et al. 2012). Although many participants in

this study appeared mentally robust, not all were resilient and a few explained the challenges of depression and anxiety on their mental wellbeing. Michael [*FI, no stigma*], explained what happened when he sought help for the extreme anxiety which was compounding his urgency problem:

I went to see the consultant again and said, 'I'm really terrible.' And, 'So I think I need some cognitive behaviour therapy or something like that,' and I explained... he said, 'Oh, I think you're depressed.' And I said, 'I'm certainly not happy, but I'm not depressed, I don't think I'm depressed.' I've got depression in the family, so I know what depression looks like. I've got a rough idea. [Michael, 46, CD]

In attempting to be pro-active in dealing with his anxiety, Michael faced gaining another stigmatising label. The social view of mental illness is so negative that Michael wished to avoid the label, especially as he thought it inaccurate. Addressing the anxiety which perpetuates urgency would improve Michael's bowel control, reduce the risk of incontinence, avoid discredit and reduce stigma.

Reggie [61, UC] also felt that IBD affected him emotionally. Despite assigning himself to the *FI, stigma* group, he spoke about depression rather than stigma:

I think it, as an emotional feeling, it's basically like a slight depression. When you are really feeling bad with it, whether it's because of the number of visits you're going to the toilet or the [other] problems that it can cause, it does at times make you feel depressed. And whether that's because you think, 'Oh well I can't go out and do something,' or it just makes you feel that way, basically for a while you do go into a depression... you can quite easily just sit and get more and more depressed about it. [Reggie, 61, UC]

Staying home and feeling depressed about IBD isolates people from their support networks, highlights differences between them (the housebound ill) and normal people going about their daily business, and increases stigma. Hatzenbuehler et al. (2009) have reported similar patterns of isolation and difference in relation to sexual minority

stigma. Janice [*FI, no stigma*] who stayed at home to avoid stigmatising experiences, suggested that IBD could compound existing feelings of low self-worth:

I think it's to do with low self-esteem and nothing to do with Crohn's... but maybe if you're bottling things up and if you're screwed up that makes Crohn's worse or makes you more vulnerable to Crohn's ... as Crohn's has isolated me, I suppose, to some extent, I've isolated myself because of the Crohn's. [Janice, 62, CD]

Janice appears to be contradicting herself about whether her low self-esteem is related to Crohn's or not. This is a 'moment' - an epiphany of understanding when the interviewee realises something for the first time (McCormack 2000a). As she talks, Janice works out the relationship between her low-self-esteem, self-enforced isolation, and Crohn's. Her full interview reveals that she doesn't feel in control, has limited social support and has not gained mastery over her condition.

Sharon was the only participant to express extreme thoughts caused by her disease-related incontinence:

I don't have [incontinence] all the time, because I lead my life to avoid it happening [but] when it happens, I just feel it's the end of the world. I can't explain how I feel really, I just feel so horrible, dirty, you know, that I don't want to live my life in this condition, real depressed, almost suicidal after an accident like that. [Sharon, 61, CD, *FI, Stigma*]

Sharon felt stigmatised by her poor bowel control and considered the loss of the local IBD support group, her only source of social support, to be the catalyst for her feelings of stigma. Suicide ideation has been linked to severe IBD symptoms, including intractable incontinence (Okoji et al. 2009), and the risk of death by suicide is greater amongst patients with IBD, particularly Crohn's disease, than in the general population (Gradus et al. 2010). Appropriate mental health support for vulnerable people with IBD is considered essential to avoid this tragic outcome (Triantafillidis et al. 2002).

10.1.2.3. Humour

In contrast, several people explained their use of humour as a coping mechanism. Goffman demonstrates how stigmatised people use humour to deflect others' negative attitudes. For example, borrowing from earlier authors, he reports a one-legged girl whose response to persistent comments of, 'My poor girl, you've lost your leg' was the retort, 'How careless of me!' (Goffman 1963a:162). Whilst rarely amusing during an illness crisis, resilient participants were able to recall previously distressing events with humour. Maeve [*No FI, no stigma*] tells the now amusing story of her behaviour at diagnosis:

[The hospital staff] were very kind and very nice and I remember bringing my letter from the hospital to the medical centre and I cried all the way home (*laughs*). I cried all the way to the medical centre and I sat in the waiting room and they moved me into another room because I was crying (*laughs*) all the time. Upsetting everybody in the waiting room (*laughs*). [Maeve, 65, UC]

Humour is an effective antidote to tension and stress which shields people against negative effects of a situation by enabling a positive re-appraisal of a challenging event (Abel 2002). As a coping mechanism, humour seems to improve people's social quality of life (Nezlek and Derks (2001), but there is a difference between laughing *with* and laughing *at* someone. Glenn (2003) explains laughing *at* as hostile laughter, designed to ridicule and demean, and laughing *with* as affiliative, giving a sense of support and shared understanding. Tina [*FI, no stigma*], whose efforts to retain stool by clenching buttocks and holding the anal sphincter in a tight squeeze whilst trying to reach the toilet cause her to perform 'funny walks' explains:

The family tend to take the Mickey out of us because they know when it's me colitis that makes us go to the toilet, because they'll, when I come out they'll go, 'Oh that was a new walk mum!' (*Laughs*). And they'll start parading up and down the living room showing us me latest walk to the toilet! [Tina, 45, UC]

Tina's family laugh *with* her about the physically amusing aspects of her disease, and in doing so, show their understanding and support. Humour could also be used to deflect negative responses. Caroline [34, UC, *No FI, no stigma*] explains:

(*Chuckles*). I went to a gig at a local pub a few weeks ago and after an hour I thought, 'Uh oh, it's playing me up, I've got to go.' So I went and oh my, it was a stinker as well and I thought, 'At least there's no one outside.' So I go out and wash my hands and two girls came in and one went, 'Oh God it smells like shit in here.' And I was washing my hands and I said, (*laughs*), and I said to her all sweetly, 'It is a toilet.' (*Laughs*). And she had no idea it was mine, and I just thought, 'What a stupid thing to say, you're stood in a toilet!' (*Laughs*)

Humour can also educate. Researchers are exploring the potential for use of cartoon materials to promote self-management in a range of chronic conditions including IBD (Kennedy et al. 2014). Elsa [*FI, no stigma*], who describes herself as a young, attractive woman, purposefully does stand-up comedy about her IBD to highlight the point that there is no relationship between person and the type of illness they can experience: 'That's why I glam myself up even more on the stage - there's nothing like talking about shit when you've got lipstick and heels on' [Elsa, 29, UC]. Elsa's use of humour is very open, and, as she explains further in her interview, can give audience members permission to talk more openly about their own difficult bowel problems:

My stand-up has gone very well and I did it to talk out, as a female, about going to the toilet and seeing how people reacted. And sometimes it's nervous laughter, but most of the time it's a relief for people to be able to laugh and talk. [Elsa, 29, UC]

Philip [*FI, stigma*] however, wryly observed that despite finding humour in toilet matters, the public still want privacy:

If you talk to the lads in the pub they'll quite openly talk about things like that, joke about things, but then when it actually comes to doing it they'll make sure they're locked in a cupboard. [Philip, 55, CD]

Humour as an antidote to, and coping mechanism for, life with a chronic illness has been demonstrated in relation to cancer, diabetes, rheumatoid arthritis and multiple sclerosis (Sullivan et al. 2003). Although it can be used against people and cause emotional harm and fear of stigma (Chapple and Ziebland 2004) humour can also be protective by rationalising challenging situations and demonstrating evidence of social support from others, which in turn promotes self-esteem and enables stigma resistance.

10.1.2.4. Perspective

Putting a positive perspective on IBD and / or incontinence seems to enhance resilience, perhaps because perspective equates with acceptance. People who are content with a mark they carry tend not to feel stigmatised by it. Goffman (1963a:17) explains:

It seems possible for an individual to fail to live up to what we [normals] effectively demand of him, and yet be relatively untouched by this failure ... he bears a stigma but does not seem to be impressed or repentant about doing so.

Self-affirmation theory provides a possible explanation (Steele 1988). The potentially stigmatised person is able to view themselves positively when one aspect of their self is threatened, by creating or focusing on another, more positive aspect. In the case of participants in this study, recognising a potentially worse alternative presented their current situation more positively. IBD could be accepted as a preferable diagnosis:

I came out [from clinic] and I had a smile on me face and [mum and dad] went, 'Why are you smiling?' And I went, 'I've got Crohn's disease, but they know what it is and they can treat it.' And she went, 'Are you sure you're okay?' And I went, 'Yes but it's not cancer mum,' because I was so convinced I had cancer. So sometimes you do have to put it in perspective with other things in life. I think, it isn't a nice illness, it's not going to be a sexy illness to have as well, but you've just got to think to yourself, 'Well, you know, you've got it, I can control it as best as I can, and it's not as bad as other things out there at all.' [Lindsey, 46, CD]

Lindsey's perspective that a diagnosis of IBD is better than one of cancer helps her accept her situation. She can protect herself against stigma because she doesn't feel that her diagnosis makes her less of a person, or that she cannot manage it. Others viewed themselves as better off compared with some with IBD either because they had better control through effective medications, or because their symptoms were milder: 'I certainly don't have the worst symptoms that some sufferers of Crohn's have. I don't have it as bad as them. I'm lucky in that respect,' [Jacob 34, CD]. For others, the wisdom of age and life experience permeated their attitudes to illness, enabling them to appreciate that 'it don't matter how bad you are, there's always someone worse off than you' [Walter, 72, UC], and that 'everybody's got something – diabetes or, you know, and you just think, you're just one of a million, million, million.' [Caroline, 34, CC]

IBD is managed by medications, surgical interventions, routine surveillance of blood and stool biomarkers, and direct visualisation techniques including colonoscopies. The latter can cause concern as bowels and bottoms are taboo areas, and people can feel stigmatised by the need for an invasive procedure which transgresses a particular physical and socio-cultural barrier (Mikocka-Walus et al. 2012). Typically, anxiety about and resistance to colonoscopy investigation dissipates post-procedure, as the experience is proven to be nowhere near as dreadful as anticipated (Mikocka-Walus et al. 2012). People with IBD undergo colonoscopies routinely, and perspective can help remove any potential embarrassment from the situation:

I sit there thinking 'That poor man [consultant] saw my bottom last week!' And then I think, 'Yes, but how many bottoms has he seen in this last month?' So, you know, just let it go. [Lindsey 46, CD, *FI, no stigma*]

Andrea [47, CD, *FI, stigma*] concurs:

It's a clinical appointment, you're there with the specialist, you know they've chosen that specialty, they're not embarrassed by people talking about poo either. Every three years he sticks a camera up my backside – he's not going to be embarrassed by that.

Both Lindsey and Andrea work on the premise that the consultant isn't embarrassed, so there is no reason they should be. Similarly, when bowel accidents occur, considering how it could have been worse enables people to rationalise the event. Charles [78, CD, *FI, no stigma*] explains what sometimes happens when he is unable to get to the toilet in time: 'Other times I've got back [home] and I haven't even got across the kitchen floor, which is not too bad - I haven't reached the carpet!' As discussed previously [Chapter 9, p. 164] dirty matter out of place can be a source of stigma, but Charles' perspective is that this dirty matter could have been in a much worse place. It would be more difficult to clean up effectively from carpet fabric than from the easily washable kitchen floor. Charles also commented that 'a bad loo is better than no loo at all,' as this at least provides privacy. Vera [69, CD, *FI, stigma*] agrees:

I've never literally had an accident, literally walking – again because I'm so careful, but I have just got to the toilets, and that's it, I've just gone, I haven't even had time to make it to the loo seat. But I haven't actually been [incontinent] out in public.

Vera's ability to secure privacy before being incontinent enables her to feel better because despite her loss of control, her problem has not been exposed in public.

Life experiences also put IBD into perspective. Aileen, [*No FI, no stigma* but a leaking fistula] explained how a previous diagnosis and successful treatment of breast cancer had completely changed her outlook on life, and on IBD:

I became much more positive about everything. The Crohn's had been diagnosed and I'd had the fistula by then as well. And I just found some inner strength and sort of something that told me that, you know, life's for living and there's no point sitting around feeling upset about whatever it is, whether it's the cancer or the Crohn's, you've got to get on with it. And, and so what's the point? You're only going to make yourself miserable and other people miserable if you feel bad about it. So that's what I did really. And so, to me, okay it's unfortunate but hey it could be worse, I could be dead with the cancer. [Aileen, 58, CD]

Earlier in this chapter, some issues were addressed around adjusting from a previous healthy identity to a new post-diagnosis identity. The impression may have been that illness always impacts negatively and that regaining a positive self-identity can be a struggle. Coming from a different perspective, some participants felt that their IBD had been helpful in contributing to their adult identity. Caroline explains the helpful impact that her diagnosis had on the person she grew up to be:

I was that kind of teenager, I was ready to go over the edge. And it was actually the Crohn's that made me stop and seriously think about what the hell I was doing with my life. So, you know, you *could* look back and pine or you think, 'Yes, well I'd probably be dead now,' or have a major drink problem, you know... **So the Crohn's has taken you in an unexpected and unanticipated direction, but that's not necessarily a bad thing?**... yes, it's taken me, made me see life in a completely different way and I would not want to not be the person I am now. I wouldn't be this person if I hadn't walked the path that I've walked, so I can't say, you know, 'Oh, it's all been terrible,' because it hasn't. [Caroline, 34, CC]

Caroline recognises that her diagnosis probably saved her from a self-destructive life path, and contributed positively to the adult she became, perhaps enhancing her resilience against stigma because she is happy with who she is. Lawrence also sees his IBD as positive because it is a physical, rather than a cognitive disorder. Diagnosed as a teenager and now in his fifties, he explains that his identity is intrinsically linked to his intellectual capacity:

I've always been more intellectually minded than physically minded. I always knew that I was going to have a thinking job and not a physical job. And when I was growing up, my identity was always attached to how my brain worked, not to how my body worked. So for me personally, the idea of being mentally ill is different from being physically ill. And I would find the former much more stigmatising than the latter ... and want to hide it, yes. But if your identity is tied up with being intelligent and a thinker, then the fact that you've got something wrong with your body is much less important. It's almost a positive thing

[because] it differentiates you, and it becomes part of your identity. And that's one of the things that happened to me with Crohn's disease, it became a way in which I could, you know, it was my thing, you know. **It's a way of being different?** It's like a way of being different, yes. [Lawrence, 52, CD]

Lawrence came from a family where intellectual ability, and expressions of individuality and uniqueness were valued and encouraged, enabling him to view his differences not as stigmatising, but as precious and welcome aspects of his identity.

In this study, more resilient participants seemed to be more positive, use humour as a coping mechanism, and place their IBD in a wider 'whole life' perspective. Resilience was weaker and stigma more evident when these aspects were less obvious, and when there were concurrent mental health problems and poor support networks.

10.1.3. Relational theme: Upbringing

The apparent link in this study between humour, perspective and resilience may not be accidental. Resilience is informed by inherent capacity (nature) and by the experiences of childhood which shape and mould an individual (nurture). Resilient children, who often become resilient adults, are characterised by features which include 'superior coping styles, task-related self-efficacy, autonomy, a sense of self-worth, capacity to plan and a sense of humour' (Smith et al. 1998:508). These features all help to build a positive image of self, a key component in resisting stigma.

Positive childhood experiences help to build resilience and facilitate *Mastery and mediation*. This relational theme of *Upbringing* addresses the influence that childhood experiences of attitudes towards disability, bodily functions and privacy had on the way participants viewed IBD as adults. Katrina [*No FI, no stigma*] raised my awareness that childhood experiences may be influential in adult adaptation to IBD, when, in the very first interview, she explained why she didn't feel stigmatised:

When I was growing up, there was no stigma for anything, there was no embarrassment for anything... my mother was partially sighted and my father was totally blind. So we were brought up [that] disability doesn't actually mean that you can't do anything. So I've grown up with that attitude - so if you've got something, deal with it, get on with your life, don't let the illness dictate what you can and can't do. [Katrina, 49, CD]

Other participants who did not feel stigmatised by their IBD also felt that attitudes in their childhood home had shaped them positively. Tina [*FI, no stigma*] explains:

I've always had an open relationship, I'm an only child. Me mam is one of me best friends, you know. Me dad's a good mate. [We] always walked about the house with no clothes on ... I have had quite an open relationship, quite laid back. [Tina, 45, UC]

Openness in their childhood home meant that as adults, participants could talk freely about IBD if they wanted to, without feeling embarrassed. Elsa [*FI, no stigma*] describes her mother's influence on her:

[It comes from] the way I was brought up, in the kind of way of equality and honesty and a very caring mum who always wanted to get to the bottom of why people feel the way that they feel or behave the way that they behave. So I always talked about it. [Elsa, 29, UC]

Elsa's childhood taught her that problems should be talked about, rather than hidden. Some people keep issues private, feeling that these are not other people's business, but concealing issues due to a sense of shame is an indication of stigma. Openness in Elsa's childhood came from her mother's approach to problem-solving, but in other families, could occur for pragmatic reasons. Charles explains how the influence of a travelling heritage on the family, and sheer numbers, led to openness:

My parents were post Victorian. My mother was born in 1902, father was born in 1898, but they were both from big families and my mother was the youngest of fourteen brought up in a fairground family. So there were no taboos in that life at all. My father possibly slightly different, but I always do remember his youngest brother. Grandma used to call out to him, ‘[...], have you lavved?’ before he was ready to go to school. So there was that approach to life. [Charles, 78, CD]

Although a practical solution to the logistics of managing a large family, regular reference to body functions desensitised family members, and this openness became their norm. A similar matter-of-factness was evident in Charles, and protected him against feeling stigmatised. In contrast, those who felt more stigmatised often reported closed family attitudes towards natural body functions, which were not discussed. Although self-assigned to the *FI, no stigma* subgroup, Jason had not told his family of his condition because of the rules he learnt in childhood:

I suppose as a family we don’t talk about those sorts of things anyway. I have even wondered if [mum] suffers from it herself, but I’ve never asked her. I suppose that’s the way I’ve been brought up – these sorts of things you keep quiet, you don’t need to talk about it. And I suppose maybe I would feel a bit embarrassed about talking about it anyway. [Jason, 48, UC]

Jason’s final comment suggests that despite his subgroup affiliation, he may well feel stigmatised by his IBD since he would be embarrassed to talk about it. Embarrassment, shame and stigma overlap [see Chapter 2.4.1: p. 25] with stigma emerging as a result of embarrassing or shaming situations. Vera [69, UC; *FI, stigma*] also felt unable to break away from the effects of her strict childhood:

I am quite an inhibited person. I was brought up quite strictly, and I’ve never lost that. **When you say strictly, what was it like?** I’m an only child, I believe quite wanted by my mother but not my father who was a very strict Victorian type man. You just didn’t talk openly about toilets or bathrooms or girls having periods or sex or anything. So I keep most of it to myself.

Vera's transcript reveals the shame she feels about UC and the fear she has of being found to be different from the image she projects. Combined with the influences from her childhood, this prevents her from sharing her concerns with her husband and she is stigmatised and isolated as a result. Marion [*No FI, stigma*] explains the relationship between family privacy, and social rules about privacy:

Before I had this condition, it was something I'd never speak about to anybody because, you know, it's a private thing to me really, going to the toilet. **Was it very private when you were growing up?** Yes, yes. You shut the door when you went to the toilet, you know, it was private to that individual really. I guess that probably does come a little bit from childhood, but also I think from society, because you don't discuss stuff like that with your friends. [Marion, 37, UC]

Marion had worked hard to overcome her aversion to discussing bowels, recognising the need to communicate effectively with her health care team, yet she still felt stigmatised because she was breaking the rules instilled in her in childhood.

Bowels were identified as taboo by stigmatised and non-stigmatised alike. In this study, almost everyone understood that this was not a subject that people want to discuss: 'So you can't talk in detail about Crohn's disease without talking about bowels and you don't talk about bowels in polite company' [Lawrence, 52, CD, *No FI, no stigma*]. Even those who were able to talk about bowels understood the majority view that the subject was usually off limits. Juliet considers where the sense of shame that can be felt about lack of bowel control comes from:

There's a real ingrained sense of embarrassment about lack of bowel control, that perhaps you get more than [from] anything else in life. It's just regarded as just so unpleasant, so horrible, that, you know, it's, yes I think that's what it is. It's ingrained in you, isn't it, that it's dirty? You know, as a little child, your mum says 'That's dog poo, dirty.' It's so deeply ingrained in you that poo is something to be ashamed of that you can't help but be ashamed of it, I think. [Juliet, 53, CD]

As discussed previously, most participants referred to social rules about bowel control. Controlling bowels also means controlling dirt, but even when ‘dirt’ is controlled and contained in a stoma bag, the unnatural manner of its containment and its visibility could be troublesome. Carl explains the self-stigmatising nature of this visible mark:

Seeing poo is disgusting to me. Seeing a cut, or inside your body is alright... [but] it’s the smell and you know, it’s the waste, and it’s just that bit that’s disgusting to me. The stoma doesn’t bother me, I know it’s part of me. But the toilet stuff isn’t part of you, it’s just waste.’ [Carl, 54, CD, *FI, stigma*]

Although some were not specific about the root cause of their self-stigma, Carl [54, CD] was quite clear about where these feelings originated from:

Just because of the way I was brought up, I was always clean and my mum was, you know, I was, I had to be clean and just from the smell or something – if you’ve had an accident you just feel really embarrassed ... it’s not the way to be.

It was not the stoma, but what it produced that caused self-stigma by undermining Carl’s need for cleanliness, ingrained from childhood. Upbringing could also influence the way participants responded to illness, often meaning that they ‘refused to give in’ until realising, with time and experience, that IBD had to be respected and managed differently. Lily [31, CD, *FI, no stigma*] explains:

Mum and dad were really brilliant, but if you were ill, it was kind of ‘Pull your socks up and get on with it’. It would be this thing of, if you’ve not got a temperature, then you’re not ill. So I kind of felt, I think with the Crohn’s being a hidden thing, I didn’t have these outward signs that I was ill. To me, it’s almost been programmed that if you’ve not got a temperature and if you’ve not got a red raw throat or something like that, then you’re not really that ill. I suppose that’s what I’d learnt over the years, that’s what ‘ill’ is and ‘ill’ means not being able to get out of bed and do anything. And of course, with a chronic illness, you do get out of bed and you can do things, because it’s not the same as being acutely ill.

Achieving *Mastery and mediation* meant overcoming deep-seated social rules and resisting the expectations on self to conform. To resist or deflect stigma, people need to accept their situation, negotiate between the demands of illness and life, and rise above the negative comments that others might make. Being open, sharing information with others, and over-riding socio-cultural and family rules learnt in childhood that silence discussion of toilet behaviours, enables development of support networks and a sense of mastery over illness. Mastery and mediation are co-dependent – in learning to mediate between IBD and life to achieve a best outcome, the individual moves towards mastery.

10.2. Summary of mastery and mediation

The relational themes of *State and flux of stigma*, *Resilience* and *Upbringing* are united by the individual's response to personal and situational changes. When this response is positive, the person *mediates* between the demands of life and illness, and achieves a sense of *mastery* over their situation. Those who achieve *Mastery and mediation* also demonstrate a sense of *Being in control* of their situation, and have an effective network of *Relationships and social support*. In contrast, those who are less adaptable and struggle to balance the needs of their IBD with the demands of life, tend to feel less masterful, less in control, and have less effective support networks.

10.3. Vignettes

Evidencing the complexities of IBD-related stigma on the page is hampered by the necessarily sequential reporting of themes and patterns. To help illustrate the interwoven, changeable nature of diverse as well as shared experiences, four vignettes are offered here, one from a participant in each of the study sub-groups. Vignettes are usually fictional and used to collect data in social sciences research (Arthur and Nazroo 2003), but are being increasingly used in health research (Hughes and Huby 2004; Miller and Brewer 2003). The use of real-case vignettes to unite study findings here is an attempt to illustrate the relationship between participants' stories and study findings.

10.3.1. Tamsin [No FI, stigma]

Tamsin is 38 and has Crohn's Colitis. Although self-assigned to the *No FI, stigma* subgroup, she suffers occasional bouts of incontinence but accepts this as part of her disease. Her greater concern is with being labelled as 'a sick person', being subjected to the pitying attitudes of others, and not being believed. The latter is compounded by her regular use of steroids which cause fluctuations in her weight, making her look healthier than she is, or pregnant. She provides examples of not being believed, reports others being overheard to say 'I don't know why she's in hospital, she looks fine to me,' and believes that they think she enjoys the attention she gets from being ill. Much of this seems rooted in her relationship with her mother, which she describes as poor. Tamsin has not told her mother about her illness, and provides examples of unsympathetic or labelling comments which confirm her belief that her mother would not be supportive. Her mother's negative reaction to an acquaintance with a stoma reinforces this belief. Tamsin's husband is critical of the foul-smelling wind she produces, and she finds his attitude distressing. Her uncertainty over how people will respond and her certainty that they will either not believe her or be disgusted, deters Tamsin from telling anyone about her illness. She accepts that understanding and support can arise if other people know, but feels that the taboo nature of the illness and its focus on bowels will deter even the most willing listener. Even when presented with an opportunity to reveal, she will pass, preferring to tell people that she has 'stomach problems' because, she believes, they don't really want to hear about bowels.

Having spent much of the past year in hospital, Tamsin is finding it increasingly difficult to hide the truth about her illness. Having told a few people beyond her close circle of friends, she has received mixed reactions. She confesses to being surprised by the few positive responses, but notices that these always come from someone who has some experience of the condition, usually because of a relative with IBD. Tamsin is unable to explain how she decides, in a split second, to tell a particular person about her illness, but does say that when she does do this, the response is often positive. She feels that better publicity and wider public knowledge about IBD would help enormously, just as TV adverts have helped those with urinary incontinence.

10.3.1.1. Tamsin's story and the study findings

Tamsin does not feel in *control* of her disease. She is bothered about giving the wrong *impression*, about not being believed, and about *revealing her IBD* to others but is being forced into being more open about her illness as it is becoming harder to conceal. She is acutely conscious of *social expectations* relating to bowel control and believes others will find her problem disgusting. Her *relationships* are less supportive than she would like. She particularly feels stigmatised by lack of support and understanding from her mother, and her husband. She is struggling to gain a sense of *mastery* and finds it difficult to *mediate* between the demands of her illness, and the demands of her life.

10.3.2. Kevin [FI, no stigma]

Kevin, now 36, has had CD since his early 20s. Previously very debilitated by weight loss, urgency, frequency and pain, Infliximab infusions have transformed his life. He did find ways of managing his urgency and risk of incontinence to keep working, but felt awkward and embarrassed, and socially isolated himself from his friends.

Kevin is a self-employed carpet-fitter. Working with a colleague was embarrassing, and he felt very concerned about his colleague would think of him for not being able to control his bowels. Infliximab had an almost instantaneous effect, and he quickly forgot about having the disease only being reminded of it, and of the impact on his life (needing to prepare a clean-up kit bag to take with him) when coming to the end of the efficacy of an infusion and approaching the next infusion. These episodes are eradicated now that optimum timings of infusions have been established.

Kevin lives with his brother and has no partner. He is clear that his disease has disrupted his ability to find a partner although he feels more hopeful about the possibility now. He verbalises concern over how and when to introduce the subject to a potential partner, and concludes that he feels happy living how he does.

He has now told his friends about his illness, but prefers them not to visit him in hospital. He is unsure if this is because he wants to be alone, or because he doesn't want them to know what his illness involves. In contrast, during previous hospitalisations for broken limbs (from motorcycle accidents) receiving mates as visitors was a welcome rite linked to the macho nature of the injury, caused by something he had done. He thinks the word 'disease' is a problem for him, in how he views the condition and perhaps expects it to be a problem for others.

10.3.2.1. Kevin's story and the study findings

Kevin's story demonstrates the *state and flux of stigma* over time; his feelings of stigma reduced as he gained better disease *control*, started to gain *mastery* over his illness, and secured the *support* of his friends. The chance of an intimate *relationship* has been compromised by his IBD as he has felt a potential partner would find the illness difficult. He is not entirely *stigma*-free, preferring not to *reveal* details about his illness to his friends. Before an effective medication routine was established, he was prepared for bowel accidents, but remained concerned over others' perceptions of him.

10.3.3. Vera [FI, stigma]

An ex-librarian, 68 year-old Vera has recently moved to a new location with her husband. They have been together for 30 years, and married for nine. He is not the biological father of two daughters, who she had during her late teens / early twenties.

Vera feels trapped by her Crohn's disease. It stops her from walking in the countryside whenever she feels like it, and from going to the cinema or the theatre. She feels that the promise of a new, retired life remains unfulfilled. Her biggest fear is losing control in public, and the effect this would have on other people's opinion of her. She desperately wants to give a good impression, and links this to the need for approval from her father who she feels did not particularly welcome her arrival into the world. She describes her

upbringing as very strict, very austere, with never any reference to bodily functions, routines or activities. Her first pregnancy at 18 (in 1961) slightly preceded the sexual revolution and flaunted the social expectation of childbirth within marriage. This deliberate strategy enabled her escape from the childhood home, but her actions brought severe disapproval from her father, which she never overcame.

Her desire to be seen in a good light causes her to hide the truth of her condition from her husband. She suspects he may know, but they have not openly spoken about her incontinence – she feels that by avoiding the subject, she is protecting him from details which he doesn't want to know, rather than protecting herself from the risk of failing to be the person he thinks she is. She hasn't even 'admitted' to having two false teeth, since she would then be proven to be something different to the image she portrays.

One of her daughters also has ulcerative colitis and whilst she finds this supportive because there is a shared need to locate toilets when they are out together, she adopts a parental role as supporter and listening ear to her daughter. She encourages her daughter's openness but does not reciprocate with her own needs.

Vera only discusses her disease-related issues with her Consultant, but is reluctant to follow his advice to use Loperamide to manage her bowel. She feels that her IBD has control of her, she has a limited network of support, and would rather have had a life with her other condition (coeliac disease) than these few years with ulcerative colitis.

10.3.3.1. Vera's story and the study findings

Vera has neither physical nor emotional *control* over her disease. She is reluctant to adopt strategies which could give her physical *control*, and is deeply concerned about other people's *impression* of her. She has not *revealed* the extent of her bowel problems to her husband, preventing the possibility of *support* from him. Although her daughters know, she resists receiving *support* from them. She worries about disrupting other's *impression* of her, and her desire for perfection may link to her austere, very 'proper'

upbringing. She appears not to feel stigmatised by having had children out of marriage in the early 1960s, but does about her bowels perhaps because she chose and has accepted *responsibility* for the first situation, but feels that people would *blame* her for the second. Although no-one has been stigmatising towards her, she anticipates *stigma* and this is not decreasing over time. Vera shows few indicators of *resilience* - she has no *mastery* over her condition and cannot *mediate* between the demands of IBD and the things she wants to do with her life, impairing enjoyment of her retirement.

10.3.4. Esther [No FI, no stigma]

Esther is 27, a trainee health professional, and has been diagnosed with Crohn's disease for four years. Overall, she doesn't feel stigmatised by her disease, only occasionally by the responses of other people towards her, and sometimes self-stigmatises due to concerns that others will think badly of her, or treat her differently if she cannot sustain an expected workload. Almost always, these concerns are her own, and not based on evidence of anyone behaving negatively towards her. She is very open about her CD to others and feels that anyone of any worth will not see her in a negative light.

An early job working with children with special needs de-sensitised her to the language of bowels, and she feels this has helped to later accept her disease. She feels supported by her family and husband, though not necessarily by her employer, and feels that she has taken control of her disease. She is determined not to be defined by it, though.

Esther describes feeling that she was treated differently when in a clinical placement. She is very open about her illness, and had decided that telling work colleagues and supervisors about her Crohn's disease would be beneficial because they would understand when she had difficulties. She felt, following a difficult relationship with her placement supervisor, that the strategy was unsuccessful, and realised that different approaches may be needed in different settings. Esther sometimes feels that her GP surgery assumes her CD to be the cause of every visit, and is bothered that this has become what defines her. She is concerned that the GP will think she is trying to get

time off work, when she does not visibly look unwell. Recently, she has deliberately worn her NHS identity badge in consultations with her GP as she has noticed this improves the interaction.

10.3.4.1. Esther's story and the study findings

Esther is physically and emotionally in *control* of her illness and has a good *support* network from those who matter to her. She now adjusts what she *reveals* about her IBD according to the social *relationship*, and uses helpful strategies to *mediate* between illness and life. Feelings of *stigma* fluctuate, depending on the situation, and although she does not feel stigmatised most of the time, she has some concerns about the *impression* others may have of her. Her sense of *mastery* is helped by good bowel control and good social *support* which gives her a sense of *control* over her disease.

10.4. Summary of Chapters 8, 9, and 10

These findings illustrate a complex, interweaving of relational themes and constitutive patterns which combine to influence the ways in which individuals experience stigma related to IBD. The temptation to label these experiences as a single unifying theme is resisted, since hermeneutics does not attempt to define what an experience *is*. Instead, the aim is to show / reveal experiences to the reader who then makes their interpretation of meaning, guided by their own background, pre-understanding and knowledge.

The findings suggest that stigma is linked both to IBD and the incontinence it can cause. Some feel stigmatised by disease and FI together, others by disease or FI. The inability to adhere to social rules relating to bowel control seems to underpin stigma in IBD but overcoming personal attitudes and beliefs regarding these social rules, developing a sense of control, and having an effective and personalised support network and a sense of mastery over disease leads to reduction in and resistance of IBD-related stigma.

In Chapter 11, these findings are discussed in relation to the existing relevant literature and recommendations for practice and future research are made. Critiques of the data analysis method and of reflexivity are also presented, along with the study limitations.

11. Discussion and conclusions

This study set out to a) explore the experience of stigma in IBD with and without faecal incontinence (FI), and the impact this has on wellbeing, and b) generate findings to inform future studies into patient experience and management of the social aspects of IBD, guided by two research questions:

- What is the experience of stigma in people with inflammatory bowel disease with or without FI?
- In what ways does stigma affect the social, emotional and personal wellbeing of people with inflammatory bowel disease, and how do they manage these issues?

The original literature review evidenced the association of stigma with a range of bladder or bowel-related disorders including IBD, and with related symptoms (diarrhoea, for example) and behaviours (urgency and frequency, for example). Some conditions were represented in quantitative and qualitative work, but the only available evidence of stigma in IBD was quantitative. Whilst this confirmed the existence of IBD-related stigma, insight into patient experience, perceptions and understanding of the phenomenon was absent. The recent literature review update [July 2014; Appendix 4] identified seven new papers. One paper (Roslani et al. 2014) was excluded from the following discussion as there was no relationship between the data collected and the stated need to develop stigma reduction strategies for community-dwelling people with FI. Findings from the remaining papers (Danielsen et al. 2013; Frohlich 2014; Shrestha et al. 2014; Saunders 2014; Taft et al. 2014; Wang et al. 2014), revealing evidence of disrupted help-seeking, illness disclosure issues, culture and taboo perspectives, and the need for support, are used to support discussion in this chapter.

Two new qualitative papers directly address stigma in IBD (Frohlich 2014; Saunders 2014). Saunders' (2014) analysis of the use of language by young adults with IBD shows that language is morally constructed to minimise feelings of shame (stigma) and blame (deviance); Frohlich (2014) explores areas of life from which stigma can arise for people with IBD, and shows that this stigma can be overcome. He indicates that further

research is needed to understand the personal characteristics which contribute to stigma resistance. The current study goes some way to addressing this recommendation. The papers from Frohlich (2014) and Saunders (2014), together with the findings discussed here, build a promising foundation for ongoing qualitative exploration of IBD.

This study design is also relatively new in health-related stigma research. Goffman and Becker both insisted that stigma could only be understood through investigation of experiences of the stigmatised. This study moves stigma research forward by also understanding the experience of the no-longer stigmatised, so that what is revealed is not only ‘what is this experience of IBD-related stigma?’ but ‘how do people overcome this experience?’ The latter reveals useful lessons which can inform support mechanisms not only in IBD, but in other stigmatised health conditions as well. Similar approaches are being used to investigate stigma resistance in schizophrenia (Sibitz et al. 2011), and the experiences of military personnel in succumbing to, or overcoming stigma to avoid or seek help for mental health problems linked to active service (Sharpe 2014; pers. comm., 14th May).

For this study, Heideggerian (interpretive or hermeneutic) phenomenology was used to explore the lived experience of stigma in IBD and Goffman’s (1963a) definition of stigma as ‘an attribute that is deeply discrediting’ was adopted; data was analysed using the hermeneutic method of Diekmann et al. (1989), with researcher influence being managed through reflexivity, recording of field notes, and supervision. The findings demonstrate that people with IBD can feel stigmatised due to the bowel disorder, the associated FI, or both; that stigma fluctuates according to the person(s) interacted with, and over time; and that the source of stigma is often rooted in the social rules relating to bowels. The individual with IBD brings their own understanding of social rules to the interaction, and whether stigma is experienced depends as much on their own experiences, socio-cultural background, and perceptions, as it does on the response of others. The creation of stigma and the capacity to resist it are influenced by the amount of emotional and physical control people feel they have, the quality of social support available to them, and their proficiency in managing the challenges of illness and life.

These features of IBD-related stigma are represented by the constitutive patterns of *Control, Relationships and social support*, and *Mastery and mediation*. This chapter:

- addresses key findings from the study in light of the research questions
- discusses these findings in the context of the wider, relevant literature
- critiques the methodology, data analysis and reflexivity
- addresses issues of credibility, trustworthiness and transferability
- makes recommendations for future research and practice
- considers implications for researchers.
- makes explicit the contribution to knowledge

11.1. The key findings

This study is one of the first to offer a detailed exploration and analysis of the experience of stigma in inflammatory bowel disease. The quantitative work of Taft and colleagues (Taft et al. 2009; Taft and Keefer 2009; Taft and Keefer 2010; Taft et al. 2011) has demonstrated the presence of stigma in IBD, focussing on perceived and internalised (self) stigma and the impact these have on disease symptoms and quality of life. Positive associations between stigma resistance and improved quality of life and symptoms have also been demonstrated (Taft et al. 2013) but quantitative work cannot explain why and how stigma has these effects or how it is resisted. The key findings are now reviewed in relation to the research questions which are addressed simultaneously, reflecting the complex web of experience of IBD-related stigma.

11.1.1. What is the experience of stigma in people with inflammatory bowel disease, with or without incontinence?; and In what ways does stigma affect the social, emotional and personal wellbeing of people with IBD, and how do they manage these issues?

The study provides an insight into the complexity of stigma in IBD, showing that it can be linked to IBD, or FI, or both. A minority of participants reported never feeling stigmatised, but most had some experience of it so that their self-allocated study sub-groups of *FI, stigma*; *FI, no stigma*; *No FI, stigma*; and *No FI, no stigma* rarely reflected their actual stigma experiences. Stigma can emerge with increased disease activity and / or with increased visibility of disease due to incontinence, and retreat during remission when there is better medical, and therefore physical, control of illness; or it remains troublesome irrespective of disease activity. Stigma also changes over time, in different social settings and relationships, with the majority feeling less stigmatised with longer disease duration. These fluctuations affect the impact of stigma. It can be very disruptive, preventing people from leaving the house, derailing social events with families or affecting mental wellbeing - or it can cause a constant low level of concern when in every social situation, there is worry about others' perceptions.

Stigma in IBD is a more nuanced and intricate experience than the perceived or internalised stigma that others have reported (Taft et al. 2013; Taft and Keefer 2009, for example). Five known forms of stigma (anticipated, perceived, enacted, self and courtesy) affecting people with IBD, and a possible new form (kinship stigma) have been identified in this study. Taft et al. (2011) have reported that stigmatising attitudes from close or intimate others have a greater negative impact on clinical outcomes than similar attitudes from other social sources, but have not identified whether this is either a unique type of stigma, or unique to IBD. Taft (2014, pers. comm., 22nd July) comments:

Your idea [of kinship stigma] makes sense. I would think it would be more distressing to have your spouse stigmatize you than your physician or his/her nurse. I'm almost positive it hasn't been done in the GI literature.

Although needing more work before it can be claimed as a new form of stigma, early evidence here suggests that there may be something different about being stigmatised by those on whom one ought to be able to depend in even the most difficult situations.

Goffman (1963a: 31) refers to those 'in the know' about a discrediting or discreditable mark as 'The Own and the Wise.' The 'Own' are the sympathetic others who share the stigma, have experience of it, and accept the marked person for who he is. In this case, the 'own' are other people with IBD, and / or with related incontinence. Goffman presents a range of benefits and disadvantages to communing with the 'own', and suggests that by doing so, the marked person must resign himself to a half-world, which, it is implied, is a lesser place to be (Goffman 1963a: 32). 'The Wise', on the other hand, are those who do not bear the stigmatising mark, but:

... whose special situation has made them intimately privy to the secret life of the stigmatised individual and sympathetic with it ... wise persons are the marginal men before whom the individual with a fault need feel no shame nor exert self-control, knowing that in spite of his failing he will be seen as an ordinary other (Goffman 1963a: 41).

For those with IBD, and any related FI, their intimate, nearest and closest family relatives, as well as specialist IBD medical and nursing staff, may be expected to be 'the wise' and to bestow all the benefits described above. Goffman (1963a:43) recognises that where a wise person is related through social structure to a stigmatised individual, the relationship will 'lead the wider society to treat both individuals in some respects as one', thus describing courtesy stigma. In this situation, however, although the wise relative might feel stigmatised by others due to their association with the marked person, they do not directly stigmatise the marked person themselves – the two are instead, in it together. Kinship stigma may, then, be the result of what happens when those believed to be 'the wise' show themselves instead to stigmatise so that there *is* shame, there *is* need for self-control, and because of his failing, the marked person *will* be seen as an abnormal other.

Perhaps if people with IBD cannot rely on unconditional support from close family, self-esteem is damaged and the expectation of disapproval and stigmatising attitudes from others is exacerbated, challenging the ability to accept themselves. Self-acceptance may be an important aspect of overcoming stigma (Hebl et al. 2000) but to enable this,

personal belief systems need reconfiguring and differences need to be accepted as ‘non-devaluing’ (Wright 1983). Self-acceptance may also disrupt the cycle of stigmatisation (Garcia et al. 2005) since it seems to enhance ‘other-acceptance’ (Hebl et al. 2000): if one projects an affirmative image of self-acceptance about a potentially stigmatising attribute, others seem to respond in a positive, non-stigmatising manner.

In this study, the less stigmatised, with or without incontinence, seemed able to access social support from close family, their wider social circle, and occasionally (William and Carol, for example) from the local community as well. The more stigmatised may or may not have close family support, but are prevented from seeking wider social support due to their anticipation of, or avoidance of the potential for, stigma. Whilst Taft et al. (2014) have established the relationship between lack of social support and increased internalised stigma in people with IBS, the benefits of social support have been demonstrated in relation to breast cancer (Alqaissi and Dickerson 2010), HIV/AIDS (Bozarth 1998; Colbert et al. 2010; Edwards 2006), mental health (Lyndsey et al. 2010), and epilepsy (Whatley et al. 2010), and in IBD (Frohlich 2014; Sewitch et al. 2001). There is some overlap between Frohlich’s work and mine: he identifies support structures, perspective and revealing IBD purposefully as strategies by which people defuse stigmatising situations, whilst I identify control, support (including revealing IBD) and mastery (including perspective) as influential in overcoming stigma. Further exploration would help to demonstrate whether stigma disrupts seeking social support, or whether lack of social support creates or compounds stigma. Frohlich (2014: 135) also comments that ‘*research needs to examine the personal characteristics beyond the disease itself that might explain the stigma people with IBD experience*’ which is where the findings of this study extend the evidence. By exploring experiences and identifying attributes of people who do, and others who do not, feel stigmatised with IBD, it is possible to start to recognize the personal characteristics which may be protective against stigma.

The complex, unpredictable and changeable nature of IBD propagates feelings of stigma because the disease affects bowel control. Bowels are taboo, and the symptoms and behaviours of IBD challenge the socio-cultural rules about bowel control.

When people feel stigmatised, their ability to engage in social interactions, access social support and manage work commitments is disrupted. Concerns about others' perceptions may lead people with IBD, with or without FI, to expect stigmatising attitudes from others even though these rarely occur. The disparity between expectations of stigma and actual experiences of stigma has been reported elsewhere in IBD research (Frohlich 2014), and in mental health research (Angermeyer et al. 2004).

IBD-related stigma can be resisted, and people can become resilient. Those whose feelings of stigma decreased over time tended to have secured a sense of emotional (if not physical) control of disease, established a robust support network and achieved or be working towards mastery of life and illness. Accomplishing this complex task was helped when humour was used therapeutically within important relationships; when able to put their situation in perspective with other life challenges; when their mental health seemed robust; and when there had been openness rather than secrecy and silence about bodily functions in their childhood years.

11.2. Study findings in relation to the wider literature

The foundation stone of this study is Goffman's definition of stigma as 'an attribute that is deeply discrediting', chosen because of the flexibility it offers in understanding and accessing experiences of stigma perceived and expressed in a variety of ways by the reporting person. In this respect, it proved effective in enabling an attitude of openness during analysis to the many representations of stigma in the data. Had the more complex definition of stigma as 'the co-occurrence of labelling, stereotyping, separation, status loss and discrimination in a power situation that allows these components to unfold' (Link and Phelan (2001:382) been adopted, there would have been minimal evidence of stigma in the data because the organisational and social structures which fuel stigmatisation - and upon which the definition depends - are not apparent in this study data. The relevance of Goffman's stigma definition and framework to the study can be demonstrated by mapping the key findings onto his concepts [Table 11-1]

<i>Types of stigma</i>	<i>Ways in which IBD stigma can be carried</i>	
	Discredited	Discreditable
1. PHYSICAL (illness)	Chronic illness, poorly understood by the public;	Hidden and unpredictable illness; risk of faecal incontinence exposing the illness.
2. CONDUCT (illness-related symptoms and behaviours)	Faecal incontinence, flatus, repeated work and social absences and disruptions; poor control of ill self and related behaviours; social rejection	Socially isolating; risk that cause of isolation may be exposed, or that illness-related symptoms and behaviours (urgency, taking steroids, for example) might expose
3. TRIBAL (cultural)	Loss of bowel control; blame	Bowel disease a taboo topic; fear of discovery; loss of adult competence

Table 11-1. Key study findings mapped onto Goffman's stigma framework

IBD and the FI that sometimes accompanies it have the capacity to discredit a person, and make them discreditable. Relating these findings to the wider literature situates IBD-related stigma in the socio-cultural context of the everyday world in which the illness is experienced. Darbyshire et al. (1999:28) advise that:

Humans are an integral part of the tradition in which they are immersed. It is in the context of everydayness that shared practices and common meanings contribute to the interplay of meanings and understandings.

The 'everyday' represents the normal (majority) status of humans' socio-cultural world; it refers to taken-for-granted rules through which complex societies function effectively (Lechner 2000) and, as a moral framework, provides the basis for law and order structures to deal with deviants (Sumner 1994). Societies have such 'everyday' rules about bowel control, social power, and language and, against a background of increasing prevalence and incidence of chronic illness, a sense of 'everyday-ness' about adjusting to chronic illness. Such adjustment includes stigma resistance.

11.2.1. The everyday of bowel control

At the very basic level, there are rules about dirt, hygiene and avoidance of threat upon which a society builds and functions (Neuberg et al. 2000). To enable smooth social interaction, progress, and prevent disease, all dirt - including that produced by humans - must be contained. For years, anthropologists and psychologists have attempted to explain why human waste presents such a problem to other humans. In 1937, Kubie suggested that the solution lies in understanding that the inner body is dirty, the outer clean – so that anything which exudes, seeps, gushes, oozes or otherwise emerges from the inner body (including tears, sweat, saliva, urine, breast milk, semen and faeces) is classified as dirt. This would be plausible but for the fact that tears have a functional cleansing role and breast milk is, in most cases, nourishing, rather than harmful. Whilst there is now a risk of mother-to-infant transmission of HIV/AIDS via breast milk (Mofensen and McIntyre 2000), the disease did not exist in the 1930s so Kubie's inclusion of breast milk as a contaminant is puzzling. Curtis and Biran (2001) offer a more credible explanation of body fluids and waste being seen as dirty when there is capacity to contaminate. Faeces, urine, mucus, saliva, (and now, in some instances, breast milk) can all transmit infection and need to be managed appropriately, supporting the theory that the learned human behaviour of responding to bodily waste with disgust is an evolutionary means of avoiding risk of contamination. The unpleasant smell of stool is another means by which people avoid potential contaminants (Low 2005). Faeces, toilets, and (in some cultures) sick people are considered disgusting due to their dirtiness, or associations with dirt, and faeces are universally the foremost elicitor of disgust. Bitton (2008) disagrees, stating that there is no support for this claim, despite clear evidence from Curtis and Biran (2001) and Tsagkamilis (1999) to the contrary. Rozin and Fallon (1987) propose that faeces are not only a universal disgust object but the first that humans learn to be disgusted by. Kubie's (1937) theory was that infants, during nappy changing, learn to despise the 'taking away' of their body products leading to the abhorrence of, and at the same time, fascination with, stool. It is perhaps unlikely that infants in nappies engage in such complex cognitive interpretations, and more likely that disgust is a learnt response. Youngsters will happily dig about in the garden, eating worms, hands in the dirt, with no concern or awareness that these

products are considered dirty until the parents convey that opinion to them. Learning that stool is dirty and disgusting more likely arises from negative responses during nappy changing or if an accident occurs, and the positive reinforcement that parents give following a child's successful visit to the potty or toilet (Rozin and Fallon 1987).

The human urge to avoid disgust and maintain physical hygiene is thus a necessity - inability to maintain appropriate control presents a risk to society due to an increased risk of disease through contamination. In recent years, the intense focus on 'the body beautiful' through relentless advertising for perfect hair, skin, teeth and feet that are brushed, conditioned, polished, nourished and toned has, in many ways, created a yawning chasm between those with 'dirty' diseases and those without.

Against this background, people with IBD live with a dirty condition (Defenbaugh 2011) which although not infectious, may well be perceived by others as such. Worldwide, people view bodily substances, vermin, and sick and dirty people as disease threats (Curtis et al. 2004). Diarrhoea is often caused by one of several pathogens, and most people have experienced loose stools due to an infectious gastroenteritis resulting from inadequate hygiene, or from ingesting contaminated food or water. Observers may interpret IBD diarrhoea (with or without incontinence) in the same way: caused by an infection, and perhaps considered the fault of the sufferer through poor hygiene practices, leading to stigmatising attitudes. If researchers (Curtis and Biran 2001; Curtis et al. 2004; Douglas 1966; Smith 2007) are correct, the clean and hygienic public without bowel disease would wish, for their own protection and health safety, to avoid someone with IBD whose illness makes them sick, dirty and a disease threat.

Disease threat and disgust decrease within familiar and close relationships, perhaps due to tolerances between proximal immune systems. Those that are used to each other, such as in families and intimate relationships, are less threatening:

Body substances in some settings are not offensive – intimate contact with the body fluids of a lover causes us few problems, but contact with those same fluids from a stranger offends us (Norton and Dibley 2012).

This is reflected in most parents' willingness to deal with their own infant's excrement and their reluctance to clean up others'. The ability of some (nurses, for example) to deal regularly with the bodily waste of unfamiliar humans, may be due to a reduced disgust trait sensitivity (Haidt et al. 2002). These factors may influence kinship stigma if the person with IBD is treated differently, perhaps even with disgust, by close family to whom they should offer no disease threat - Tamsin's husband who was intolerant of her odorous wind, for example [Chapter 9: p. 191].

Maintaining appropriate bowel control is also an indication of maturity. As described previously [Chapter 8: p. 149] bowel control is achieved by the developing infant during early childhood, and is essential to enable functioning in the wider social world (Kelly and Field 1996). As-yet unlearned control indicates immaturity, but loss of control represents loss of adult maturity and competence which may afflict, for example, the very elderly (Garcia et al. 2005), people with rectal cancer (MacDonald and Anderson 1984) and those who have had colorectal cancer surgery (Rozmovits and Ziebland 2004). Normal adult control is compromised, challenging the individual's perception of self as mature and competent. This can lead to stigma if the adult with IBD is discovered to not be as adult as he appears when it comes to bio-physical control.

Physical, social and psychological maturation enables adult humans in most cultures to make their way out into the world where they work in some capacity to contribute to the overall social machine (Giddens 1989). Through this process, they become part of the majority group of 'normals', all adhering to the social rules (including bowel control) which enable the culture to function. IBD disrupts the ability to follow this path (Marri and Buchman 2005). The disease itself affects capacity to work by intermittently and unpredictably causing health deteriorations which force numerous illness-related absences (Bernklev et al. 2006; Longobardi et al. 2002). Any incontinence causes greater disruption to the working day and, mindful of the already identified perils discussed above, potentially impacts negatively on colleagues. Stigma arises because the person with IBD cannot be relied on to fulfil their economic role, to do their share of the work, or keep their bowel problem contained. Similar issues have been identified amongst women in Nepal who, experiencing uterine prolapse as a consequence of

childbirth, endure isolation, abuse and stigma because they cannot complete the tasks expected of them in their society (Shrestha et al. 2014)

The everyday of bowel containment and control also refers to the taboo that surrounds this normal body function. Despite the fact that all humans must excrete their waste, that everyone knows everyone else does it, there is a social expectation that these matters are not addressed openly:

It is the social-unacceptability of bowel functions that is at issue ...societal views that it is taboo to talk about, or to know about, others' bowel habits, especially when these are irregular in some way (Saunders 2014:14).

Since the silencing of toilet behaviours in 16th Century Europe (Elias 2000), excretion should not be spoken of, alluded to, or evidenced in any way (Smith 2007) except in specific circumstances, such as in medical settings and with clinical personnel. The increasing privatisation of toilet matters, as discussed in Chapter 2, means that infants are soon socialised to understand that urine and stools are private and dirty matters, and that stool - human or otherwise - particularly is taboo. Defenbaugh (2013) addresses the social performance involved in managing IBD illness identity, and those with an intestinal stoma also risk being discredited if their situation is discovered (Danielsen et al. 2013); taboo ensures that these issues are rarely discussed openly.

In this study, Juliet recalls being admonished about the perils of dog mess by her mother. The attitudes of the child towards dirt, toilets, and faeces likely depends on the attitudes conveyed to them by their parents (Bitton 2008) which are carried forward into adulthood. Heidegger's *thrownness* refers to the way our past experiences of *being-in-the-world*, our *Dasein*, naturally *throw* us forward into the way we experience future events. If, for instance, we have a particular experience in childhood, this *throws* us towards future encounters with the same or similar experiences which we then interpret in a particular way, because of our past experience. In this way, our past is always before us: 'The being of having-been is the past, such that in such a being I am nothing but the *future* of Dasein and *with it its past* (Heidegger 1985:238, emphasis original).

In this study, participants brought up in stricter households where personal body matters were never addressed or where there were fastidious hygiene rules, tended to feel more stigmatised by IBD than those growing up with more openness, or who had overcome their childhood attitudes towards bowels and stools. Paterson (2000) evidences a similar issue in men with post-prostatectomy urinary incontinence – coming to terms with incontinence means overcoming ingrained childhood rules about containment.

Since the everyday cultural context demands perfect control, maturity and silence about bowel matters, there is a great incentive for people with IBD to hide their condition. Jones et al. (1984) include ‘concealability’ as one of six dimensions which determine how stigmatising a mark is and numerous authors since have debated the influences on and consequences of hiding or revealing a stigmatising mark (for example, Crocker et al. 1998; Goffman 1963a; Joachim and Acorn 2000a; Quinn 2006), but Crocker et al. (1998) argue that the two most important dimensions of stigma are ‘visibility’ and ‘controllability’. Conditions tend to be polarised as either visible *or* invisible, as if there is a clear choice about which state dominates. For some marks, such as facial disfigurement (see www.changingfaces.org.uk) or skin colour, there is no choice. The mark is fully visible, there for all to see. In other circumstances - for example infertility or sexual orientation - the bearer of the mark can choose to keep their difference hidden. The problem with IBD is that it is not one thing or the other: ‘while it often remains invisible to others, the condition has an unwelcome tendency to become outwardly perceptible at times, to varying degrees’ (Saunders 2014:14). The person with IBD may choose to keep their condition to themselves, and if their illness is mild or well-controlled with effective medication, there is no reason that anyone need know they are unwell. If they experience severe urgency or unpredictable incontinence, however, their ability to reliably control both action and disease information is significantly compromised. The rush to the toilet demanded by urgency, or any FI, can ‘out’ the person with IBD against their will, so that the choice to reveal or conceal is taken away. This potential and unwanted exposure adds to disease uncertainty, reduces the sense of control and increases stigma. The stigma comes from knowing that the nature of the mark (bowel disease and incontinence) is taboo in the wider social world, and that poor control is linked to immaturity or incompetence.

Invisibility of a condition can also be stigmatising (Joachim and Acorn 2000a). Without obvious evidence of illness, others can behave in a stigmatising way towards people with IBD who may appear to be ‘making it up.’ Despite often being disgusted by illness and disease, the public is distrustful of those who do not give a clear indication of illness yet behave as if they are ill. In these circumstances, the public finds it difficult to determine which ‘category of persons’ amongst those available, the person belongs to (Goffman 1963a). People with IBD can look well, especially if taking steroids which tend to add weight, and uninformed onlookers may struggle to make sense of the disconnect between appearance (looking well) and behaviour (behaving ill).

11.2.2. The social power of the everyday

Theorists have insisted that stigma arises when a power imbalance develops due to one party in a relationship being weakened by a stigmatising feature in the other (Link and Phelan 2001; Schur 1980). Others have demonstrated the impact of social, economic and political power in stigma creation whereby those with the financial, educational and material resources have power over those with less, or without (Crocker et al. 1998; King et al. 2010; Oliver 1990). These concepts have been brought into the health arena to demonstrate how the social power of being healthy (normality) stigmatises the weakness of illness (abnormality) (Corrigan 2004; Mason et al. 2001; Scambler et al. 2006). Pursuing this idea, Link and Phelan (2001:382) define stigma as: ‘the co-occurrence of labelling, stereotyping, separation, status loss and discrimination in a *power situation* that allows these components to unfold’ (emphasis mine).

People with IBD are products of the same socio-cultural influences as others in their society, and understandably would perceive that others might view poor bowel control negatively. People with IBD might also get labelled as dirty, be subjected to stereotypical views about what constitutes illness, be isolated socially because of the unpleasant threat they present, be thought less of and be treated differently because of their disease and any related FI, but it is difficult to perceive the power in this situation. The need for good bowel control operates at such a fundamental level, long before

social, economic or industrial aspects of power come into play. Power can create stigma when it is used to purposefully disadvantage others. For example, stigma can arise in the physically disabled when others who have the power to enable access to facilities fail to do so, thereby exerting control. No-one else controls another person's bowels. Stigma in IBD comes instead from the individual's inability to adhere to a fundamental social rule, and if power is an influence here, perhaps it is that social rules exert a moral power over the individual who cannot obey them – as evidenced by the shame and isolation of women with stress urinary incontinence in China (Wang et al. 2014).

Link and Phelan suggest that power may not be visible, but is always there even if it is not expressed (2014; pers. comm., 14th May); there was no evidence in this data that participants either felt powerless or perceived others as more powerful than them, and it is inappropriate to insist on the presence of power without any evidence. Recently, they have proposed that a stigmatised person who avoids situations which stigmatise them further by keeping a low profile, staying in, or moving away is succumbing to the power of the majority group which in subtle ways forces these behaviours – behaviours which may otherwise be assumed to be stigma-coping strategies (Link and Phelan 2014). Thus, 'stigma power' enables the exploitation, control, and exclusion of others in subtle ways which may go unnoticed. In this study, Janice [61, CD] had assigned herself to the *FI, no stigma* group. At interview it was clear that in fact she felt deeply stigmatised, so she stayed at home to avoid stigmatising situations. Whether this is (social) power or whether it is a coping strategy, is a matter of interpretation.

Goffman has been criticised for focussing on stigma in personal interactions, while others, (Falk 2001; Heatherton et al. 2000, for example) have addressed the influence of social structures on stigma development. Link and Phelan (2014) suggest that these social structures are the very mechanisms through which stigma power is exerted to 'keep people in' (line) and 'keep people away' (isolate disease). In IBD, both may play a part. The social structures of hygiene, containment and bowel control rules may be as influential on the individual with IBD as the personal interactions which threaten to discredit them, supporting the view that factors other than 'the exercise of power and oppression' (Saunders 2014) contribute to feelings of stigma in IBD.

11.2.3. The everyday of language

‘Disease’ and ‘bowels’ are dirty (soiled) words. In this study, Kevin identifies that he has a problem with the word ‘disease’ in the label of his illness. Although there are a few medical conditions with the label of ‘disease’ which are not infectious (for example, chronic kidney disease, coronary artery disease), there are many more that are. Hence the Hospital for Tropical Diseases in London, and many sexual health clinics situated throughout the UK, deal with illnesses which are often virulent in their capacity to contaminate. Mode of spread is often via a body fluid – so that blood, stool, urine and droplets of breath become the carriers that transport the causative organism to other humans, disseminating the condition.

Faeces, and any synonyms or related words, are also dirty. As children we learn that these words, which represent dirtiness of matter, should not be used. Kubie (1937) suggested that the association between dark and dirt caused dark-skinned people to be considered ‘no better than dirt’ whilst white-skinned people thought themselves purer and cleaner. Blay (2011) confirms this, evidencing the relationship between face-whitening, skin bleaching and ‘white supremacy’ throughout world history. If faeces were neither dark nor malodorous, humans may feel less disgusted by stool.

The misfortune is that the person with IBD has two indicators of dirt in the name of their illness – bowels are dirty, disease is dirty. Given the perceptions of disgust in relation to dirt discussed above, the extrapolation is that observers may perceive the person to also be dirty, and from that misconception springs the potential for stigma.

11.2.4. The everyday of chronic illness management and stigma resistance

In this study, the receiving person’s experiences of feeling stigmatised and of stigma resistance are addressed. Stigma is an experience, action and attitude which can affect adjustment to chronic illness. Stigmatising attitudes can be directed towards others (action) but whether or not it is felt (experienced) depends on the receiving person’s

ability to resist these attitudes. If the person is negatively affected they feel stigmatised, but even if able to resist, will recognise attitudes directed at them as stigmatising.

The aim of successful chronic illness management is to reposition the condition from being prominent in the person's life to becoming absorbed into the regularity of the day to day so that it becomes the person's background normality. Normalisation is not about fitting the majority normal, but about adjusting to a changed situation and accepting it as the new normal (Deatrick et al. 1999; Robinson 1993). Royer (1995) has previously demonstrated the similarities between adjusting to chronic illness and managing stigma; this study indicates that these similarities also extend to IBD-related stigma. Chronic illness normalisation and IBD-related stigma both require the person to gain a sense of physical and emotional control, develop strong and effective support networks, and learn to accept and work with their condition rather than against it - processes that usually develop over time. Certain factors offer risk of, or protection against mal-adaptation to chronic illness:

Emotionally supportive relationships set the stage for positive adjustment to chronic disease, whereas criticisms, social constraints, and social isolation impart risk. Positive generalized and disease-specific expectancies, general perceived control and mastery, and a sense of control over specific disease related domains also promote adjustment (Stanton et al. 2007:578).

As for those with a permanent stoma (Danielsen 2014), good quality support for people with IBD is influential in overcoming stigma (Frohlich 2014). Social support also promotes self-management, encouraging the maintenance of medication regimens and other specific disease-related behaviours, resulting in better disease control (Gallant 2003). For some participants in this study, better control of bowels reduced stigma because decreased risk of incontinence secured greater invisibility. This study suggests there is a relationship between social support, control (which aids normalisation) and stigma in IBD, supporting Joachim and Acorn's (2000b) argument for considering stigma and normalisation together in chronic illnesses research.

Adjusting to chronic illness means relinquishing the previous established identity and moving forward with the illness incorporated into a new identity. As people learn to live with demands of their illness and gain mastery in managing their medical needs, they develop a sense of competence and familiarity with their disease. The challenge for people with IBD is that many ways of knowing are needed, because the disease pattern is inconsistent. Avoiding the trigger which prompted a previous flare-up will not necessarily avert the next one. This constant underlying uncertainty makes mastery and acceptance a difficult challenge in IBD (Kiebles et al. 2010), and one which has similarly been reported in rheumatoid arthritis, cancer, and heart disease (Sanderson et al. 2011; Stanton et al. 2007). Fluctuating diseases require the development of ‘multiple normalities’ which are adopted according to the demands of the illness at any one time (Sanderson et al. 2011). In this study, stigma also fluctuated, sometimes associated with active disease, or driven by different interactions and relationships, requiring participants to ‘wear different hats’ in different situations. Andrea [*FI, stigma*] for example, demonstrated an open and pragmatic relationship seemingly devoid of stigma with her IBD consultant, which contrasted with and required a different approach than the guarded, stigmatised relationships with her family, friends, and the general public.

All study participants who did not feel stigmatised seemed content with their illness identity. Acceptance of a negative attribute of self is vital in stigma resistance (Millen and Walker 2000). Regardless of others’ opinions, if the bearer of the mark is content with that mark, they are less likely to feel stigmatised. In sexual identity, and mental illness, for example, ‘coming out proud’ is significant in learning to live well with a previously stigmatising mark (Corrigan et al. 2013). Although stigma is not routinely addressed in chronic illness texts, the current study findings support emerging evidence that managing stigma is an integral component of normalisation in chronic illness (Audulv et al. 2009; Joachim and Acorn 2000b; MacDonald and Anderson 2011).

Normalisation takes time. Although there is conflicting evidence on whether health-related quality of life (HRQoL) improves (Beaulieu et al. 2009; Casellas et al. 2002; Jäghult et al. 2011), deteriorates (Canavan et al. 2006) or is unaffected by longer disease duration in IBD (Kuriyama et al. 2008; Mnif et al. 2010), the weight of evidence is for

improvement. Taft et al. (2013) have shown that IBD-related stigma negatively affects clinical outcomes and HRQoL, but that stigma resistance improves it. The current study suggests that, for many people, IBD-related stigma decreases with longer disease duration. There may be a relationship between stigma reduction, resistance and HRQoL, with related issues adjusting in parallel with each other. Normalisation or mastery of illness resulting in stigma reduction may increase HRQoL; or stigma reduction may permit mastery, improve disease control and outcomes and hence enhance HRQoL; or improved disease control may permit mastery, reduce stigma and enhance HRQoL.

HRQoL in IBD is affected by stress (Hart and Kamm 2002; Mawdsley and Rampton 2008). C-Reactive Protein (CRP) is a marker of tissue inflammation used to monitor disease activity in patients with IBD, although its response to inflammation is less intense in patients with ulcerative colitis (Vermiere et al. 2004). Discriminatory and prejudicial actions and attitudes can cause feelings of stigma which stress the individual (Miller and Kaiser 2001), and there may be a relationship between elevated CRP levels and persistent, daily discrimination stress in racial minority groups (Lewis et al. 2010). Gut-focussed responses to stress evidence the relationship between acute and chronic stress and inflammatory processes in IBD (Hart & Kamm 2002). Stigma-related stress in IBD *might* contribute to raised CRP, increased gut-focussed responses and increased disease activity, and be one influence which negatively affects patient outcomes, but a lot more work is required to convince of the relationships between these factors.

11.2.5. Profiles of those with IBD who do and do not feel stigmatised

As a piece of qualitative enquiry, this study did not set out to build profiles of those with IBD who are more or less likely to feel stigmatised, and hermeneutics profoundly resists attempts at categorisation since the focus is on revealing meaning. However, since this academic exercise supports the presentation of new knowledge, it is perhaps appropriate to report, albeit cautiously, on profiles of those with IBD who may be more or less likely to feel stigmatised [Table 11-1].

Feature	The stigmatised person with IBD	The non-stigmatised person with IBD
Gender	Male and female	Male and female
Disease duration	Shorter	Longer
Medical control of IBD	Poor	Good or poor
Emotional control of IBD (feeling in control irrespective of level of physical control)	Poor	Good
Shares disease information with others	Rarely, reluctantly	Often, more readily
Support network	Often absent or minimal	Usually strong and effective
Coping skills:	Weaker	Stronger
Humour	Rarely used in relation to IBD	Often used in relation to IBD
Perspective on life / illness	Positive perspectives rarely applied	Positive perspective often applied
Mental wellbeing	Less robust	More robust
Childhood influences	Attitude towards bodily functions more likely to have been negative or private in the childhood home	Attitudes towards bodily functions more likely to have been positive or open in the childhood home
Sense of mastery over IBD	Less likely to be established	More likely to be established

Table 11-2. Tentative suggestion of profiles of people with IBD who are more or less likely to feel stigmatised by their disease, related incontinence, or both

This study data suggests that men and women are equally likely to experience feelings of IBD-related stigma. Those with shorter disease duration, poor medical control (thus poor symptom control), poor psychological or emotional adjustment to their situation so that they do not *feel* in control, limited ability to tell others about their condition resulting in a weak or absent support network, and who do not have beneficial coping skills, are less likely to have established a sense of mastery over their situation and are more likely to feel stigmatised.

Robust, well-designed research would be needed to establish whether there are convincing profiles of those with IBD who are more or less likely to struggle with stigma and whether other factors, such as disgust trait sensitivity (Haidt et al. 2002) are also influential. Nahon et al. (2012) have also identified disease and socio-economic characteristics, including severe disease, flare-ups, non-adherence to medication and socio-economic deprivation, which increase the risk of anxiety and depression in people with IBD. The link between socio-economic status (SES) and stigma is well-established with evidence of the relationship in terms of neighbourhood (Atkinson and Kintrea 2001), HIV/AIDS (Amuri et al. 2011), and education (Johnson et al. 2011) for example. There was little clear evidence of poor SES amongst the participants in this study (based on a subjective assessment of accommodation), suggesting that IBD stigma may develop independently of SES or that the range of social classes are not represented in this study population.

Further research may reveal if there are any other socio-cultural influences on IBD-related stigma, and evidence the gap in public knowledge of the disease. Recommendations are made below [p. 270].

11.3. Critique of the methodology

Although Heideggerian (interpretive) phenomenology was the most appropriate framework for this study, it did present challenges. Set against the expectation to follow a prescribed route by adhering to a research protocol, hermeneutics encourages the researcher to be-in-the-moment with the research, to resist certainty and ‘confront and wrestle with the restlessness of possibilities’ (Smythe et al. 2008:1391). In so doing, one creates a balance between the solid principles of research, and being in a situation which constantly changes as one’s own understanding evolves. This section critiques the aspects of the research which created particular challenges, or were at risk of disruption.

11.3.1. Heideggerian phenomenology

Three challenges of the philosophy are that to recognise others' experiences, understandings and interpretations, one must first recognise oneself; that in making an intelligible interpretation of the study data and the range of others' lived experiences, one must deal concurrently with similarities and differences; and narrating others' stories means also narrating one's own identity (Ricoeur 2005).

11.3.1.1. Recognising oneself

To conduct interpretive phenomenological research with its emphasis on pre-understanding and co-constitution the researcher must first know themselves. Recognition of self guides reflexivity during data collection, co-constitution and analysis, and necessarily requires giving sufficient evidence of background to enable the reader to understand the perspective the researcher brings to the study. In Chapter 1, I explained my experience of what it is to feel stigmatised, and that this had changed over time, but I came to understand my position more during data collection and analysis. The temptation is always to make an enthusiastic pseudo-intellectual grab at anything in the data which resonates with one's own experience, as in my emotional response to reading Goffman for the first time. Knowing self means recognising this tendency, and appreciating the importance of stepping away from first responses and reactions to take a slower, more thoughtful path towards interpretation. Knowing self also enables one to do the right thing by participants through a morally robust analysis, interpretation and revealing of meanings within the data (Taylor 1989).

My identity naturally leads me towards a particular interpretation of others' stories, and risks favouring those which align with my own horizon. To overcome this, an attitude of unconditional positive regard (Rogers 1957) was required; I presented an open demeanour towards participants, so that they felt accepted, understood, and prepared to risk offering aspects of their self which may have felt threatening to them. The approach can have unanticipated therapeutic benefits for interviewees (Gale 1992), especially if it

gives voice to the vulnerable or marginalised (Hutchinson et al. 1994); in this study, Kevin commented that he had found it beneficial to be able to talk openly about his experiences, for example. Although unconditional positive regard can be emotionally challenging for the researcher, it recognises and supports the role of the self in capturing and understanding others' lived experiences.

11.3.1.2. Making an intelligible interpretation and dealing with differences and similarities in the data concurrently

Recognising self also influences interpretation. Hermeneutic phenomenology requires the researcher to show / reveal the essence of an experience, and what is shown / revealed will always be an interpretation of events influenced by one's own horizon, background and pre-understanding (Gadamer 2004). Witnessing and translating others' experiences imputes a new meaning, and although the phenomenological researcher is responsible for presenting as balanced and reasonable a view as possible, the end result is likely just the best that can be achieved. 'Truth', even carefully arrived at, is not absolute - there may be falsehoods and though stated with good intention, they are themselves unintended. The hermeneutic phenomenologist has to accept, and trust that their readers understand, that it is not possible to prove the truth of an interpretation:

One will never be able to *prove* - what we call "prove" ... this stems from the fact that the other is secret. I cannot be in the other's place, in the head of the other. I will never be equal to the secret of otherness. The secret is the very essence of otherness. (Derrida 2005:165)

In interpreting others' stories I bring to analysis recognition of myself, and an acceptance that I can never reach an absolute truth – and yet it is my responsibility to create as reasonable an understanding as any researcher might make, to take the mass of chaotic data and transform it into a meaningful representation of experience. The challenge lies in dealing with a whole range of 'truths' emerging from different participants' stories, whilst finding that as interpretation and understanding of others'

experiences progresses, one's own perspective changes. In this study, dealing with a range of 'truths' resulted, for example, in the constitutive pattern of *Being in or out of control* addressing several perceptions of what control is, or what absence of control means, to study participants. My pre-understanding of what emotional control means was enhanced by understanding others' perceptions of feeling in control of their self even if physical control of bowels was absent. Yet however 'finished' analysis and interpretation feels, there will always be unfinished business, always other ways that data could be represented, other stories that could be told (Turner 2003). The responsibility lies with the researcher to tell a 'good enough' story, and accept that the reader makes the final interpretation which will itself be influenced by their own horizon, background and pre-understanding (Koch 2006).

11.3.1.3. Narrating others' stories and narrating one's own identity

Recognising self and offering an interpretation of others' experiences based on one's own horizon, background and understanding means that the researcher's identity is inextricably bound up in the narration of others' stories: 'all understanding involves self-understanding' (Moran 2000). This requirement of hermeneutics is balanced with the need to manage self to avoid negative bias, and with one's presence in the research for the study's benefit. Gadamer calls this 'prejudice', and Koch (2006:92) explains:

Our situatedness as interpreters, our own historicity, do not constitute an obstacle. Prejudices are the conditions by which we encounter the world we experience as something. We take value positions with us into the research process. These values, rather than getting in the way of research, make research meaningful.

I bring my understanding of feeling stigmatised, now not feeling stigmatised, and the knowledge that this decreased over time into the research event, yet am required to bring the self to the foreground and place it in the background simultaneously. Although I own this experience and, without revealing it to them, have used my understanding of it to question, probe and explore participants' experiences of stigma, I also had to be

careful that what emerges from the data reveals what is really there, and is not simply a reflection of my own experiences. The findings have to be shown to emerge through a rigorous process of hermeneutic interpretation to be credible.

There are no instructions for how to achieve this during data collection. Only through knowing that I should bring my 'self' to consciousness and be mindful of my own history, culture and pre-understanding which were with me in each interaction, did I learn how to draw on my past to achieve shared understanding. The difficulty continued through data analysis, when necessarily my pre-understanding informed detailed consideration of the many new horizons co-constituted at interview, so that the eventual meaning offered to the reader is a sharing of participants' identities with my own (Lowe and Prowse 2001).

11.3.2. Sampling bias

The study sample was self-selected from an existing database of research-keen participants who may have more concerns than others with IBD who did not take part. The imbalance in number of participants across study sub-groups [*FI, stigma* n= 12; *FI, no stigma* n= 15; *No FI, stigma* n = 4; *No FI, no stigma* n=9] may have resulted in a bias towards those with FI [*FI*, n= 27; *no FI*, n=13] and those without stigma [*No stigma*, n= 24; *stigma*, n=16]. However, membership of these sub-groups proved to be fluid, with some self-assigned to the *No stigma* groups revealing experiences of stigmatisation, whilst a couple in the *stigma* groups gave no indication of feeling stigmatised. Self-assignment to any study sub-group was often speculative, perhaps reflecting the often fluctuating experience of stigma over the course of the disease. Those with more robust mental health, and therefore more resilience, may have been more inclined to volunteer. The members of the sample may have had previous or current experience of feeling stigmatised which prompted them to volunteer, but since the purpose of the study was to understand the meaning of the experience, not measure prevalence, this was appropriate.

11.3.3. Data collection bias

Data was collected through forty semi / unstructured interviews, and it could be argued that it was predictable that stigma was found since that was what was looked for. As indicated above, the aim of the study was not to find and measure the prevalence of stigma, but to understand the meaning of the experience – the focus on stigma during data collection was therefore essential. The use of reflexivity [Chapter 6: p. 102; this chapter: p. 265] attempted to reduce the risk of researcher bias during data collection. Much of the data was captured through use of an open question which did not ask about stigma directly, but about how IBD made participants feel – that stigma emerged in the data anyway might indicate its significance.

11.4. Critique of the data analysis method

Interpretation and presentation of human experience is complex and challenging. Achievement depends on researcher capability and suitability of the analysis method. Critical review of the hermeneutic method (Diekelmann et al. 1989) can enhance trustworthiness of study findings. The case for using the approach (hereafter referred to as Diekelmann's method) was made in Chapter 6 [p. 96]. Here, its effectiveness and the challenges it presented are considered.

11.4.1. Suitability of the data analysis method

Creswell (2007:150) advises that the qualitative researcher should move in a data analysis spiral rather than have a fixed linear approach, entering with data and exiting with an account achieved by taking a path through several layers of analysis. This supports Heidegger's focus on the hermeneutic circle, where one moves back and forth between own understanding and that of the other in the interaction, to build, over repeated interpretations, a final agreement of what the experience being addressed, means. Diekelmann's method incorporates these recommendations and by demanding

repeated iterations through the data, moves analysis beyond descriptions of ‘this is what stigma in IBD is’ towards ‘this is what stigma in IBD means.’ The method thus offers a framework to lead the researcher towards interpretation, in keeping with the philosophy of interpretive phenomenology.

Overall, the method was effective. From hundreds of pages of raw data an interpretative shape and structure of the meaning of experiences of stigma in IBD emerged. Team analysis and revisiting of previously analysed transcripts encouraged reflexivity and reduced the risk of negative bias – of interpretations being driven purely by my own understanding and experience of stigma. As layers of analysis were completed, so the interpretation became increasingly refined. The stages provided a helpful framework to lead me through and encouraged reflexive thoughtfulness. With each return to the data, I found myself carefully reconsidering, reviewing and rethinking until satisfied that I had ‘let the text speak’ (Smythe et al. 2008), so that understanding had come from the data. The final report is only one interpretation; there may be others, because as Crist and Tanner (2003:205) also point out: ‘interpretation is an unending process - readers of the report make the final interpretation’. Co-constitution with participants at interview and between myself and my supervisors at analysis added to the credibility of the findings. Diekelmann’s method enhanced the rigour of the study by strengthening the tie between philosophy and analysis, ensuring careful adherence to and reporting of analysis processes and procedures, and producing findings which retain context and which may have an emotional impact on the reader – features described by de Witt and Ploeg (2006) as balanced integration, openness and resonance.

11.4.1.1. Balanced integration

Balanced integration refers to ‘the intertwining of philosophical concepts in the study methods and findings, and a balance between the voices of study participants and the philosophical explanation’ (de Witt and Ploeg 2006:215). An example of this is the relationship between Heidegger’s *thrownness* and adult responses to childhood attitudes towards dirt [this chapter: p. 243]. Thus, new understanding is a co-constitution between

past knowledge and new experience. Through Diekelmann's method I have been able to bring my own history, pre-understanding and fore-structure of understanding to analysis, as I did to data collection, but manage it reflexively for the benefit of the study. Through co-constitution, a balanced integration of self and participants reveals representation of the meaning of stigma in IBD.

11.4.1.2. Openness

Openness is the 'systematic, explicit process of accounting for the multiple decisions made throughout the study process' (de Witt and Ploeg 2006), otherwise known as an audit trail. Diekelmann's seven stage method provided structure which aided openness through co-constitution with others in development of findings, and through reflexivity - evidenced in the detail of the analysis method presented in Chapter 7.

11.4.1.3. Concreteness

Concreteness reflects the relationship between findings and the real world so that the reader appreciates the situatedness of the phenomenon, and understands the application of that phenomenon within the participant's world (de Witt and Ploeg 2006, van Manen 1997). In this study, one example is the experience of having to 'jump the queue' to use a public toilet; every reader has the experience of queuing to use a public toilet, of expecting themselves and others take their turn, and this aids understanding of the dilemmas facing those who, because of IBD, need to push to the front of the queue. Diekelmann's method supports Heidegger's embrace of the researcher's role and experiences in understanding the experiences of others, which enables the presentation of findings in real-world context.

11.4.1.4. Resonance

Resonance refers to the impact that findings have on the reader, in the way that Goffman's seminal 1963 text resonated with me when first I read it, because I *felt* it. Resonance is what Frank (2004:431) describes as 'allowing the reader to discover the body, and then keeping them interested in it.' In this study, 'the body' is revealed as the IBD-related stigma experience of the participants. If analysis of this study data is competent, it should resonate with those to whom the findings have pertinence. People with IBD should find familiarity in the experiences portrayed, and those who stigmatise people with IBD should recognise their stigmatising attitudes and be able to appreciate a different understanding of those attitudes (Koch 1999). Those who have neither experienced IBD-related stigma, nor behaved negatively towards those with IBD, may come to understand the way that social customs and rules enable stigma to emerge. Identification of constitutive patterns in Diekelmann's method enables the researcher to find and present the body or bodies - the essence(s) which express 'this is what the experience means to these participants.'

11.4.2. Challenges of the data analysis method

Diekelmann's method is not without challenge. I resist the word 'disadvantages' because it is inaccurate – the method seems very well-designed to do what it is meant to do so any difficult aspects cannot be disadvantages but are worth consideration. The main challenges were that analysis is very time consuming, that it demands an enormous emotional effort, that even at the conclusion of the process loose ends may remain, and that relational themes may map onto more than one constitutive pattern.

11.4.2.1. Analysis as a thief of time

Analysis was very time-consuming but, having prior experience of qualitative data analysis, this was expected. It took several months, repeatedly handling and facing the

data and thinking deeply about it, although this improved the quality of analysis and compensated for not transcribing interviews myself. Decisions were not hurried. Each theme or pattern that emerged was thought about, reconsidered, debated, checked against data and field notes, and discussed with supervisors, interested colleagues and peers. I learnt how to be-in-thought and let the meaning come to me. Hopefully, the extended time taken for analysis resulted in more robust findings.

11.4.2.2. The emotional challenge

Qualitative analysis demands an intense emotional effort, sometimes described as ‘emotion work’ (Dickson-Swift et al. 2007; Dickson-Swift et al. 2009). Analysis was difficult and discomfiting *because* it forced me to strip away my public presentation of self, and open myself up to the possibilities of what may lie within the data. In doing so I uncovered issues which, because they touched my own experiences, were emotionally challenging. This led me to question whether I was finding meanings in the data because of my own experiences, or whether those meanings were actually there. Diekelmann’s method also demands researcher reflexivity. I debated this issue with my supervisors, arguing that meaning existed in the data independently of my experiences which nonetheless enabled me to notice it. In this way, awareness of the self moves beyond ‘egocentric fascination’ (Bradbury-Jones 2007) and becomes the means by which the less apparent stories of participants – those which have a quieter voice within the text or tell a very different experience - can be told. Frohlich (2014) concurs that ‘deviant stories shed additional light on how IBD does or does not cause stigma’.

11.4.2.3. Loose ends

Diekelmann (2001) states that identification and description of constitutive patterns represent the highest form of analysis, but having confirmed three constitutive patterns in the study data another level of analysis which would describe a relationship between these three patterns seemed possible. Ignoring this possible relationship felt like leaving

loose ends, and accepting that there may not be a tidy outcome, that questions may not be answered, can feel a bit like failure. Diekelmann (2014, pers. comm., 10th March; emphasis original) advised:

Your methodological question is an important one and indeed there are ways to extend your level of analysis using our method. But this must be *very carefully* executed ... The danger in doing this kind of research is becoming *reductive!* We live in a world of science that is always trying to weigh, measure and organize! The tighter and more discrete the better. This kind of analytic thinking is at-hand [nearby] that it threatens at times to take over. What you are seeking is UNDERSTANDING of an experience or phenomenon. As such what you want to do is *call folks who read your research to think the as-yet unthought*. To see something anew.

The advice is clear – avoid reductive influences, let the work speak for itself and allow readers to make their own interpretation. What appears as a central idea in this study is instead the starting point – my question of ‘what is this experience like?’ - which is illuminated and informed by the constitutive patterns and relational themes arranged around it. The reader therefore creates their understanding of the phenomenon from the meanings presented via the constitutive patterns and relational themes.

11.4.2.4. Crossing over of themes

Although reassured that loose ends do not need tidying, I had concerns that some relational themes linked with more than one pattern. I had developed a pictorial representation of the complexity of the stigma experience in IBD, but was also aware that no other researcher reporting use of this data analysis method in a Heideggerian phenomenological study (Alqaissi and Dickerson 2010; Chang and Horrocks 2006; Nelms 2002; Saunders 1994) had described this crossing-over of themes. Diekelmann (2014, pers. comm., 1st March) further advised that in hermeneutic phenomenology, crossings enable seemingly unrelated ideas and isolated thoughts to permeate each

other, leading to an array of possibilities, rather than to a single predetermined ‘answer’. In this study data, the relevance of some relational themes to more than one constitutive pattern represents permeation of ideas and supports the inter-relationship between themes and patterns. It is when ideas and dialogue interconnect with each other that the opportunity for a new (different) understanding exists because there is *always* interpretation, and we (humans) are *already* doing it (Diekelmann and Diekelmann 2009:14). When crossing-points, and what lies to the left and right of them, go unnoticed, the unusual can get lost amongst the everyday (Diekelmann and Diekelmann 2009). Rather than take a direct path from one point in the data to another, Diekelmann and Diekelmann suggest that stopping to look around and to consider other routes enables the richer, more complex interpretation of experience. Without crossing points which make paths from a relational theme to more than one constitutive pattern, aspects - such as the multi-faceted definitions applied to relational themes and patterns which then add variety and richness to the understanding and interpretation of experience - would be obscured.

11.4.3. Summary of the data analysis method critique

Despite the challenges it presented, Diekelmann’s method aligned well with the study philosophy and enabled a seemingly robust and thorough analysis of the data. On reflection, this was a good choice of analysis method as it enabled complex stigma experiences to be revealed within the framework of interpretive phenomenology.

11.5. Trustworthiness (rigour) of the study

Trustworthiness, referring to the quality of research, is synonymous with rigour in quantitative studies and employs strategies which then ensure the relevance, usefulness and contribution of the findings to ongoing scientific endeavour. Trustworthiness is demonstrated through credibility, dependability, confirmability and transferability (Lincoln and Guba 1985), and each has been supported by a range of strategies within

this study [Table 11-2]. No study is perfect, and there are always weaknesses and biases which influence outcomes, but the researcher should demonstrate that they have made the best effort possible to manage these aspects so that the reader can trust the outcomes. Tobin and Begley (2004) evidence the debate between constructive and evaluative procedures, the former attending to quality during the research process, and the latter addressing the issue after the event. Overlooking quality issues during the process of research runs the risk of failing to see serious errors until it is too late, and these cannot then be corrected (Morse et al. 2002). Ongoing reviews of these aspects during the study helped maintain a high standard of trustworthiness.

Approaches to trustworthiness	Strategies	How managed in this study
<p>Credibility Conducting research in a believable manner and being able to demonstrate that believability (Houghton et al. 2013); likelihood that this research, conducted in this manner by this researcher asking these questions, would yield these results (Miles and Huberman 1994)</p>	<ul style="list-style-type: none"> • Prolonged engagement and persistent observation (of data) • Triangulation • Peer debriefing • Member checking 	<ul style="list-style-type: none"> ▪ Sufficient interviews to demonstrate shared as well as varied experiences ; ▪ Iterative analysis ▪ Comparing perspectives of people from different points of view (Patton 1999): study sub-groups; ▪ Involvement of supervisors in data analysis to agree early relational themes and constitutive patterns, and process by which these were reached [Chapter 7]; ▪ Scripts not returned to participants [See Chapter 6: pp. 92-93 for rationale]. Co-constitution employed [See Chapter 6: p. 93]
<p>Dependability Stability of the data (Tobin and Begley 2004); ability of reader to determine how findings were reached (Koch 2006)</p> <p>Confirmability Establishing that interpretations of findings arise from the original study data (Tobin and Begley 2004)</p>	<ul style="list-style-type: none"> • Audit trail • Reflexivity and audit trail 	<ul style="list-style-type: none"> ▪ Researcher credentials: competence, position, and background made transparent [Chapter 1]; ▪ Rationale for all design decisions presented [Chapter 6]; ▪ Amendments to protocol (new approach to interviews, change of data analysis framework) explained clearly [Chapter 6]; ▪ Detailed description of data analysis process given [Chapter 7]; ▪ Range of findings, evidenced by verbatim quotes [Chapters 8, 9 & 10] ▪ Sample transcripts with original analysis notations provided [Appendixes 8 & 9] ▪ Self-awareness of researcher made evident through audit trail, and field notes and reflexive diary [Appendix 7]; use of verbatim quotes [Chapters 8, 9 & 10].
<p>Transferability* The extent to which the findings are relevant in other contexts or with other participants / groups (Thomas and Magilvy 2011)</p>	<ul style="list-style-type: none"> • Thick descriptions 	<ul style="list-style-type: none"> ▪ Appropriate use of verbatim quotes; context provided through interpretation and vignettes; relationship of findings with wider literature
<p>Table 11-3. Strategies to determine trustworthiness (rigour) and methods employed for achieving this in the current study *The success of the transferability strategies built into the study cannot be determined until the study has been completed</p>		

11.5.1. Critique of reflexivity in this study

The role of the researcher is also of interest in qualitative research, and particularly in Heideggerian phenomenology, as she is an integral part of data collection and analysis (Holloway and Wheeler 2010; Horsburgh 2003; Koch 2006; Smith 1999, for example). Reflexivity is essential for managing this role and, further to presenting the rationale for adopting a reflexive approach [Chapter 6: p. 103], I here offer a critique of whether a reflexive stance was successfully achieved throughout data collection and analysis.

Reflexivity was an essential, consistent companion during this study. Aware that my pre-understanding, horizons and experiences could influence data collection and analysis, I exposed myself to an often uncomfortable self-examination of attitudes, suppositions and opinions. This thoughtful, conscious self-awareness (Finlay 2002) is both unsettling and affirming. I have had to admit to letting my previous experiences (and sometimes prejudices) cloud my thinking, but I have also avoided making an interpretive mistake, or have recognised and subsequently rectified such an error.

I entered this study assuming that IBD and related FI would be stigmatising and that it would disrupt relationships, but with no opinion on whether others' experiences of stigma would match mine. I leave it with the understanding that whilst IBD and FI, together or separately, are stigmatising for some and do disrupt some relationships, this is by no means the case for all; and that whilst there are some similarities between my experiences of stigma and those of my participants, the experience of IBD-related stigma is wide and varied even though the origins of stigma (illness and its consequences, bowels and bowel control) are seemingly similar for all in this study who feel it. I was surprised by some participants facing major disease challenges yet having a firm sense of emotional control and a feeling of mastery over their situation; and by others who, faced with problematic incontinence, refuse to seek help or refuse offered help, especially when that help could help them regain physical control. I was surprised at the amount of social, emotional and physical discomfort some tolerated, and while it was encouraging to meet people who have learnt to resist stigma, it was distressing to meet those who are socially crippled because of it.

11.5.1.1. Reflexivity during data collection

Reflexivity played its hand in many ways: determining whether to continue with a difficult, intractable interviewee, and re-phrasing questions as I was asking them to avoid making an assumption based on my experiences, are two examples. On occasion, I also withheld a response to avoid suggesting disbelief – such as when Carl explained that his wife had left him because of his Crohn's disease [Chapter 9: p. 191] and I smothered my outrage on his behalf because I know, without question, that my partner has been, is, and will remain with me despite the challenges that life throws at us.

Another example of successful reflexivity arose when I phoned Andrew on the day of interview to ensure he was happy to proceed. He insisted on providing very detailed directions, despite my explanation that I knew how to find his address. I battled to contain my immediate reaction of 'Why do men always think women cannot read a map?' only to discover, on arrival, that he was wheelchair-bound and now unsure of his identity and role in life. Giving me directions was one thing he could still do, and had I objected, I would possibly have risked losing what was a deeply-affecting interview.

Reflexivity can also promote positive aspects. For example responsibility, self-awareness and care for the participant guided my careful questioning of Andrea about her relationship with her partner in which neither are addressing the obvious yet unspoken monster that is her incontinence [See Appendix 8: Andrea's interview, p. 385], and my concern for Carl over his inability to accept his stoma even though it is unlikely that it can be reversed [See Appendix 9: Carl's interview, p. 399]. Field notes and extracts from my reflexive journal [Appendix 6] provide further evidence of the impact of reflexivity on decisions made during the study and enhance the audit trail.

11.5.1.2. Reflexivity during data analysis

The connectedness between researcher and researched in hermeneutics means that the researcher has an influence on data analysis, but reflexive analysis is challenging:

Much commitment, care, time and skills go into reflexive analysis and to do it well takes practice. Immersing oneself in [analysis] can prove a painful business (Finlay 2002:541).

I cannot disagree. Diekelmann's method provided structure and integrated reflexivity within its stages, but analysis was still an emotionally challenging experience in which I constantly considered whether my analysis of co-constituted ideas from interviews was guided by what was there, or by what I thought was there. It would have been safer to step back from the emotional challenge and take an easier, less exposing path, but this would not have done justice to the data nor have been appropriate in a hermeneutic study. Hence, I struggled with emerging ideas which exposed old wounds, agonised over whether my themes and patterns revealed the meaning I sensed was there, and over whether these themes and patterns even really existed. Reflexivity demands this, yet should not be used as 'confession, catharsis or cure' (Pillow 2003:175), or to wallow in self-examination (Finlay 2002). Instead, the self should only be exploited whilst doing so benefits the study. In data analysis, the danger is that the self becomes over-represented in the findings as the researcher gets caught in an unending reflexive spiral in which nothing is actually achieved (Gergen and Gergen 2000). Aware of this sense of 'getting stuck' I regularly presented my concerns to one or other of my supervisors, both of whom wisely questioned any assumptions I might have been making.

The aim of reflexivity in analysis is to address the influence of self but foreground the voices of participants in the study data (Finlay 2002). Rather than starting with the self and then considering the relationship with the data, the researcher should begin with the data, and follow with a reflexive consideration of self to challenge, reject or confirm findings. I took this approach, starting with the first early themes and progressing through the stages of analysis re-considering my position, my understanding, and my interpretations. Consequently, there is confidence in the findings and in their relevance and contribution to the evidence base.

11.6. Recommendations for future research and practice

The wider literature has provided cultural, social and research contexts for study findings which help to explain why bowels and stools are stigmatising, the relationship between stigma and normalisation, the value of social support in managing chronic illnesses, the impact of psychological stress on bowel symptoms and control, and the potential for such stress which reduces health-related quality of life (HRQoL) to be linked to stigma. Several topics have been revealed which would benefit from further qualitative, quantitative or mixed methods research:

1. Further exploration of kinship stigma, especially in the light of the importance of social support in resisting and reducing stigma; early indications are that there may be something unique about stigma arising from negative attitudes of close relatives or intimate partners. A qualitative study exploring experiences of those who feel stigmatised by these relatives would enable rejection or development of this emerging potential theory.

2. Ongoing exploration of the factors that protect against stigma in people with IBD, with or without incontinence; humour, perspective, mental wellbeing and upbringing appear to be influences which enhance resilience against stigma – but other factors may have been missed here, or not represented. Some people journey into and out of stigma and it would be useful to know their characteristics. Another qualitative study working with people with IBD who do not feel stigmatised can focus on unpacking these aspects in more detail.

3. Building on these first two recommendations, development of stigma reduction educational strategies for the public and those with IBD; feelings of stigma disrupt the social and emotional wellbeing of some of these participants, with evidence of social isolation, disruption of the parenting role, and an impact on close relationships. Stigma is a two-way street – a person can give out stigmatising attitudes, another can receive or reject them. Stigma reduction strategies need to be directed at the stigmatised

and the stigmatisers as the diagnostic criteria, as applied by doctors and nurses, can itself be labelling.

4. Determining what the public does or doesn't know about IBD; most participants believed that the public knows very little about IBD, and this is the source of much anticipated and perceived stigma; a mixed methods study, qualitative focus groups or interviews followed by a quantitative survey based on focus group / interview findings, could reveal the extent of public knowledge and inform education interventions.

5. Further exploration of the risk factors for stigmatisation in IBD, to include personality, disgust trait sensitivity, social support, socioeconomic status, anxiety and depression, and disease duration; a quantitative cross-sectional study, using validated measures and collecting relevant demographics could reveal further evidence which would help build reliable profiles of those more likely to feel stigmatised. Profiling could enable more targeted delivery of psychological support therapies to those most likely to need them.

6. Investigation of the relationship between stigma, stress, disease activity and health-related quality of life; a quantitative cross-sectional study, again using validated measures could demonstrate these relationships and evidence that HRQoL is dependent on more than control of disease-symptoms.

7. Exploration of the link between stigma, normalisation and disease duration; a qualitative, longitudinal study with repeated interviews at regular intervals over a 5 – 10 year period to track patterns of stigma and normalisation. Evidence of a decrease in stigma with normalisation over time would support the case for actively teaching stigma reduction and normalisation skills in the early stages following diagnosis.

8. Develop coming-out initiatives to facilitate and strengthen support networks for people with IBD: building on previous work which identified the main techniques used by gay men and women for telling others about IBD (Dibley et al. 2014), to promote coming-out skills in the wider IBD population which will enable people with IBD to

talk to others about their disease. These skills, and the work on kinship stigma (no. 1, above) and stigma-resistance characteristics (no. 2, above) can enable people with IBD to develop and strengthen essential personal support networks.

The study also has implications for those working in the field of IBD, particularly relating to emotional and psychological support of patients. It is recommended that clinicians:

- advise newly-diagnosed patients of the role of emotional control, social support and mastery in reducing stigma and living well with IBD, and that stigma does usually reduce with increasing disease duration. Patients can then be pro-active earlier in their disease history, and this may be of particular benefit to those patients who are less able to identify these strategies for themselves;
- assess the patient's level of concern about having a bowel disorder, including their attitudes towards bowels, toilets and control learnt in childhood. Those with more restrictive childhood influences may feel more stigmatised and need more support.
- consider the role that counselling or other psychotherapeutic interventions may have in helping patients adjust to their new illness identity, and in dealing with any self-stigma that arises due to not being able to abide by social bowel control rules;
- recognise that stigma is relational; a patient might not appear stigmatised during clinical encounters, but may be struggling to manage stigmatisation in daily life; asking if they are coping in the real world may show a different emotional picture.

11.7. Implications for researchers

Further to the recommendations for research presented above, a full systematic review of the relationship between stigma and normalisation across a range of chronic illnesses would inform subsequent research into understanding the role of stigma and stigma

reduction in coming to terms with IBD and other chronic illnesses. Future chronic illness and normalisation research needs to address psychosocial aspects of chronic illness and practical strategies for self-management together, rather than continuing to view to the two domains separately.

11.8. Limitations

The concept of limitations in hermeneutic phenomenology presents difficulties, since this suggests a failure of research to reach a pre-defined end. Hermeneutic research does not give definitive answers, and because ‘there is always a surplus, always more to understand’ (Ironside 2014, pers. comm., 9th June) it becomes impossible to begin to identify what the study has not achieved. To state, for example, that findings may not be transferable to others with IBD who may not have the same experiences of stigma, is to undermine the meaning of the experience for those participating here. Instead:

In seeking to make the decision trail clear to others, the researcher must [extract] the philosophical principles which are necessarily subjective and set these out in a way that is accessible and open to scrutiny (Whitehead 2004).

From this evidence, the reader makes their own judgement of the quality of the study.

11.9. Contribution to knowledge

This study has demonstrated that stigma linked to IBD and related incontinence also aligns with normalisation, and that as people with the disease gain a sense of emotional control, build effective support networks and learn to live with their condition, normalisation progresses and stigma decreases. Whilst this tends to happen for most people gradually over time, it occurs more rapidly and effectively in those who not only develop the core skills of control, support and acceptance, but who are also able to draw on positive traits such as robust mental health, a sense of perspective and use of humour

as a coping mechanism. The most influential factor in acceptance of disease appears to be childhood training in respect of toilet habits, cleanliness and bodily functions. By asking people at diagnosis about the attitudes in their childhood home towards these issues, it may be possible to identify those who are more likely to be stigma-vulnerable and who may need more support to achieve normalisation.

Enabling all patients to adjust to their chronic illness earlier will likely reduce illness burden and enhance emotional quality of life and wellbeing.

11.10. Summary

IBD-related stigma occurs in some people regardless of continence status and can cause emotional, social and interpersonal distress. Emotional control over disease, time, experience, and a suitable support network enhance stigma resilience.

Further research is needed to confirm features which enable resilience, and to develop stigma-reduction strategies that will promote resilience in this patient group. The bulk of evidence on the value of understanding stigma in order to reduce it comes from the mental health literature, where recommendations include addressing public concerns of responsibility (blame), repulsion (disgust) and threat (peril) (Barney et al. 2009). Because stigma is relational, programmes need to address public and patient attitudes, each requiring a different interventional approach (Watson and Corrigan 2011). Achieving this is challenging – biomedical and contextual stigma-reduction models have had no long-term effect on reduction of depression-related stigma (Rusch et al. 2010) although contact between the stigmatised and stigmatisers has been shown to reduce stigmatising attitudes as communication dispels myths and misunderstandings (Anderssen 2002). Web-based communication platforms facilitate communication and the dissemination of information, and may offer a way forward in this respect (Kim and Stout (2010). A recent example is the use of Facebook®, the online social media platform, by one young Crohn's sufferer with an intestinal stoma to post a photo of herself sunbathing and openly displaying her stoma bag. The image has been viewed

worldwide over 11 million times, drawing admiring and encouraging comments from others for her role in raising public awareness of CD and stomas (Waterhouse and Collinson 2014).

Specifically relevant to IBD, Taft et al. (2013) have demonstrated that increased internalised (self) stigma impacts negatively on HRQoL, whilst effective stigma resistance behaviours are positively correlated with a better HRQoL. Whether stigma reduction interventions can enable improvement in HRQoL in those whose HRQoL is negatively affected by IBD-related stigma, is yet to be determined.

11.11. Conclusion

Prior to this study, there was no qualitative evidence of the lived experience of stigma in IBD. Quantitative evidence has reported only that perceived or internalised (self) stigma is present amongst people with IBD, that it negatively affects patient outcomes, but that it can be resisted (Taft et al. 2013). The findings from this study evidence that there are numerous types of stigma experienced by people with IBD, including the newly-identified possibility of kinship stigma; that stigma in IBD is a complex psycho-social and emotional experience which can be socially and emotionally debilitating but which can also be overcome through achieving a sense of control, developing a strong social support network, and developing mastery of, and mediation between, life and disease. These findings support and add weight to the very recently-published work of Frohlich (2014), who evidenced that IBD-related stigma could be overcome, but drawing his data from a sample which did not feel stigmatised, offered no indications of how the transition from stigmatised to non-stigmatised is made. By exploring the experiences of the currently, the no longer, and the never stigmatised, my work offers an insight into the differences between these groups of participants and sheds some light on individual characteristics which may facilitate stigma resistance.

There are also similarities with Saunders' (2014) paper, as we both identify components of shame (which prevents disclosure of IBD to others) and blame (when symptoms are

misunderstood) within this taboo illness, and that stigma in IBD appears to be unrelated to power or oppression. My study findings extend Saunders' work on the way people with IBD use language, by evidencing that behaviours linked to IBD are driven by the same intention – to avoid shame and blame.

A complex picture of the lived experience of stigma in IBD and the meaning this has for these study participants has been revealed. Further research is needed to understand resilience against IBD-related stigma so that effective stigma-reduction strategies can be developed.

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APPENDIX 1

Characteristics of studies included in the literature review

AUTHOR	STUDY POPULATION	STUDY DESIGN	OUTCOME MEASURES	MAIN RESULTS
Author, Year, Country	(1) number of participants; (2) socio-demographic details; (3) disease focus;	(1) methodology; (2) sampling method;	(a) psychological health (b) quality of life (c) physical health (d) social health (e) miscellaneous	
Brittain & Shaw 2007 UK	(1) 20; (2) mean age 68.5 yr; 65% female; (3) Urinary incontinence (UI)	(1) qualitative (grounded theory); (2) purposive	(a) nil; (b) nil; (c) nil; (d) nil; (e) focused individual interviews on carer perspectives	Carers face 'bodywork' and 'dirty work' and, with cared-for, become stigmatised; dealing with leakage, odour and home adjustments to appear socially acceptable is disruptive; home becomes the container for the unbounded (incontinent) body.
Dancey et al. 2002 Canada	(1)117; (2) mean age 54 yr; 54% female; (3) irritable bowel syndrome (IBS)	(1) quantitative; (2) convenience	(a) nil; (b) IIRS; IBS-QOL; (c) self-report IBS symptoms; (d) m-f-s perceived stigma questionnaire (e) nil	Illness intrusiveness rating scale is relevant in IBS and affects quality of life; link between perceived stigma and IBS not demonstrated.
Desnoo & Faithfull 2006 UK	(1) 7; (2) mean age 69 yr; 72% female; (3) Anterior resection syndrome (ARS)	(1) qualitative (grounded theory); (2) purposive	(a) nil; (b) nil; (c) nil; (d) nil; (e) semi-structured interviews	Physical problems of ARS cause social and psychological difficulties. Problems with unpredictable control, altered bowel pattern and bowel focus to condition create stigma.
Dibley & Norton 2013 UK	(1) 611; (2) mean age 50.3 yr; 71% female; (3) Inflammatory bowel disease (IBD)	(1) mixed methods (2) random purposive	(a) nil; (b) nil; (c) nil; (d) nil; (e) m-f-s self-report (written questions; semi-structured interviews	IBD-related faecal incontinence is a complex and unique experience. Domains include: emotional & psychological impact; feelings of stigma; limited lives; symptoms; practical coping strategies; access to facilities; fear of incontinence.
Table A1 Characteristics and main findings of included studies (n=20) describing study population, design, outcome measures used, and main findings reported IBS-QOL = Irritable Bowel Syndrome-Quality of Life; IIRS = Illness Intrusiveness Rating Score; m-f-s = made for study				

AUTHOR Author, Year, Country	STUDY POPULATION (1) number of participants; (2) socio-demographic details; (3) disease focus;	STUDY DESIGN (1) methodology; (2) sampling method;	OUTCOME MEASURES (a) psychological health (b) quality of life (c) physical health (d) social health (e) miscellaneous	MAIN RESULTS
Drossman et al. 1991 USA	(1) 991; (2) mean age 42.8 yr; 60% female;(3) IBD	(1) quantitative (scale development) (2) purposive, then random	(a) SCL-90-R;SIP (b) nil; (c) SIP; IBD and disease symptoms questionnaire; (d) SIP; (e) RFIPC; m-f-s wellbeing and health; m-f-s healthcare utilisation	Four indices identified: a) impact of disease; b) sexual intimacy; c) complications of disease; d) body stigma (e.g. feeling dirty or smelly) RFIPC performs well compared with other measures of health status
Drossman et al. 2009 USA	(1) 16; (2) mean age 53 yr; 81% female; (3) IBS	(1) mixed methods (2) purposive	(a) nil; (b) nil; (c) BEST; FBDSI; IBS-SS (d) nil; (e) focus group interviews	IBS impacts on social, physical and psychosocial dimensions of life; stigma arises from belief that intimate / significant others do not understand IBS; stool subtype not influential these factors.
Elstad et al. 2010 USA	(1) 151; (2) mean age 55.5 yr; 49.6% female; (3) UI	(1) qualitative (grounded theory); (2) purposive, then random	(a) nil; (b) nil; (c) nil; (d) nil; (e) focus groups and individual in- depth interviews	Urgency and frequency lead to behaviours (such as visiting the bathroom very often) which create stigma by making urinary control problems visible.
Goldman et al. 2009 USA	(1) 147; (2) mean age not stated; 50.3% female; (3) colorectal cancer screening	(1) qualitative (ethnography) (2) purposive, stratified	(a) nil; (b) nil; (c) nil; (d) nil; (e) individual semi-structured interviews	Stigma limits colorectal cancer screening behaviours in Dominican and Puerto Rican populations in the USA; men are particularly influenced by cultural machismo and misperceptions about the screening processes.

Table A1 (Cont.) Characteristics and main findings of included studies (n=20) describing study population, design, outcome measures used, and main findings reported BEST questionnaire is a point-of-care illness severity index; FBDSI = Functional Bowel Disorder Severity Index; IBD = Inflammatory Bowel Disease; IBS = Irritable Bowel Syndrome; IBS-SS = Irritable Bowel Syndrome Severity Scale; m-f-s = made for study; RFIPC = Rating Form of IBD Patient Concerns; SCL-90-R = Symptom Checklist 90 (revised); SIP = Sickness Impact Profile; UI = Urinary Incontinence.

AUTHOR Author, Year, Country	STUDY POPULATION (1) number of participants; (2) socio-demographic details; (3) disease focus;	STUDY DESIGN (1) methodology; (2) sampling method;	OUTCOME MEASURES (a) psychological health (b) quality of life (c) physical health (d) social health (e) miscellaneous	MAIN RESULTS
Jones et al. 2009 USA	(1) 197; (2) mean age 41 yr; 88% female; (3) IBS	(1) mixed methods (scale development) (2) purposive	(a) nil; (b) nil; (c) nil; (d) nil; (e) semi-structured interviews; validation of the Perceived Stigma Scale – IBS (PSS-IBS)	Interviews: six areas of perceived stigma in people with IBS – disclosure attitudes, knowledge about IBS, validity of the diagnosis, seriousness, and blame. Validation: development of new PSS-IBS. Areas of perceived stigma rated against potential sources of stigma. Primary sources of stigma are co-workers, employers, healthcare providers and friends.
Macdonald & Anderson 1984 UK	(1) 420; (2) mean age not stated; 50% female; (3) Rectal cancer	(1) quantitative (survey); (2) purposive	(a) Leeds scale (assessment of anxiety & depression); (b) nil; (c) Disability assessment; (d) nil; (e) self-completion of m-f-s semi-structured questionnaire (supervised).	Stigma is associated with cancer, and exaggerated by presence of a colostomy; stigma does not decline over time post-surgery; development of self-rated stigma scale proposed.
Paterson 2000 Australia	(1) 3; (2) mean age not stated; 0% female; (3) post-prostatectomy UI	(1) qualitative (collective case study)	(a) nil; (b) nil; (c) nil; (d) nil; (e) unstructured in-depth interviews	Men with UI following prostatectomy have two identities – one public, and one private. Intractable UI means building a new understanding of their leaking body, against a background of gender, family history, body knowledge and ability to reject own lifelong cultural attitudes towards UI.
Roach et al. 2000 USA	(1) 103; (2) mean age not stated; 23.3% female; (3) Spinal cord injury (SCI)	(1) quantitative (survey); (2) convenience	(a) nil; (b) Andrew & Whitley Satisfaction with Life measure; (c) m-f-s bowel dysfunction measures; (d) nil; (e) m-f-s impediments to community integration measure	Acquired bowel dysfunction is associated with impaired community integration and quality of life; recommends stigma reduction programmes.

Table A1 (Cont.) Characteristics and main findings of included studies (n=20) describing study population, design, outcome measures used, and main findings reported m-f-s = made for study; IBS = irritable Bowel Syndrome.

AUTHOR Author, Year, Country	STUDY POPULATION (1) number of participants; (2) socio- demographic details; (3) disease focus;	STUDY DESIGN (1) methodology; (2) sampling method;	OUTCOME MEASURES (a) psychological health (b) quality of life (c) physical health (d) social health (e) miscellaneous	MAIN RESULTS
de Rooy et al. 2001 Canada	(1) 259; (2) mean age 35.5 yrs; 53.3% female; (3) IBD	(1) quantitative (survey); 2) convenience	(a) nil; (b) RFIPC; (c) m-f-s IBD symptom measure; (d) nil; (e) nil	Wellbeing is affected by physical IBD symptoms, and by disease stigma. Older women, those with longer disease duration, or unemployed due to illness most affected.
Smith et al. 2007 USA	(1) 718; (2) mean age 52.5 yr; 63.7% female; (c) Colostomy	(1) quantitative (unmatched case- control) (2) convenience	(a) D8Scale; m-f-s colostomy disgust measure; (b) m-f-s quality of life scale; satisfaction with life scale (c) m-f-s colostomy symptoms measure (d) nil; (e) m-f-s stigma measure	Disgust trait sensitivity predicts adjustment to colostomy in patient group, and desire to avoid those with colostomy in control group. Disgust trait is highly correlated with stigma
Stjernman et al. 2010 Sweden	(1) 447; (2) mean age 45 yr; 58% female; (3) Crohn's disease (CD)	(1) quantitative (scale validation) (2) convenience	(a) PGWB; (b) RFIPC; SF-36; IBD-Q; (c) PGA; CDAI; SHS; (d) nil; (e) nil	Swedish version of RFIPC is valid, reliable measure of CD- related issues, although reduced sensitivity to changes in disease activity; CD complications affect life more than intimacy or self-image concerns do. Being female, having more active disease and higher body mass index predicts higher degree of worry and concerns.
<p>Table A1 (Cont.) Characteristics and main findings of included studies (n=20) describing study population, design, outcome measures used, and main findings reported CDAI = Crohn's Disease Activity Index; IBD = Inflammatory Bowel Disease; IBD-Q = Inflammatory Bowel Disease Quality of life questionnaire; IBS = Irritable Bowel Syndrome; PGA = Physician's Global Assessment; PGWB = Psychological General Well-Being; RFIPC = Rating Form of IBD Patient Concerns; SF-36 = Short Form 36; SHS = Short Health Scale.</p>				

AUTHOR Author, Year, Country	STUDY POPULATION (1) number of participants; (2) socio-demographic details; (3) disease focus;	STUDY DESIGN (1) methodology; (2) sampling method;	OUTCOME MEASURES (a) psychological health (b) quality of life (c) physical health (d) social health (e) miscellaneous	MAIN RESULTS
Taft et al. 2009 USA	(1) 211; (2) mean age 46.5 yr; 78% female; (3) IBD	(1) quantitative (cross-sectional correlation) (2) purposive	(a) PSS-IBS; RSES; GSES (b) RFIPC; IBD-Q; (c) BSI (d) nil; (e) nil	Perceived stigma is present in IBD patients and negatively affects quality of life and health outcomes
Taft et al. 2011 USA	(1) 496; (2) mean age not stated; 82.2% female; (3) IBS and IBD	(1) quantitative (cross-sectional correlation) (2) purposive	(a) PSS-IBS; BSI-18; RSES; GSES; (b) nil; (c) SF-12; (d) nil; (e) nil	PSS-IBS a reliable measure of perceived stigma (PS); significantly more stigma reported in IBS than in IBD patients from all sources (friends, family, health care professionals, spouse, co-workers and employer); PS in both groups negatively affects clinical outcomes; IBS patients more affected by stigma from family members, spouse or significant other; IBD patients more affected by stigma from friends and health professionals.
Taft et al. 2013 USA	(1) 191; (2) mean age 38.7 yr; 71% female; (3) IBD	(1) quantitative (cross-sectional correlation) (2) purposive	(a) ISMI; BSI-18; RSES; IBDSES; (b) IBD-Q; (c) nil; (d) nil; (e) nil	Internalised stigma (IS) is reported more, and stigma resistance behaviours reported less, amongst less educated, urban living participants. IS is a significant predictor for poorer patient outcomes (quality of life, psychological functioning, self-efficacy and self-esteem) and is linked to flare severity.

Table A1 (Cont.) Characteristics and main findings of included studies (n=20) describing study population, design, outcome measures used, and main findings reported BSI = Brief Symptom Inventory; BSI-18 = Brief Symptom Inventory-18; CDAI = Crohn's Disease Activity Index; GSES = General Self-Efficacy Scale; IBD = Inflammatory Bowel Disease; IBD-Q = Inflammatory Bowel Disease Quality of life questionnaire; IBDSES – Inflammatory Bowel Disease Self-Efficacy Scale; IBS = Irritable Bowel Syndrome; ISMI = Internalized Stigma Scale for Mental Illness; PGA = Physician's Global Assessment; PGWB = Psychological General Well-Being; PSS-IBS = Perceived Stigma Scale-Irritable Bowel Syndrome; RFIPC = Rating Form of IBD Patient Concerns; RSES = Rosenberg Self-Esteem Scale; SF-12 = Short Form-12; SF-36 = Short Form 36; SHS = Short Health Scale.

AUTHOR Author, Year, Country	STUDY POPULATION (1) number of participants; (2) socio-demographic details; (3) disease focus;	STUDY DESIGN (1) methodology; (2) sampling method;	OUTCOME MEASURES (a) psychological health (b) quality of life (c) physical health (d) social health (e) miscellaneous	MAIN RESULT
Thompson 2013 USA	(1) 12 interviews plus unknown (numbers for participant observation data not stated; (2) mean age not stated; % females not stated; (3) IBD	(1) qualitative (ethnography); (2) purposive	(a) nil; (b) nil; (c) nil; (d) nil; (e) participant observation; field notes; personal reflections, semi-structured interviews	Even in apparently 'safe' support groups, people with IBD resist or are discouraged from speaking openly about their bowels and bowel actions, referring to these with euphemisms and polite subtexts. Openness is only 'allowed' in the presence of clinicians, or in the face of satire - otherwise direct reference to faecal matter and bowel activity is resisted, as a means of preventing the 'soiled' disease' from invading the self.
Wilde 2003 USA	(1) 14; (2) mean age not stated; 64% female; (3) UI (indwelling urinary catheter)	(1) qualitative (phenomenology) (2) purposive	(a) nil; (b) nil; (c) nil; (d) nil; (e) semi-structured interviews	Living with a catheter as 'part of me' is positive, and as a visible sign of vulnerability or stigma is negative. Negative aspects are fuelled by the disruption the catheter causes to activities, or exposure leading to embarrassment or stigma. Connects to emerging theory of people's ability to shift between illness-in-the-foreground, and wellness-in-the-foreground.

Table A1 (Cont.) Characteristics and main findings of included studies (n=20) describing study population, design, outcome measures used, and main findings reported IBD = Inflammatory Bowel Disease; UI = Urinary Incontinence.

APPENDIX 2

Philosophy and design quality of studies included in the literature review

AUTHOR Author, Year, Country	PURPOSE Aim explicitly stated	METHODOLOGY / DESIGN (1) methodology; (2) ethics statement; (3) consent; (4) data collection; (5) data analysis;	RIGOUR (RELIABILITY / TRUSTWORTHINESS) (a) level of rigour; (b) design consistency (c) miscellaneous	LIMITATIONS
Brittain & Shaw 2007 UK	Yes: impact of stroke survivor UI on informal carers	(1) qualitative; (2) no statement of ethics approval; (3) statement of informed consent; (4) focused individual interviews (45 – 90 mins); audio-recorded / notes, transcribed by author; (5) Constant comparison and deviant case analysis.	(a) high; (b) all stages of design consistent with methodology / philosophy; (c) analysis process described in detail verbatim extracts linked to existing and emerging theory	One annotated interview due to equipment failure. Problem of accuracy and recall bias
Dancey et al. 2002 UK & Canada	Yes: intrusiveness of perceived stigma & effect on quality of life in IBS	(1) quantitative; (2) no statement of ethics approval; (3) statement of informed consent; (4) structured questionnaires: validated measures of quality of life and illness intrusiveness, non-validated measure of perceived stigma; (5) Statistical analysis including split-plot ANOVAs, correlation coefficients, and hierarchical multiple regression analysis	(a) low; (b) methodology inconsistent with study design; cited as naturalistic but describes and reports scientific (quantitative) methods, tests hypotheses; (c) some evidence of link between data, analysis and findings.	Possible recruitment bias from existing pool of research-keen participants; convenience sample limits generalisability
Desnoo & Faithfull 2006 UK	Yes: physical and psychosocial issues linked to ARS	(1) qualitative; (2) statement of ethics approval; (3) statement of informed consent; (4) semi-structured interviews; audio-recorded & transcribed by author. (5) Constant comparison	(1) high; (b) all stages of design consistent with methodology / philosophy; (c) analysis process described in detail; verbatim extracts linked to new and current theory.	None identified
Dibley & Norton 2013 UK	Yes: experience and concerns of people with IBD-related FI	(1) mixed methods;(2) statement of ethics approval; (3) statement of informed consent; (4) qualitative semi-structured interviews, free-text self-completed responses to help-seeking items in main quantitative study questionnaire; interviews audio recorded, transcribed professionally; (5) Thematic analysis	(1) high: (b) all stages of design consistent with methodology / philosophy; (3) theme development process described in detail, demonstrated, sample questions provided, verbatim extracts used to illustrate findings.	Higher proportion of women in sample; self-selected sample may not be representative of wider IBD community.
Table A2 Methodological rigour of included studies (n=20), assessing methodology, design, and study limitations				
ANOVA = Analysis of variance; ARS = Anterior Resection Syndrome; FI = Faecal Incontinence; IBD = Inflammatory Bowel Disease; IBS = Irritable Bowel Syndrome; UI = Urinary Incontinence.				

AUTHOR Author, Year, Country	PURPOSE Aim explicitly stated	METHODOLOGY / DESIGN (1) methodology; (2) ethics statement; (3) consent; (4) data collection; (5) data analysis;	RIGOUR (RELIABILITY / TRUSTWORTHINESS) (a) level of rigour; (b) design consistency (c) miscellaneous	LIMITATIONS
Drossman et al. 1999 USA	Yes: identify concerns in IBD patients & develop new assessment scale - RFIPC	(1) quantitative; (2) statement of ethics approval; (3) statement of informed consent; (4) structured questionnaire; (5) Factor analysis, multiple regression to establish psychometric properties of Rating Form of IBD Patient Concerns	(a) high; (b) all stages of design consistent with methodology / philosophy; (c) results presented in tabular form; statistical processes explained.	Cross-sectional study – causality not clear. Possible sample bias: milder disease in community IBD patients.
Drossman et al. 2009 USA	Yes: understand patient experience of IBS and factors affecting severity	(1) mixed methods (quant → qual); (2) no statement of ethics approval; (3) consent procedures partially described; (4) structured questionnaire -data used to allocate to focus groups by stool type (IBS-C ^a , IBS-D ^b , IBS-M ^c); focus groups; (5) quantitative data analysis not described; focus group data analysed by study authors and two independent reviewers.	(a) low; (b) all stages of design consistent with methodology / philosophy; (c) demographic details provided but statistical details missing; no theoretical basis to qualitative analysis, process described only briefly; no verbatim extracts used to link findings to data.	Selection bias: higher proportion of women with more severe symptoms; low turn-out for focus groups - comparisons across groups unreliable.
Elstad et al. 2010 USA	Yes: typify daytime urinary frequency & urgency in diverse sample	(1) qualitative; (2) statement of ethics approval; (3) consent procedures not described; (4) focus groups (90 mins) and individual in-depth interviews (60 mins); (5) constant comparison: open coding, coding framework, patterns across transcripts.	(a) high; (b) all stages of design consistent with methodology / philosophy consistent with study design; (c) reporting detailed and transparent; verbatim extracts used; sample size implies saturation	No back translation of Spanish interviews may hide language subtleties
Goldman et al. 2009 USA	Yes: colorectal cancer health literacy and screening in two ethnic groups	(1) qualitative; (2) statement of ethics approval; (3) statement of informed consent; (3) individual semi-structured interviews (90 mins); (5) no analysis framework, but process described fully; all desirable aspects of qualitative data analysis present.	(a) high; (b) all stages of design consistent with methodology / philosophy; (c) verbatim extracts used; transparency and detail in reporting of findings;	Study participants from one location; affect relevance to Latinos from other areas / backgrounds

Table A2 (Cont.) Methodological rigour of included studies (n=20) assessing methodology, design, and study limitations

IBD = Inflammatory Bowel Disease; IBS = Irritable Bowel Syndrome; ^a = IBS Constipated; ^b = IBS Diarrhoea; ^c = IBS Mixed; RFIPC = Rating Form of IBD Patient Concerns

AUTHOR	PURPOSE	METHODOLOGY / DESIGN	RIGOUR (RELIABILITY / TRUSTWORTHINESS)	LIMITATIONS
Author, Year, Country	Aim explicitly stated	(1) methodology; (2) ethics statement; (3) consent; (4) data collection; (5) data analysis;	(a) level of rigour; (b) design consistency (c) miscellaneous	
Jones et al. 2009 USA	Yes: identify role of stigma in IBS, and develop new measurement scale – PSS-IBS	(1) mixed methods; (2) statement of ethics approval; (3) consent procedures not described; (4) interviews (30-60 mins) audio recorded, transcribed; scale validation; (5) independent content analysis of interviews by study team → scale development; validation data analysed statistically	(a) high; (b) all stages of study design consistent with methodology / philosophy; (c) interview data informed design of IBS-SS [#] Stigma Scale; good analysis techniques; transparent reporting.	Participants sourced from clinic population, results may not be generalisable to wider population. Women over-represented in sample.
Macdonald & Anderson 1984 UK	Yes: exploration of stigma experience in patients with rectal cancer	(1) quantitative; (2) statement of ethics approval; (3) consent procedures partially described; (4) validated, and made-for-study measures in structured interviews; (5) statistical analyses conducted but not clearly described.	(a) medium; (b) all stages of study design consistent with methodology / philosophy; (c) study components under-reported; measure development and statistical analysis not described	Cross-sectional study – causality not clear. Other causes of stigma not considered
Paterson 2000 Australia	Yes: exploring social implications of UI after prostatectomy	(1) qualitative; (2) no statement of ethics approval; (3) consent procedures not described; (4) unstructured in-depth interviews; (5) thematic analysis; process not described; process of combining data extracts not explained.	(a) medium; (b) all stages of study design consistent with methodology / philosophy; (c) data analysis process, data combining methods not described; female researcher / male participants in sensitive research not addressed; ethical assurances absent.	Very small sample (n=3); possible sample bias from those with greater concerns
Roach et al. 2000 USA	Yes: develop scales to measure impact of SCI on community integration	(1) quantitative; (2) no statement of ethics approval; (3) consent implied; (4) m-f-s scales designed by researchers and two clinicians; (5) quantitative: descriptive statistics, <i>t</i> – and chi square test, principle components analysis, Spearman Rho and Pearson correlations.	(a) medium; (b) all stages of study design consistent with methodology; (c) m-f-s scales not tested before use in study; no link between findings and stigma statement presented in conclusion; ethical assurances absent.	Convenience sample may be biased; statistical analyses descriptive rather than inferential. May not be predictive of community integration

Table A2 (Cont.) Methodological rigour of included studies (n=20) assessing methodology, design, and study limitations

IBS = Irritable Bowel Syndrome; IBS-SS = Irritable Bowel Syndrome-Stigma Scale; m-f-s = made for study; PSS-IBS = Perceived Stigma Scale-Irritable Bowel Syndrome; SCI = Spinal Cord Injury; UI = Urinary Incontinence.

AUTHOR	PURPOSE	METHODOLOGY/DESIGN	RIGOUR (RELIABILITY / TRUSTWORTHINESS)	LIMITATIONS
Author, Year, Country	Aim explicitly stated	(1) methodology; (2) ethics statement; (3) consent; (4) data collection; (5) data analysis	(a) level of rigour; (b) design consistency; (c) miscellaneous	
de Rooy et al. 2001 Canada	yes: identify concerns of clinical sample of patients with IBD	(1) quantitative; (2) statement of ethics approval; (3) statement of informed consent; (4) self-compelction of RFIPC and made-for-study questionnaire; (5) statistical, including Student's <i>t</i> test, factor analysis, multivariate analysis of variance (MANOVA), multiple stepwise regression analysis	(a) high; (b) all stages of study design consistent with methodology / philosophy; (c) results given as tables; statistical processes explained	Cross-sectional study – causality not clear. Impaired wellbeing may arise from other non-disease factors
Stjernman et al. 2010 Sweden	Yes: to test psychometric properties of Swedish RFIPC	(1) quantitative; (2) no statement of ethics approval; (3) consent procedures not described; (4) cross-sectional study; self-completion of Swedish version of RFIPC, plus four validated health-related QoL questionnaires; (5) statistical, including Chi square tests, Mann-Whitney U test, Kruskal-Wallis, Wilcoxon sign test, Spearman's rho.	(a) medium; (b) all stages of study design consistent with methodology / philosophy; (c) results presented in tabular form; validated measures and statistical processes explained in detail; ethical assurances absent.	Reduced applicability in intervention studies due to low sensitivity to change.
DM Smith et al. 2007 USA	Yes: to test if disgust trait predicts response to or avoidance of colostomy	(1) quantitative; (2) no statement of ethics approval; (3) consent procedures not described; (4) self-completion of validated disgust trait scale (D8Scale) incorporated into a made-for-study questionnaire; (5) statistical, including mean, standard deviation, Cronbach's alpha, regression analysis, path and structural equation modelling.	(a) moderate; (b) all stages of study design consistent with methodology / philosophy; (c) sampling method weak; made-for-study measure not described but provided as appendix; ethical assurances absent.	Low internet response rate and untested measure limit generalisability; results offered as first findings
Taft et al. 2009 USA	Yes: to identify role of perceived stigma in IBD	(1) quantitative; (2) statement of ethics approval; (3) consent procedures described; (4) self-completion of series of validated measures; (5) statistical, including Pearson chi square analyses, independent samples <i>t</i> tests, and analysis of variance (ANOVA).	(a) high; (b) all stages of study design consistent with methodology / philosophy; (c) results presented in tabular form; validated measures; statistical processes explained fully.	Stigma varies over time - cross-sectional study limits analysis; other non-disease factors may influence stigma; sampling method affect stigma reporting
Table A2 (Cont.) Methodological rigour of included studies (n=20) assessing methodology, design, and study limitations				
D8Scale = disgust trait measure; IBD = Inflammatory Bowel Disease; RFIPC = Rating Form of IBD Patient Concerns.				

AUTHOR Author, Year, Country	PURPOSE Aim explicitly stated	METHODOLOGY / DESIGN (1) methodology; (2) ethics statement; (3) consent; (4) data collection; (5) data analysis;	RIGOUR (RELIABILITY / RUSTWORTHINESS) (a) level of rigour; (b) design consistency; (c) miscellaneous	LIMITATIONS
Taft et al. 2011 USA	Yes: to compare perceived stigma in IBS and IBD patients	(1) quantitative; (2) statement of ethics approval; (3) consent procedures not described; (4) self-completed (online / hard copy) validated questionnaires (n=6).	(a) high; (b) all stages of study design consistent with methodology / philosophy; (c) validated measures, statistical processes and results explained in detail; limitations identified.	Illness severity / disease activity and IBS sub-type ^(a,b,c) not assessed; self-reported diagnosis; risk of duplicate responses with online methods; findings not generalisable to non-Caucasians.
Taft et al. 2013 USA	Yes: to typify stigma in IBD patients and if illness outcomes are affected by it	(1) quantitative; (2) statement of ethics approval; (3) consent procedures described; (4) Internalised Stigma Scale for Mental Illness (ISMI) plus self-completed (online / hard copy) validated questionnaires (n=4).	(a) high; (b) all stages of study design consistent with methodology / philosophy; (c) validated measures, statistical processes and results explained in detail; limitations identified.	Risk of response bias in self-reported measures; diagnosis confirmed only in clinic-recruited participants; ISMI not validated for IBD populations; findings not generalisable to non-Caucasians.
Thompson 2013 USA	Yes: how bodies manage and contain chronic illness and the language of containment	(1) qualitative; (2) no statement of ethics approval; (3) consent procedures partially explained; (4) participant observation, field notes, personal reflections, semi-structured interviews (n=12)	(a) medium; (b) all stages of design consistent with methodology / philosophy; (c) verbatim extracts from all data sources used to support discussion of findings, linked to relevant literature; reflexivity; author experience informed interview guide; consent procedures unclear.	Unclear if consent gained for participant observation stage of study; no interview guide provided: unable to assess relationship between interview process, data and findings.
Wilde 2003 USA	Yes: to interpret the lived experience of long-term users of indwelling urinary catheters	(1) qualitative; (2) statement of ethics approval; (3) consent procedures described; (4) individual semi-structured interviews, audio-recorded & transcribed by author; (5) hermeneutic analysis, simultaneous with data collection.	(a) high; (b) all stages of design consistent with methodology / philosophy; (c) interview prompts provided; independent reviewers supervised analysis – transparent, detailed reporting; data extracts used to support discussion; reflexivity.	No minority groups represented despite efforts to include them
Table A2 (Cont.) Methodological rigour of included studies (n=20) assessing methodology, design, and study limitations				
IBD = Inflammatory Bowel disease; IBS = Irritable Bowel syndrome.				

APPENDIX 3

Characteristics of the research methodology review papers

Methodology / philosophy (Example)*	Key attributes	Researcher position	Potential for use in current study	Reason for rejection
Ethnonursing George (1999) Nursing care of chronically mentally ill in day centre+	Based on Lieninger's Culture Care Theory: the delivery of nursing care in context of cultural norms	Not explicitly stated; either inside or outsider (emic or etic)	IBD stigma has cultural basis and may come from nursing care interactions; insider research possible	Focus too narrow; origins of IBD stigma unknown but may be social, cultural and situational; insider researcher role not certain.
Case study research Patterson et al. (2008) Drug treatment services in England: user perspectives	Explores identified issues via one or more cases (individuals OR settings)	Not explicitly stated	Case study of individual's or group stigma experiences in specific setting may add new situational knowledge	Focus too narrow; would not uncover range or depth of stigma experiences; transferability limited; insider researcher role doubtful.
Oral history Kampf (2008) Stigma, gender and narratives of venereal disease contact tracers	Explores changes in specific issues over time; useful in researching rare experiences in great depth with very few participants	Not explicitly stated	Stigma experience and cause changes over time; historical aspect relevant; insider research possible.	Focus too narrow; would not provide insights into range or depth of stigma experiences; would limit transferability; insider researcher role not certain.
Narrative research Goodman (2001) Jewish narratives of mental illness; Chapple et al. (2004) Financial benefits access: lung cancer patients' perceptions	Captures personal experiences told in a classical story format (chronological, beginning, middle and end)	Can be insider or outsider	Stigma experiences can have a sequential, chronological pattern; insider research possible.	No guarantee that people will think about or report stigma experiences in an ordered way;
Stigma theory Roura et al. (2009) HIV in Tanzania; Balfe et al. (2010b) Chlamydia screening for young Irish women	Uses existing stigma theory (Deacon 2005; Goffman 1959; 1963) to guide data collection and analysis	Can be insider or outsider	Could offer data collection and analysis frameworks to give structure, focusing exclusively on known issues in stigma experiences	Focus too narrow; underpinning philosophy indistinct; frameworks limit potential for new aspects of stigma to emerge; descriptive (not interpretive) results; insider researcher role not certain.

Table A3 Critique of qualitative stigma research papers assessing methodological suitability for the current study: miscellaneous philosophies *Examples from results of Search 2: papers to inform methodology; + = abstract only.

Methodology / philosophy (Examples)*	Key attributes	Researcher position	Potential for use in current study	Reason for rejection
<p>Grounded Theory</p> <ul style="list-style-type: none"> • Crisp (2000) Disabled persons perceptions of health and rehabilitation professionals; • Brown (2006) Obesity in primary care; • Laganá and Maciel (2010) Sexual desire among Mexican-American older women; • Orner et al. (2010) HIV+ pregnant women and decision-making about abortion in South Africa 	<p>Suited to exploring subjects where little is known about social processes; involves series of structured stages to eliminate ambiguity and researcher influence; data collection occurs alongside analysis, the former being informed by the latter; data saturation and constant comparison is important – continue collecting, comparing and analysing data until nothing new emerges; deductive – breaks data down into sections, then inductive – builds theory. Findings, and any resulting theory, clearly ‘grounded’ in the data</p>	<p>Outsider</p>	<p>Little known about some of the complex processes in IBD stigma; encourages completeness via data saturation; has potential to generate new theory</p>	<p>Social processes of stigma known, although not specifically linked to IBD; dismantling data breaks up relationships between concepts; stigma influences are multi-faceted and inter-related – need preserving; ‘true’ data saturation unachievable if belief that an individual’s experience is unique is upheld; collecting and analysing data until saturation is time-consuming – impossible to predict how long it will take / how much it will cost; insider researcher role not possible.</p>
<p>Table A3 (Cont.) Critique of qualitative stigma research papers assessing methodological suitability for the current study: Grounded Theory *Examples from results of Search 2: papers to inform methodology.</p>				

Methodology / philosophy (Examples)*	Key attributes	Researcher position	Potential for use in current study	Reason for rejection
<p>Exploratory qualitative research</p> <ul style="list-style-type: none"> • Lindsey (2003) Home-based care in Botswana; • Atuyambe et al. (2005) Pregnant adolescents in Uganda; • O'Mahoney and Donnelly (2007) Providers perspectives of immigrant women's mental health care experiences; • Motswasele and Peu (2008) Informal home-based care giving in Pretoria; • Blignault (2008) Barriers to mental health services amongst Chinese immigrants in Australia; • Becker et al. (2010) Barriers to care for people with eating disorders. 	<p>Specific focus; gathers preliminary evidence to support future related studies; collection and analysis of new data, or secondary analysis of existing data; deductive, rather than inductive.</p>	<p>Not explicitly stated</p>	<p>Limited; could have serve as scoping study to prove need for current study;</p>	<p>Focus is too specific; data analysis is deductive, outcomes are descriptive; insider role of researcher doubtful.</p>
<p>Table A3 (Cont.) Critique of qualitative stigma research papers assessing methodological suitability for the current study: Exploratory qualitative research *Examples from results of Search 2: papers to inform methodology.</p>				

Methodology / philosophy (Examples)*	Key attributes	Researcher position	Potential for use in current study	Reason for rejection
<p>Ethnography</p> <ul style="list-style-type: none"> • Hinton et al. (2000) Recruitment of Chinese-American family caregivers for dementia research; • Scanlon et al. (2006) Barriers to cancer prevention and detection in Irish people living in Britain • Lazear et al. (2008) Depression in low-income women of colour • Sanjobo et al. (2008) Adherence to antiretroviral treatment in Zambia • Manning (2009) Childhood onset mental illness⁺ • Robillard (2010) Severe and persistent mental illness in Peru 	<p>Used to research social and cultural group dynamics and influences; researcher enters field of study for extended periods to observe group processes; data collected via participant or non-participant observation</p>	<p>Insider – either ‘emic’ (in group and part of it) or ‘etic’ (in group but not part of it)</p>	<p>Stigma in IBD may develop over time, and be influenced by socio-cultural influences on group interactions; insider researcher role necessary</p>	<p>Study aims to gather individuals’ perceptions of their experiences, not group data; lengthy immersion in field impractical due to time and financial constraints.</p>
<p>Table A3 (Cont.) Critique of qualitative stigma research papers assessing methodological suitability for the current study:</p>				
<p>Ethnography</p>				
<p>*Examples from results of Search 2: papers to inform methodology.</p>				

Methodology / philosophy (Examples)*	Key attributes	Researcher position	Potential for use in current study	Reason for rejection
<p>Mixed methods research</p> <ul style="list-style-type: none"> • Haque-Kahn (1997) Muslim women and mental health help;* • Díaz et al. (2008) AIDS stigma in Puerto Rican health professionals; • Clayton (2010) HIV-AIDS-related stigma in Wyoming;* • Moses (2010) Mental health disorders in adolescents; • Shellenberg (2010) Abortion stigma in the United States* 	<p>Contains both quantitative and qualitative aspects; aim is to collect data in more than one way to enhance validity / robustness of findings; philosophical underpinning is often underplayed</p>	<p>Unclear</p>	<p>Possible to collect quantitative data perhaps measuring impact of stigma, or stigma perceptions</p>	<p>Measurement is not focus of study; intention is to understand lived experience so quantitative aspect inappropriate; insider research role uncertain.</p>
<p>Table A3 (Cont.) Critique of qualitative stigma research papers assessing methodological suitability for the current study: Mixed methods research *Examples from results of Search 2: papers to inform methodology.</p>				

Methodology / philosophy (Examples)*	Key attributes	Researcher position	Potential for use in current study	Reason for rejection
<p>Phenomenology (unspecified)</p> <ul style="list-style-type: none"> • Tryssenaar (2003) Older persons with serious mental illness • Mollen (2006) Voluntarily childfree women • Milliard (2007) Alcoholism in older women⁺ • Grofik (2008) Barriers to choosing psychotherapy⁺ • Kiliñç and Campbell (2009) Epilepsy stigma 	<p>Collect qualitative data about specific experience using interviews; use of thematic framework to guide analysis; verbatim extracts used to support findings</p>	<p>Either inside or outside</p>	<p>Allows exploration of lived experience so could be used; enables insider researcher role</p>	<p>Indistinct processes; underpinning philosophy not clearly defined; insider researcher role not compatible with descriptive approaches</p>
<p>Interpretative phenomenological analysis (IPA)</p> <ul style="list-style-type: none"> • Osborn and Smith (1998) Chronic benign lower back pain • Knight et al. (2003) Stigma in schizophrenia • Birch (2005) Physical health care in women with mental illness • Richardson (2010) Reasons for young people declining Chlamydia testing in the UK 	<p>Used to understand human experience; double hermeneutic; captures experience via interviews using semi-structured schedule; structured data analysis develops ordinate and super-ordinate themes, and interpretive commentary; participants often interviewed more than once.</p>	<p>Inside</p>	<p>Suitable for exploring personal experiences of stigma; underpinned by phenomenology and includes hermeneutic (interpretive) elements; enables partial insider researcher role</p>	<p>Indistinct relationship between descriptive and interpretive phenomenology; data analysis fragments participant's accounts; influence of researcher obscured by data analysis method – role not transparently managed; reflexive processes obscure.</p>
<p>Table A3 (Cont.) Critique of qualitative stigma research papers assessing methodological suitability for the current study: unspecified phenomenology and Interpretative Phenomenological Analysis (IPA)</p> <p>*Examples from results of Search 2: papers to inform methodology; + = abstract only</p>				

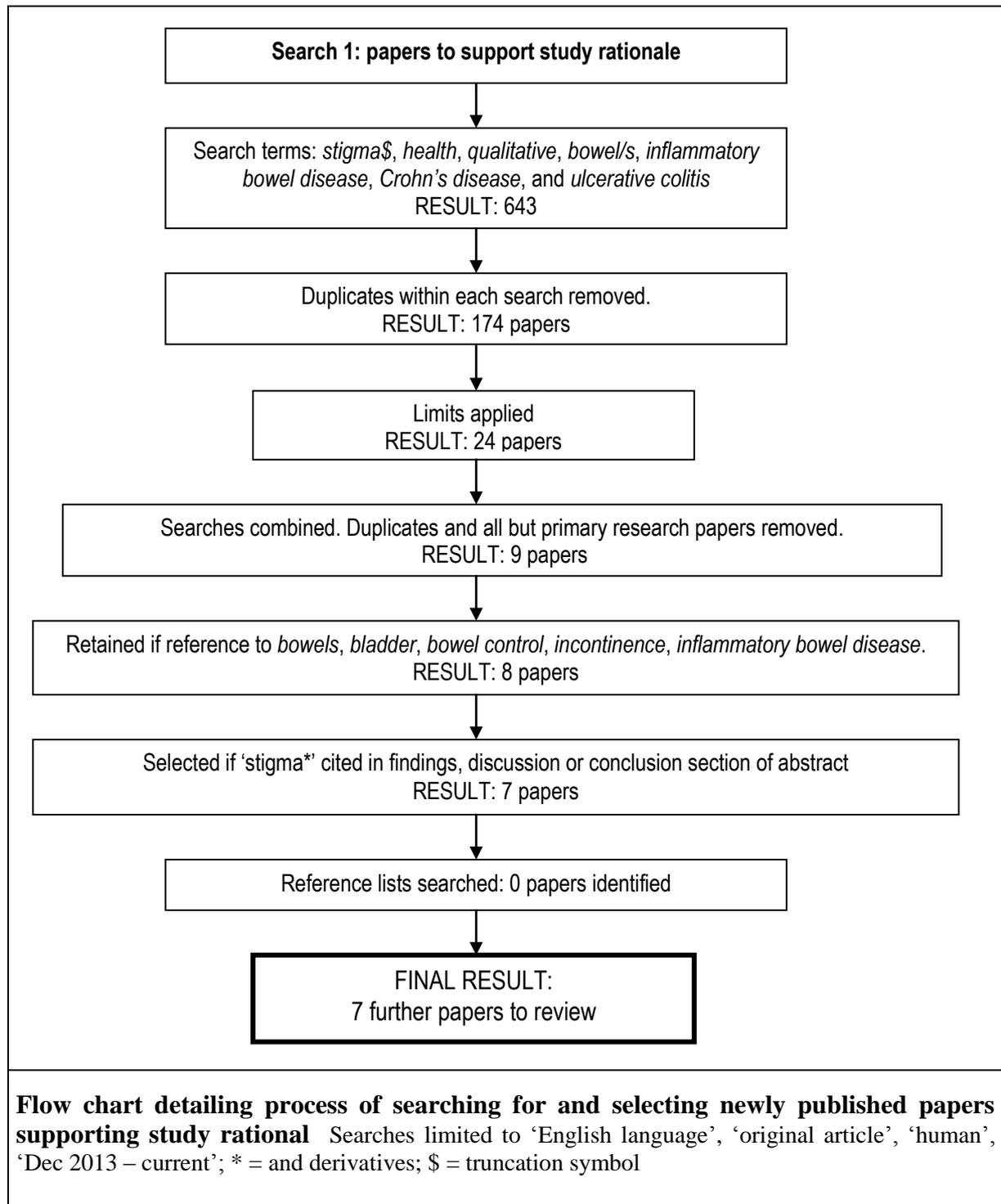
Methodology / philosophy (Examples)*	Key attributes	Researcher position	Potential for use in current study	Reason for rejection
<p>Descriptive phenomenology</p> <ul style="list-style-type: none"> • Lillibridge et al. (2002) Nurses who misuse substances • Cluver and Gardner (2007) Children orphaned by AIDS in Cape Town • Ntswane and van Rhyn (2007) Mothers caring for mentally-retarded children in South Africa • Bertram (2008) Women with abnormal Papanicolaou smears • Proudfoot et al. (2009) Experiences following diagnosis of bipolar disorder • Zauderer (2010) Postpartum depression in orthodox Jewish women+ 	<p>Collect qualitative data about specific experiences using interviews; use of thematic framework to guide analysis; verbatim extracts used to support findings; generates descriptive account of phenomenon; 'bracketing'- suspension of existing knowledge and understanding to avoid influencing meaning</p>	<p>Outside</p>	<p>Suitable for exploring personal experiences of stigma; underpinned by sound philosophical position; several analysis frameworks available to guide researcher</p>	<p>Produces descriptive (<i>this is what it is</i>) data, rather than interpretive (<i>this is what it means</i>) data; researcher separated from data collection and analysis by bracketing; difficult to 'suspend all pre-existing knowledge.'</p>
<p>Interpretative (hermeneutic) phenomenology</p> <ul style="list-style-type: none"> • Pejler (2001) Parenting an adult child with severe mental illness • Chang and Horrocks (2006) Family caregivers of mentally ill relatives • Alqaissi and Dickerson (2010) Jordanian women with breast cancer • Raingruber et al. (2010) Female Ghanaian sex workers, HIV, and AIDS 	<p>Used to understand human experience; hermeneutic; captures experience via in-depth interviews using semi-structured schedule; researcher key part of research process – pre-understanding aids data collection, analysis and interpretation; reflexivity required to balance influence.</p>	<p>Inside</p>	<p>Suitable for exploring personal experiences of stigma; sound philosophical position; based on hermeneutics (interpretation); insider researcher role vital; several analysis frameworks available to guide researcher</p>	<p>Reason for acceptance</p> <p>Clear relationship between processes and theory; hermeneutic analysis enables interpretation of participant experiences; researcher embraced as part of research design; influence managed by reflexivity, journaling, field notes and supervision.</p>
<p>Table A3 (cont.) Critique of qualitative stigma research papers assessing methodological suitability for the current study: Descriptive and Interpretative Phenomenology *Examples from results of Search 2: papers to inform methodology; + = abstract only</p>				

APPENDIX 4

Updated literature review

Updated literature search strategy

The literature was searched again for new relevant research papers published between December 2013 and July 2014 using the strategy detailed in Chapter 4 [Search 1; p. 43].



Results of updated search December 2013 – July 2014

Seven further papers (three quantitative, three qualitative, one mixed methods) relevant to the study rationale were identified and reviewed using the same adapted CASP guidelines followed in the original review [Chapter 4; p.43]. Rationale for, and critique of approaches to, research have been discussed previously in Chapter 4.

Characteristics of included studies

The seven papers addressed stress urinary incontinence (Wang et al. 2014), faecal incontinence (Roslani et al. 2014), urinary incontinence and bowel symptoms due to uterine prolapse (Shrestha et al. 2014), internalized stigma in IBS (Taft et al. 2014), living with a permanent stoma due to cancer, chronic constipation or IBD (Danielsen et al. 2013), deviance and morality in IBD (Saunders 2014), and social support in IBD (Frohlich 2014).

1724 participants were reported; sample sizes ranged from 14 to 1000. Most participants (n=1430; 83%) were female. Two studies (Shrestha et al. 2014; Wang et al. 2014) addressed female-only issues, so had no male participants, whilst Frohlich (2014) recruited equal numbers of each gender. Across six studies, ages ranged from 18 and 83 years; Roslani et al. (2014) provided median age (38 years) and inter-quartile range (24 years). Participants were recruited from specific aetiology groups: those with conditions leading to stoma-forming surgery (Danielsen et al. 2014), with a uterine prolapse following pregnancy and childbirth (Shrestha et al. 2014), or with IBD (Frohlich 2014; Saunders 2014). In the remaining studies participants had mixed aetiology or functional syndromes (Roslani et al. 2014; Taft et al. 2014; Wang et al. 2014). See Table A1 below [p.346] for detailed characteristics.

Quality of included studies

The methodological (philosophical and methods (design) quality of these studies are critiqued below and summarised in Table A2, below [p.348].

Research paradigm and fit with methods

There was a good fit between paradigm and methods in all seven studies. The quantitative studies (Roslani et al. 2014; Taft et al. 2014; Wang et al. 2014) all used a cross-sectional design, an appropriate approach when no intervention is being tested. The qualitative studies of Danielsen et al. (2014), Frohlich et al. (2014) and Saunders (2014) explained the philosophical approach in varying degrees of detail. The single mixed methods (Shrestha et al. 2014) study used an exploratory approach suitable for a first investigation of the experience of uterine prolapse in women in Nepal.

Sampling methods

Although convenience sampling is considered a weak strategy in quantitative research as it affects the generalisability of study findings, it was used in two quantitative studies (Roslani et al. 2014; Shrestha et al. 2014). It may have been selected in the latter study due to the access difficulties presented by the difficult terrain in Nepal. All other studies used purposive sampling to recruit people with the feature of interest using a range of techniques including via specialist nurses (Danielsen et al. 2013), online routes (Frohlich 2014), online and university-based outpatient clinics (Taft et al. 2014), community settings (Wang et al. 2014) and through universities, clinics and disease-specific support groups (Saunders 2014). Danielsen et al. (2014) increased the breadth of their sample through maximum variation sampling.

Ethical considerations

All studies gave a clear statement of ethical approval, but evidence of informed consent was inconsistent. Only three studies stated that informed consent was secured prior to data collection (Roslani et al. 2014; Shrestha et al. 2014; Wang et al. 2014). In Taft et al.'s (2014) study, consent was implied by return of self-completed questionnaires. The remaining studies made no statement that informed consent was secured.

Data collection, analysis and reporting

Validated measures are preferred in quantitative cross-sectional studies because these have been tested and evidence of their stability and reliability is available. Taft et al. (204) used several validated measures, and further validated the Internalised Stigma of Mental Illness tool (ISMI) for use in IBS research. The remaining studies (Roslani et al. 2014; Wang et al. 2014) used previously validated and made-for-study measures. All three quantitative studies measured variables, reporting these either descriptively (Roslani et al. 2014) or inferentially (Taft et al. 2014; Wang et al. 2014). Results were presented clearly in tables, and analysis methods explained with varying degrees of detail.

In qualitative studies, the aim is to avoid preconceptions either by suspending one's own knowledge, or managing this appropriately within the study. The latter is a central tenet of hermeneutic phenomenology research. All three qualitative studies explored either the concept of stigma in relation to a specific condition (Frohlich 2014; Saunders 2014), or identified stigma as part of an illness-related experience (Danielsen et al. 2013). Verbatim extracts from the study data supported the presentation of findings.

The single mixed-methods study (Shrestha et al. 2014) began with supervised completion of a non-validated made-for-study measure, necessary due to the high level of illiteracy amongst Nepalese women. Data was analysed descriptively through SPSS, and used to later analyse in-depth data captured in individual interviews. Extending quantitative findings with qualitative interviews is a recognised mixed-methods approach (Creswell and Plano-Clark 2007). Findings from both sets of data were reported together using appropriate methods.

Weaknesses and limitations

Overall, all studies had moderate to high levels of rigour, although some had limitations. Of the quantitative studies, Roslani et al. (2014) may have introduced bias towards those with more FI problems by using a sample of convenience of patients and relatives in clinics at a medical facility. Conversely, the inclusion of relatives in the study may have resulted in a

sample more representative of the wider community. Although the study conclusion reports the need to increase public awareness of FI in order to reduce stigma, data reporting stigma, shame or embarrassment were not collected and there is no link between data and this conclusion. Consequently, the study findings are excluded from further discussion. Both Taft et al. (2014) and Wang et al. (2014) acknowledge that their cross-sectional studies prevent them from determining causality. Taft et al. comment that their mixed online and clinical sample may affect generalisability, although this mix may be more representative demographically. A more likely influence on generalisability is the gender mix, with a preponderance of women (86%) participating.

Amongst the qualitative studies, Danielsen et al. (2013) offer no philosophical theory, and the relationship between their reported use of hermeneutic phenomenology techniques and the method of data analysis is weak. Absence of data analysis method is the only weakness in Frohlich's (2014) study – the findings seem likely but the reader cannot determine how these were reached. Saunders' (2014) study has a high level of trustworthiness, the only weakness being the failure to confirm that informed consent was obtained.

Discussion of findings from included studies

The findings add to the existing evidence of stigma associated with a range of bladder and bowel-related issues, and provide emerging qualitative evidence of the experience of stigma in IBD. Issues relating to help-seeking, disclosure, culture and taboo, and support emerge.

Disrupted help-seeking

The stigma linked to stress urinary incontinence (SUI), and the degree of social isolation it causes, prevents some women in China from seeking care whilst prompting others to seek help (Wang et al. 2014). Those with high levels of perceived social rejection, and moderate levels of internalised stigma (shame) are more likely to seek care. Women with low or high levels of internalised stigma are less likely to seek care. Women in Nepal with uterine

prolapse (UP) leading to urinary and defecation problems, avoided care-seeking due to shame, fear of stigma and discrimination (Shrestha et al. 2014). The persistence of these debilitating symptoms disrupts family, social and intimate relationships, and negatively impacts on quality of life.

Disclosure

Issues of disclosure impact on the lives of those with permanent intestinal ostomies (Danielsen et al. 2013). Choosing to disclose to avoid being discredited is difficult when it is perceived that others' 'do not know what it is' and the person with the ostomy finds themselves having to reveal more than they wanted to; yet disclosing is also beneficial, as it offers the opportunity to communicate openly and be oneself. People have to adjust to being different, and need information to help them learn how to live with a stoma. Stigma is also evidenced through covering and concealment practices, including wearing clothes to disguise the presence of an ostomy, and self-enforced isolation. In IBD, the sense of shame which prevents disclosure can lead to blame as symptoms are misunderstood by others, adding a moral component to the experience (Saunders 2014).

Culture and taboo

In all studies, culture and taboo play a part in perceptions of stigma. For Chinese women with SUI, the shame brought to the individual and family if the SUI becomes known about by others, leads to social isolation (Wang et al. 2014). In Nepal, the gender inequalities between men and women increase the stigma women feel, and the abuse they suffer, if they are unable to carry out their expected tasks. The cultural expectation that UP is a normal consequence of childbirth, and the culture of silence and shame about reproductive health prohibits health care-seeking (Shrestha et al. 2014). Danielsen et al. (2013) evidence that there is a high risk of being discredited if discovered to have a stoma, as the taboo about bowels and stomas makes it more difficult to talk about. People with IBS who report greater stigma, also experience more anxiety and depression, reduced health-related quality of life,

and believe themselves less competent in managing their health. The stigma can arise from the cultural perceptions of functional diseases which cannot be definitively diagnosed, and lead others to believe sufferers to be responsible for their condition, or to be ‘making it up’ (Taft et al. 2014). In young adults with IBD, stigma is related to the taboo nature of the disease and emerges from a sense of shame, in contrast to deviance which comes from blame. Taboo increases the risk of disclosure, because of the social unacceptability of bowel issues, and there is a moral component to stigma arising from cultural expectations in the UK for people to have a strong attitude towards illness (Saunders 2014).

Support

Being able to draw on the help of friends to re-affirm identity is important to those learning to live with a permanent stoma, as is the appropriate educational support post-discharge and peer-group support (Danielsen et al. 2013). In IBS, lack of support, particularly from significant others, increases internalised stigma (Taft et al. 2014). Support from a range of social relationships can enable people with IBD to overcome stigma (Frohlich 2014).

Conclusions drawn from reviewed papers

As with the original literature review [Chapter 4], visibility, concealability, cultural and taboo issues influence stigma perceptions and experiences. Help-seeking can be prompted or disrupted by stigma; whilst a moderate degree of social rejection and internalised stigma (IS) can prompt women with SUI with strong motivations to resolve their stigmatising problem, women with high or low levels of IS are less likely to seek help. Likely causes for this are that those with low levels of IS find their SUI insufficiently troublesome to warrant help-seeking, whilst those with high levels of IS fear further stigmatisation so that they keep the SUI secret (Wang et al. 2014). Similarly, Nepalese women with bladder and bowel problems due to UP resist help-seeking due to fear of condemnation by their communities and families, so their problem remains hidden (Shrestha et al. 2014). People with IBD rarely

avoid medical care for their condition, but do avoid help-seeking for related faecal incontinence (Dibley and Norton 2013; Duncan et al. 2013)

Although culture does influence the development of stigma, social interactions also play a part. Further evidence from Taft et al. (2014) addressing stigma in IBS reinforces findings from their earlier work that stigma experiences differ depending on who originates these. Whilst this quantitative work cannot indicate the ways in which these attitudes are different, these findings do offer support for the emergence of kinship stigma as a plausible construct.

New qualitative evidence revealing the experience of stigma in IBD is beginning to emerge. Saunders (2014) focuses primarily on how young people's language constructs ideas of stigma and deviance in IBD, and in doing so, reveals many of the dilemmas that emerge about revealing / concealing. He also confirms the point that it is: 'taboo to talk about, or to know about others' bowel habits – especially when these are irregular in some way.' Frohlich (2014), reflecting my own findings, adds that stigma is anticipated and perceived by people with IBD more often than it is enacted towards them; that it tends to decline over time, and that support is essential. He does not explore the mechanisms behind stigma reduction, but recommends that further work is needed to understand personal characteristics which might explain the stigma which people with IBD experience.

Summary

The review of these additional seven papers supports the findings of the original review, and broadens understanding of the range and complexity of stigma experiences in bladder and bowel-related disorders, enhanced by newly-emerging qualitative evidence. Findings from this review are incorporated in the Discussion chapter [Chapter 11; p.xxx].

AUTHOR Author, Year, Country	STUDY POPULATION (1) number of participants; (2) socio-demographic details; (3) disease focus.	STUDY DESIGN (1) methodology; (2) sampling method.	OUTCOME MEASURES (a) psychological health; (b) quality of life; (c) physical health; (d) social health; (e) miscellaneous.	MAIN RESULTS
Danielsen et al. 2013 Denmark	(1) 15; (2) median age 66yr; 53% female; (3) permanent stoma	(1) hermeneutic phenomenology; (2) purposive with maximum variation	(a) nil; (b) nil; (c) nil; (d) nil; (e) focus group interviews	Two key themes of 'Being different' and 'Training in how to live with a stoma'. Stigma evidenced through covering, disclosing and concealment strategies, including self- enforced isolation. High risk of being discredited as stomas considered taboo.
Frohlich 2014 USA	(1) 14; (2) mean age 32.6 yrs; 50% female; (3) Inflammatory bowel disease (IBD)	(1) phenomenology (van Manen); (2) purposive	(a) nil; (b) nil; (c) nil; (d) nil; (e) individual interviews (via Skype)	Stigma is commonly linked to initial diagnosis, romantic relationships, work and school, surgery and medicine, and is anticipated and perceived more often than actually experienced. Decreases over time, assisted by social support
Roslani et al. 2014 Malyasia	(1) 1000; (2) median age 38 yrs; 76% female; (3) faecal incontinence (FI)	(1) quantitative (cross- sectional survey; (2) convenience	(a) nil; (b) nil; (c) Wexner Continence Scale; (d) nil; (e) m-f-s questionnaire.	FI associated with increasing age, defaecation frequency and diabetes mellitus.
Saunders 2014 UK	(1) 16; (2) Age range 18-29 yrs; 62.5% female; (3) IBD	(1) qualitative (discourse analysis; (2) purposive	(a) nil; (b) nil; (c) m-f-s questionnaire; (d) nil; (e) individual semi-structured interviews	Stigma in IBD is related to the taboo nature of the disease and emerges from shame, in contrast to deviance, which comes from blame. A sense of shame which prevents disclosure can lead to blame as symptoms are misunderstood by others. Stigma in IBD appears to be unrelated to power or oppression

Table A4-1 Characteristics and main findings of studies (n=7) identified in literature review update (Dec. 2-013 – July 2014), describing study population, design, outcome measures used, and main findings reported; m-f-s = made for study

AUTHOR Author, Year, Country	STUDY POPULATION (1) number of participants; (2) socio-demographic details; (3) disease focus.	STUDY DESIGN (1) methodology; (2) sampling method.	OUTCOME MEASURES (a) psychological health; (b) quality of life; (c) physical health; (d) social health; (e) miscellaneous.	MAIN RESULTS
Shrestha et al. 2014 Nepal	(1) 131(115 + 16); (2) age range 23 – 82 yrs; 100% female; (3) uterine prolapsed (UP)	(1) mixed methods (quant → qual), descriptive exploratory; (2) convenience	(a) nil; (b) nil; (c & d) m-f-s questionnaire; (e) semi- structured interviews	Women were multi-parous (mean = 9), and reported urinary, bowel and sexual difficulties due to UP. The Problem is taboo in Nepal and affects intimate and familial relationships. Stigma and perception of UP as normal prevents help-seeking.
Taft et al. 2014 USA	(1) 243; (2) Age 38 yrs ± 13.5 yrs; 86% female; (3) Irritable bowel syndrome (IBS)	(1) quantitative; (2) purposive	(a) NIH-PROMIS short form anxiety and depression scales; ISMI; PSS-IBS; (b) IBS-QOL; (c) nil; (d) nil; (e) PHCS	Internalised stigma (IS) in IBS leads to alienation, social withdrawal and discrimination; more stigma is perceived to come from significant others than from healthcare providers, and some cultural groups report more perceived stigma than others. Symptom severity, disruptiveness and treatment choices influence stigma perception and internalisation.
Wang et al. 2014 China	(1) 305; (2) age range 40 – 65 yrs; 100% female; (3) Stress urinary incontinence (SUI)	(1) quantitative; (2) purposive	(a) Social Impact Scale; (b) nil; (c & d) ICIQ-UI SF; m-f-s questionnaire;(e) intention to seek care for SUI	Women with moderate internalised shame (stigma) have stronger intentions to seek care than those with low or high levels of internalised shame. Greater social rejection predicts greater intention to seek care.

Table A4-1 (Cont.) Characteristics and main findings of studies (n=7) identified in literature review update (Dec. 2-013 – July 2014), describing study population, design, outcome measures used, and main findings reported;

IBS-QOL = Irritable Bowel Syndrome – Quality of Life; ICIQ-UI SF = International Consultation on Incontinence Questionnaire – Urinary Incontinence Short Form; ISMI = Internalized stigma of mental illness; m-f-s = made for study; NIH-PROMIS = National Institute for Health Patient Reported Outcome Measures Information System; PHCS – Perceived Health Competence Survey; PSS-IBS = Perceived Stigma Scale – Irritable Bowel Syndrome; quant = quantitative; qual = qualitative;

AUTHOR	PURPOSE	METHODOLOGY / DESIGN	RIGOUR (RELIABILITY / TRUSTWORTHINESS)	LIMITATIONS
Author, Year, Country	Aim explicitly stated	(1) methodology; (2) ethics statement; (3) consent; (4) data collection; (5) data analysis	(a) level of rigour; (b) design consistency; (c) miscellaneous	
Danielsen et al. 2013 Denmark	yes: to explore impact of stoma on daily life and understand related education needs	(1) hermeneutic phenomenology techniques; (2) statement of ethics approval; (3) no statement of consent; (4) focus group interviews; (5) content analysis and NVivo 8	(a) moderate;(b) detail on hermeneutic philosophy minimal but evidence of co-constitution and management of researcher bias; (c) weak data analysis method; verbatim extracts support reported findings	Identified 'limitations' are not limitations in this type of study. Actual limitation is an absence of philosophical theory and weak relationship between this and the data analysis method.
Frohlich 2014 USA	yes: to understand how people with IBD experience stigma	(1) hermeneutic phenomenology (van Manen); (2) statement of ethics approval; (3) no statement of consent; (4) individual semi-structured interviews via Skype	(a) moderate; (b) all stages of study design consistent with methodology / philosophy; (c) data analysis method not described; verbatim extracts support reported findings	Absence of data analysis detail: findings are likely but no evidence of how these were revealed.
Roslani et al. 2014 Malaysia	yes: to estimate prevalence of faecal incontinence in a mixed population	(1) quantitative: cross-sectional survey; (2) statement of ethics approval; (3) verbal consent obtained; (4) self-completed m-f-s questionnaire; WCS; (5) descriptive statistical analysis including chi-square, means, medians, SD and IQR	(a) high; (b) all stages of study design consistent with methodology; (c) results given as tables; statistical processes outlined	Convenience sampling weak in quantitative research; prevalence may be higher in sample drawn from specific clinics at an academic medical facility; stigma reported in conclusion but no related data collected in study.
Saunders 2014 UK	yes: to explore discursive construct of stigma in young adults with IBD	(1) qualitative (discourse analysis); (2) statement of ethics approval; (3) data anonymised but no statement of consent; (4) individual semi-structured interviews; (5) open-coding aided by MAXQDA and RDA	(a) high; (b) all stages of study design consistent with methodology / philosophy; (c) verbatim extracts used to evidence findings	None identified, beyond lack of confirmation that consent was obtained

Table A4-2 Methodological rigour of studies (n=7) identified in literature review update (Dec. 2-013 – July 2014), assessing methodology, design, and study limitations IBD = inflammatory bowel disease; IQR = inter-quartile range; MAXQDA = Max (Weber) Qualitative Data Analysis software ; m-f-s = made for study; RDA = rhetorical discourse analysis; SD = standard deviation; WCS = Wexner Continence Score

AUTHOR	PURPOSE	METHODOLOGY / DESIGN	RIGOUR (RELIABILITY / TRUSTWORTHINESS)	LIMITATIONS
Author, Year, Country	Aim explicitly stated	(1) methodology; (2) ethics statement; (3) consent; (4) data collection; (5) data analysis	(a) level of rigour; (b) design consistency; (c) miscellaneous	
Shrestha 2014 Nepal	yes: to explore experience and impact of UP on daily life and care-seeking practices	(1) mixed methods (quant → qual); (2) statement of ethics approval; (3) statement of informed consent; (4) m-f-s questionnaire completed at interview; in-depth interviews; (5) Quant – variables categorised via SPSS; qual – content analysis	(a) high; (b) all stages of study design fit with methodology / philosophy; (c) relationship between first phase quant data and second phase qual data is transparent; quant findings presented as tables, qual findings use verbatim extracts.	Absence of any mixed-methods theory. Limitations regarding generalisability minimal as this clearly a first exploratory study into this issue.
Taft et al. 2014 USA	yes: to evaluate internalised stigma in people with IBS	(1) quantitative: cross-sectional survey; (2) statement of ethics approval; (3) no overt statement of consent but implied by return of anonymous questionnaires; (4) paper or online completion of m-f-s and validated questionnaires; (5) statistical analysis .	(a) high; (b) all stages of study design fit with methodology / philosophy; (c) data presented as tables; validated measures used; statistical processes fully explained.	Cross-sectional study – causality not clear; authors feel online and clinical sample a limitation which could affect generalisability – conversely, it could aid it with broader demographic spread. Mostly women in sample.
Wang et al. 2014 China	yes: to examine relationship between stigma and intention to seek help for SUI	(1) quantitative: cross sectional survey; (2) statement of ethics approval; (3) statement of consent; (4) supervised self-completion of m-f-s questionnaire, and SIS; (5) statistical analysis including hierarchical regression modelling	(a) moderate; (b) all stages of study design fit with methodology / philosophy; (c) data presented as tables; statistical processes fully explained; non-validated measures expect for SIS	Cross-sectional study – causality not clear; intention to seek care may not reflect future care-seeking behaviours;

Table A4-2 Methodological rigour of studies (n=7) identified in literature review update (Dec. 2-013 – July 2014), assessing methodology, design, and study limitations IBS = irritable bowel syndrome; m-f-s = made for study; qual = qualitative; quant = quantitative; SIS = Social Impact Scale; SPSS = Statistical Package for the Social Sciences; SUI = stress urinary incontinence; UP = uterine prolapse

APPENDIX 5

Study information leaflet, consent form, and ethics approvals

Note to examiners: this study commenced in October 2010 whilst I was employed at Buckinghamshire New University and continued after my relocation to King's College London in September 2012. Although all participants had been recruited by then, the information leaflet was reproduced on King's paper and with current contact details, although it was not requested by any recruited participant. It is not provided here to avoid repetition. Both versions of the consent form are provided as both were used.

Participant information leaflet



Stigma in IBD Study

Information Sheet

Thank you for your interest in the Stigma in IBD Study. Please read this information sheet with care. It will help you to decide if you do or do not want to take part. You do not have to take part, and you do not have to tell us why you do not want to take part. Do ask for help if you do not understand. You can ask friends and family, your Doctor or Practice Nurse, or the researcher (Lesley Dibley) to help you. Lesley's contact details are on the final page.

Why we are doing the research

We know from other studies we have done that many people with IBD feel stigmatised. This means being made to feel bad about yourself because of what other people think about you. Even if other people do not think badly of you, you may worry that they do. Many people with IBD feel stigmatised because they have an illness which affects their bowels. They may not be able to control their bowels well and may make a mess. This can happen when they are with other people, at work, or at home. We know from other studies that stigma happens with other long-term health problems, such as mental illness. We also know that people who feel stigmatised often avoid seeking help. We know that lots of people with IBD do have problems controlling their bowels, but very few people seek help for this. We want to find out whether people with IBD do not seek help for loss of bowel control because they feel stigmatised. If we can find out what stops people from seeking help, we can find better ways of supporting them. We can also start to design helping services which people can access with ease, and which meet their needs.

Why have you asked me to take part?

In 2010, we asked you to take part in our 'Continence in IBD Study.' In your answers, you told us that you were willing to be interviewed. You may also have told us that you feel badly about yourself and you may even have used the word 'stigma.' This may be simply because of your IBD, or because your IBD causes poor bowel control. We are also interested in whether some people with poor bowel control do not feel stigmatised. Exploring all of these angles will help us to understand peoples' experiences. We would like to invite you to take part in this Stigma Study because you have told us that you either do or do not feel stigmatised.

What will I be asked to do?

If you agree to take part, you will be interviewed by the researcher (Lesley Dibley). Lesley will arrange to visit you in your own home at a date and time which suits you. This means that you will not need to travel and you will have access to your own facilities. It may also reduce your anxiety. Lesley will put you at ease to help you to talk about any stigma linked with your IBD. She will draw on the comments you made when you responded to the Continence in IBD study. You will be able to talk about your feelings in whichever way you feel you need to. The interview will take no more than one hour, and will be recorded on a digital voice recorder. This device is about half the size of a TV remote control, makes no noise and you will soon forget it is there. The interview will be typed up later, and the audio file will then be deleted.

Are there any benefits or risks involved?

It may seem that there will be no benefits to you from taking part in this study, but sharing your experiences with us may help a great many other people with IBD. What we learn from you will help us to design better support services. This can make it easier for people with IBD who feel stigmatised to ask for help.

Talking about tough issues can be hard for people. We know that it can help a lot to be able to talk freely with someone who is keen to hear what you want to say and who will not think badly of you. If you do feel stigmatised, there is a risk that you will find it upsetting to talk about how you feel. Some people learn things which they had not thought of before and this

can take them by surprise. Lesley has done a lot of interviewing before – she will look after you and make sure that you feel safe again before she leaves you.

What if I change my mind?

You do not have to take part, even after you have said you will. You can withdraw from the study at any time before, during or after interview without telling us why. If you do withdraw, it will not affect your rights in any way at all. You can do this up until 31st December 2012. After this time, we will be sorting all the data and writing articles ready to be published. We will not then be able to separate your words from the rest. If you do withdraw before this date, we will delete all records we have about you as well as the typed copy of your interview. Please keep this leaflet in a safe place so that if you do wish to withdraw, you can contact Lesley using the details on the final page.

If I do take part, how will you keep my details safe?

We will only keep information about you for as long as you are taking part in the study, unless you have instructed us otherwise. We will keep your data safely. This means that we will keep all personal data such as your name and contact details, as well as the transcript of your interview, on a computer which only Lesley can access. There will be a password to stop anyone else looking at the data. Lesley must keep your identity safe. This means that whilst she knows who you are, and which interview is yours, she will not tell any other person. Before anything is published, Lesley will also take things out of the data which could help other people to know who you are. This means that names, places and places of work, for example, will be taken out or changed. If we need to refer to you by name in the published data, Lesley will change your name for a false one.

Who is funding and managing the project?

The research is being self-funded. Lesley is doing this research for her PhD. The study is hosted by Buckinghamshire New University. Their rules ensure that the study is done properly. The full title of the study is *'Is stigma a barrier to accessing health support in people with inflammatory bowel disease-related faecal incontinence?'* Lesley has two supervisors on this study: Professor Christine Norton and Professor Elizabeth Whitehead.

Prof. Norton is an expert on bowel problems and works at St Mark's Hospital, Harrow. She is also Professor of Clinical Nursing and Innovation at Bucks New University and Imperial College, London.

Professor Elizabeth Whitehead is an expert on health-related stigma. She is Professor of Social and Health Care, and Head of Research Dept. in the Faculty of Health & Social Care at Chester University.

What do I do now?

If you would like any more information, or if you are happy with the information provided here and would like to take part, please contact:

Lesley Dibley – Research Fellow

Faculty of Society & Health

Bucks New University, 106 Oxford Road, Uxbridge UB8 1NA

Tel: 01494 522141 x4418 Mobile: 07985 647292

email: lesley.dibley@bucks.ac.uk

Lesley is not always in the office, so email is the best way to get hold of her. If you do leave a message on either phone, Lesley will get back to you as soon as she can.

Buckinghamshire New University Consent Form



Consent Form for the Stigma in IBD Study

Please tick the appropriate boxes

I have read and understood the project information sheet.....

I have been given the opportunity to ask questions about the project.....

I agree to take part in the project. Taking part in the project will include being interviewed by Lesley Dibley in my own home, and the interview being audio recorded on a digital voice recorder.....

I understand that my taking part is voluntary; I can withdraw from the study at any time and I will not be asked questions about why I no longer want to take part.....

Select only one of the next two options:

I would like my name used where anything I have said or written as part of this study will be used in reports, publications and other research outputs so that anything I have contributed to this project can be recognised.....

I do not want my name used in this project.....

I understand my personal details such as phone number or address will not be revealed to people outside of this project.....

I understand that my words may be quoted in publications, reports, and other research outputs but my name will not be used unless I requested it above.....

I understand that other researchers will have access to these data only if they agree to preserve the confidentiality of these data.....

I understand that other researchers may use my words in publications, reports, and other research outputs but my name will not be used unless I have requested it above.....

I agree to assign the copyright I hold in any materials related to this project to Lesley Dibley.....

On this basis I am happy to participate in the [name of project] study

Name of Participant Signature..... Date.....

Name of Researcher..... Signature..... Date.....

If you have any queries or concerns, please contact:

Lesley Dibley – Research Fellow

Faculty of Society & Health, Bucks New University, 106 Oxford Road, Uxbridge UB8 1NA;

Tel: 01494 522141 x4418 mobile: 07985 647292 email: lesley.dibley@bucks.ac.uk

One copy to be kept by the participant, one to be kept by the researcher

King's College London Consent Form

CONSENT FORM FOR PARTICIPANTS IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.



Title of Study: Feelings of stigma in people with inflammatory bowel disease who do or do not experience faecal incontinence

King's College Research Ethics Committee Ref: PNM 12/13-24

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Please tick or initial

- I understand that if I decide at any time during the research that I no longer wish to participate in this project, I can notify the researcher involved and withdraw from it immediately without giving any reason. Furthermore, I understand that I will be able to withdraw my data up until 31st May 2013.
- I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the UK Data Protection Act 1998.
- I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications
- I agree that the research team may use my data for future research and understand that any such use of identifiable data would be reviewed and approved by a research ethics committee. (In such cases, as with this project, data would not be identifiable in any report).
- I consent to my interview being audio recorded.

Participant's Statement:

I _____ [Name in capitals]

agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed

Date

Investigator's Statement:

I _____ [Name in capitals]

confirm that I have carefully explained the nature, demands and any foreseeable risks (where applicable) of the proposed research to the participant.

Signed

Date

Proof of ethics approval from Bucks New University



29th April 2014

Ms Lesley Dibley
Research Associate
Florence Nightingale School of Nursing & Midwifery
King's College London
Rm 2:25
James Clerk Maxwell Building
57 Waterloo Road
LONDON
SE1 8WA

Dear Lesley,

I am writing to confirm that Ethical approval was granted by the Faculty of Society and Health Ethics panel of Buckinghamshire New University on the 17th February 2011 for your project titled:

"Is stigma a barrier to accessing healthcare in people with inflammatory bowel disease-related faecal incontinence?"

I hope that your research project goes well.

Yours sincerely,

A handwritten signature in blue ink, appearing to read "M. Nakisa".

Dr M. Nakisa
Secretary to the University Ethics Panel
Research Unit
Academic Quality Directorate

Proof of ethics approval from King's College London

Lesley Dibley
Florence Nightingale School of Nursing and Midwifery
James Clerk Maxwell Building
57 Waterloo Road
London SE1 8WA

18 October 2012

Dear Lesley

PNM/12/13-24 Feelings of stigma in people with inflammatory bowel disease who do or do not experience faecal incontinence.

Review Outcome: Full Approval

Thank you for submitting an application to the **PNM RESC** which was reviewed on **16 October 2012**. I am pleased to inform you that these meet the requirements of the PNM RESC and therefore that full approval is now granted with the following provisos:

1. Section 1.4: The name of the transcriber should be listed in this section and submitted to the Research Ethics Office.
2. Section 6.1: Please inform the committee if you need to increase participant numbers in order to reach data saturation.
3. Section 10b: For future reference, please complete all sections of the application form as individual questions and do not refer to other sections of the form.
4. Information Sheet:
 - I. State that the study has been approved by King's College London, Psychiatry, Nursing and Midwifery Research Ethics Subcommittee.
 - II. Check grammar and typographical errors. In the first paragraph you have stated 'I am completing this project for her PhD'.
 - III. Under the heading 'Who is funding and managing the project?' please delete the sentence 'Their rules ensure that the study is done properly'. It is the responsibility of the researcher to ensure that the study is conducted in an appropriate manner.

Please ensure that you follow all relevant guidance as laid out in the King's College London Guidelines on Good Practice in Academic Research (<http://www.kcl.ac.uk/college/policyzone/index.php?id=247>).

For your information ethical approval is granted until **16 October 2013**. If you need approval beyond this point you will need to apply for an extension to approval at least two weeks prior to this explaining why the extension is needed, (please note however that a full re-application will not be necessary unless the protocol has changed). You should also note that if your approval is for one year, you will not be sent a reminder when it is due to lapse.

Ethical approval is required to cover the duration of the research study, up to the conclusion of the research. The conclusion of the research is defined as the final date or event detailed in the study description section of your approved application form (usually the end of data collection when all work with human participants will have been completed), not the completion of data analysis or publication of the results. For projects that only involve the further analysis of pre-existing data, approval must cover any period during which the researcher will be accessing or evaluating individual sensitive and/or un-anonymised records. Note that after the point at which ethical approval for your study is no longer required due to the study being complete (as per the above definitions), you will still need to ensure all research data/records management and storage procedures agreed to as part of your application are adhered to and carried out accordingly.

If you do not start the project within three months of this letter please contact the Research Ethics Office.

Should you wish to make a modification to the project or request an extension to approval you will need approval for this and should follow the guidance relating to modifying approved applications:

<http://www.kcl.ac.uk/innovation/research/support/ethics/applications/modifications.aspx>

The circumstances where modification requests are required include the addition/removal of participant groups, additions/removal/changes to research methods, asking for additional data from participants, extensions to the ethical approval period. Any proposed modifications should only be carried out once full approval for the modification request has been granted.

Any unforeseen ethical problems arising during the course of the project should be reported to the approving committee/panel. In the event of an untoward event or an adverse reaction a full report must be made to the Chair of the approving committee/review panel within one week of the incident.

Please would you also note that we may, for the purposes of audit, contact you from time to time to ascertain the status of your research.

If you have any query about any aspect of this ethical approval, please contact your panel/committee administrator in the first instance (<http://www.kcl.ac.uk/innovation/research/support/ethics/contact.aspx>). We wish you every success with this work.

With best wishes

Yours sincerely

Catherine Fieulleateau

Senior Research Ethics Officer

For and on behalf of

Professor Gareth Barker, Chairman

Psychiatry, Nursing and Midwifery Research Ethics Subcommittee (PNM RESC)

Cc: Professor Christine Norton

APPENDIX 6

Examples of field notes made during interviewing, and reflexive journal entries made during the study

Examples: Field Notes Stigma Interviews 28th May – 5th December 2012

UC = Ulcerative colitis, CD = Crohn's disease, CC = Crohn's Colitis

[...] = identifying text removed; non-italicised = pre-interview thoughts; italicised = post-interview reflections

Interview 1: Katrina [48, CD, *No FI, no stigma*]

Heading for my first interview and feeling a little nervous. I have [my partner] with me to share the driving, so finding our way is easy with me to map-read. We park in a parking area to the side of Katrina's address, in the shade since it is unseasonably hot for May, and for Scotland. This lady reports no FI and no stig, so I have to try and get to understand whether there has been or could be stigma associated with IBD when there is no incontinence, and how she avoids stigma. I make my usual advance warning phone call to see if she is still alright for the interview – and she is out – had forgotten I was coming. Seems she's only a short distance away and will be home very soon.

Well that was quick. I was in there all of 10 minutes but it doesn't mean the experience was wasted. Katrina lives on the top floor of a three-storey building, but although physical activity does increase bowel activity in some people with IBD, this doesn't present a problem to her. She is very positive and matter-of-fact about life, and her IBD. I asked where that approach came from, and she described her life growing up with one totally blind and one partially sighted parent – the attitude of working with what ability you have, and seeing that as normal, was instilled in her from an early age and she applies to every area of her life now. I was tempted to feel disappointed that the interview was over so quickly, but I have learnt that there is value in every interaction – it may not be obvious to start with, but it is there. In this case, perhaps the brevity of the interview is the point – it's just not an issue.

Interview 3: Maeve [65, UC, *No FI, no stigma*]

Maeve has asked me if we can meet at the hospital in [...] as she's going to be there anyway today. She has made the arrangements for a room and has emailed directions. As we drive up towards [...] we find ourselves on the coast road, and my heart and soul is lifted by

the sight of the sea. There is something about the sea, its big, huge openness that I just love. So I arrive in [...] feeling calm and relaxed. Maeve is another person who reports no FI and no stig, so it will be interesting to see how this one goes. Finding a parking space is challenging, but we manage – and I'm then surprised to find that I don't have to pay! But this is Scotland of course. At home – there would be a charge.

Maeve is a volunteer patient to the medical students, which is why she was due to be at the hospital today. She talked very openly about her remote and uncaring husband (now deceased) and her ability to minimise the impact of her IBD symptoms by being able to afford to employ help with more physical tasks. I recall thinking that she was unusually fortunate to be in this situation, and how that made such a difference to her ability to be in control of her illness. I am finding these non-stigmatised people difficult to interview – I can't very well ask them why they don't feel stigmatised – it's all too direct and makes it sound like I think they should be! Perhaps a way forward will emerge as I think about this over time.

Interview 4: Carol [64, CD, FI, no stigma]

It's quite a drive [...] but we have made good progress and have arrived safely. The streets are narrow in places, with minimal parking, and all the houses here have granite frontages with huge, broad stone lintels and frames to the doors and windows. It's nearly tea-time, so [partner and son] are going to go and find some supper whilst I do these interviews – I'll get something later. Carol reports FI and no stigma, so I'm interested to learn how she deals with her incontinence.

Just when you think you understand something, you have an experience which challenges that understanding. I had always assumed that it would be more difficult to be in a small community with a sensitive condition because there is nowhere to hide, whilst in a large community like a city, one can be relatively anonymous. Carol's experience turns that on its head. For her, there is more support and safety in a small community where her friends know of and understand her situation, and are thoughtful and supportive – than she experienced when she lived in a big town at the other end of the country. She has talked openly about being the middle child and feeling she didn't have a voice, and much of her

acceptance and ease with her illness seems to lie in the trust she has in her husband, and his support. It's an interesting dichotomy though – I had been getting the feeling that confidence and self-esteem and personality were related to the way that people manage the potential stigma linked to IBD. But Carol doesn't feel stigmatised, manages her illness and its consequences in very open and pragmatic ways and yet expresses a certain feeling of being left out of things, of being the forgotten, unheard child.

Interview 6: Carl [54, CD, FI, stigma]

We are back in [...] and heading home after this interview. My eagerness to get on my way back home must not prompt me to rush this interview. It has to be given the time it needs. Carl reports FI and stigma, so another chance for me to try and get to the nub of why stigma develops. It's still not easy – I am conscious all the time of whether I am leading, guiding too much – although I do appreciate now that a lot of what I do in the course of the interview is what Gadamer would call fusion of horizons. In reflecting issues back on the interviewee to clarify or confirm, we are co-constituting a shared understanding.

That was quite an emotional event. Carl has lost everything – his job, his wife, his sense of identity as a result of his IBD and his stigma may come from the very clear message from his ex-wife that his illness is the root cause of her departure. Unable to work or to maintain their previous lifestyle, he has become quite reclusive. It's very sad.

Interview 7: Cheryl [29, UC, No FI, no stigma]

I'm pleased Cheryl is taking part. She is in her late 20s and few people in this age group have signed up to the study. She reports no FI, no stig with her IBD, and I am not sure how to go about this interview.

Mmm, interesting. Cheryl was very professional, I think ... I feel like I just got a performance from her. I could not get past the façade she presented and her responses were very matter of fact, almost dismissive. She has a clear opinion that others who do struggle with their IBD are being weak and feeble-minded, and it was difficult for me to keep quiet, to stop myself from coming out in their defence. I suspect her IBD is well-controlled (as is she) and as yet, she has little experience of her illness at its worst. She was also quite newly-

married – less than a year, but there seemed to be a strange awkwardness between her and her husband, or perhaps that was because I was there. Who knows? But there will be something in her data of interest.

Interview 8: Vivienne [52, UC, No FI, no stigma]

Am heading north into [...] to meet with Vivienne. I feel very rested, having stayed in a wonderfully quiet and peaceful B&B last night. It's not far to Vivienne's house but I know these roads - they can be notoriously slow, so I'm giving myself plenty of time.

Vivienne sees communication and sharing illness info with close friends as critical in protecting against stigma as friends then understand when plans, for example, have to change. She believes her professional background as a nurse is influential in her acceptance and understanding of the illness. After recording stopped, she talked more about her parents. This is clearly a BIG issue for Valerie, and she realised that in terms of stigma, her life is in two parts – she doesn't feel at all stigmatised with her friends, her husband, or at work (tho concedes it might be different if she had a different type of job) – but gets a strong sense of disapproval regarding her illness from her parents, and doesn't speak to her sister. I'm really struggling to concentrate, but don't know why. It is much, much harder to interview for non-stigma without introducing the perception that people OUGHT to feel stigmatised by IBD ... and there do seem to be personality differences between stigmatised and non-stigmatised.

Interview 9: Deirdre [56, UC, FI, stigma]

I'm having to wait for Deirdre to get back from work and have arrived early so am waiting in a nearby street. Because I schedule time in for delays, when they don't happen, I spend a lot of time waiting – but that is better than being late and feeling rushed. Deirdre reports FI and stigma.

Interesting interview – clear contrast between certainty over how to manage bowels (happy to poo in any toilet however often) and concerns about others opinions. Great example of self / anticipated stigma. Talks about dirt, unclean, control and concealability.

I am still struggling to concentrate. I tried using Jones' dimensions as a framework for questions which of course means that it WILL be in the interview, but that might be okay?? Don't feel convinced and probably will not use that approach again. I could do analysis with McCormack but keeping open to themes etc, and then frame discussion around Jones?

Interview 10: William [72, UC, FI, no stigma]

William reports FI and no stigma, and I really need to try and get to grips with how to draw information out of the non-stigmatised without making assumptions. So far, this aspect is proving the most difficult to manage successfully.

Had a bit of difficulty finding William, but got there eventually. He was very forthcoming, and the first person who reports not feeling stigmatised who has been able to explain how they avoid the common feelings of guilt, shame and embarrassment that often go with feeling stigmatised. Not sure whether the success of this interview was down to him or to me doing a better job. I had just read an IBD paper re: control and normalising – which made what William said, make sense. My head hurts from concentrating so hard, driving and listening. I need to be very careful on the motorways.

Interview 11: Marion [35, UC, No FI, stigma]

Looking forward to meeting Marion – she's been signed up for this study right from the start so it will be good to finally meet her. Am somewhere in [...] – feeling out of place in this big city, not sure I feel all that safe, or that the car is safe from theft. Whilst I'm waiting for Marion, I see a lot of the locals come past – kids playing in the street, toddlers being yelled at, but also different generations of families living next to, or near to each other – and being always in and out of each other's houses. It's a different place to what I'm used to.

Great interview! We sat to start in the lounge, with her partner and son in the kitchen – Marion seemed happy with this but then decided we should move upstairs. We sat on her bed – and she was able to be very open and honest in describing how she feels about her condition. I get the feeling that stigma is almost always anticipated, but people are rarely

able to describe experiences of outright disapproval from others, and it seems to depend on their own feelings about privacy, dirt and bodily functions.

On leaving, I had a near-miss at the traffic lights when despite having a green filter to turn right, the oncoming traffic suddenly started moving towards me!

Interview 12: Lindsey [45, CD, FI, no stigma]

Lindsey describes herself as an expert patient who experiences FI but does not feel stigmatised. This could be interesting, though there is always the danger in talking to those who identify themselves as expert, that they perform at interview, rather than talking openly. We shall see ...

Excellent interview. Lindsey had a lot to say, all of it relevant – about how she NOW doesn't feel stigmatised by her condition despite FI. I see similarities between her and William – if life throws you lemons, make lemonade! – positive (not resigned) acceptance, working within the limitations of the illness and adapting it into life, rather than life into it. Communication and support from family, friends and health care professionals is critical – shared responsibility and awareness that support needs can fluctuate. The key word is control – for everyone – those that feel less stigmatised have a better perceived sense of control, even if they have bowel accidents – perhaps because they have a plan of what to do. Those that feel more stigmatised have a poorer perceived sense of control and greater concerns about others' perceptions of them – they frequently do not inform others about their IBD. The less stigmatised are more open.

Interview 19: Charles [78, CD, FI, no stigma]

We have had a traumatic journey to [...]. I have the family with me so we can combine the trip with a bit of a holiday, but the car broke down on the way and we have been delayed by several days, so that I have had to re-schedule the whole week of interviews. Luckily, everyone has been very flexible and understanding, and I need to put the events of the last few days at the back of my mind, and concentrate on what I came here to do. [Partner] and the kids are at the beach, and I am on my way to do this interview.

Charles was very interesting. A cycling enthusiast he has only recently given up, and showed me an amazing tricycle in his garage with the double wheels at the front. Charles reports FI and no stigma, and again, I'm not sure I got to the bottom of why that is. Even though I think I see a pattern, I am trying hard not to assume that in subsequent interviews, but I still don't feel like I've got the hang of getting people to open up about not feeling stigmatised without me leading them.

Interview 20: Lillian [61, CD, FI, stigma]

Lillian has been keen to meet me for a while. She describes herself as an expert patient, has written several articles and books about being an ostomate, and is a retired journalist. She sent me a copy of her book (co-authored by husband). I haven't read it all but enough to feel it rather self-indulgent and not all that well written. However, I will approach this interview with an open-mind, and see what I get.

What I got was rather odd! They were both very welcoming, but it was all a bit strange. I had trouble finding the house (which is seriously remote) but when I did, I was lead through a labyrinth of rooms to the far end of the house, where Lillian was ensconced in her bed. It was clear, by the table beside her with laptop, papers and other paraphernalia, that this was the norm. On one hand, I was surprised that she had not made the effort to get up, whilst on the other I was flattered that she didn't feel she had to do that for me. I later learnt that she has also had a stroke so mobility is tricky for her.

There was nowhere for me to sit and I was invited to sit on the bed, but this meant I would have to twist my head to see her. [Husband] resolved the problem by bringing his mother's wheelchair through for me to sit in. So there I was, sitting in a wheelchair, in the bedroom of a woman I had never met before, trying to do an interview. It was very hard to keep her on track, but when I could, her interview was a performance. I felt I didn't get to her, and her personal feelings about stigma – what I got was her take on how it is for 'people with IBD, or with a stoma.'

Interview 24: Belinda [55, CD, *No FI, no stigma*]

I have had no confirmation from Belinda, do not have a phone number for her and do not know if she is expecting me. I have decided I will head for her address anyway, and in the meantime, will ask [my contact] at C&CUK to try and get in contact with her, and then let me know if I can call.

I got the okay from [my contact] so carried out my interview with Belinda. A lovely, vibrant, Jamaican woman with a deep-seated faith which is at the centre of her attitude towards her IBD, along with a rich and challenging life history that places IBD, and the difficulties it causes, way down on her list of challenging things she has dealt with. For her, there has been so much worse, that this is nothing.

Interview 26: Andrea [47, CD, *FI, stigma*]

I'm unsure about how this interview will go. I have had one or two emails from Andrea and things feel a bit tense but she is keen to take part. We shall see ...

Mmm – intriguing. Andrea struggles with FI and stigma, and has not told her long-term partner about her continence problem. He was banned from the house throughout my time there. Hiding FI adds to her stress, but she feels revealing it will create more concern for others who worry about her and she wants to protect them from that. She does not talk to anyone, except health professionals about her IBD, and does not have the support, sense of control, or adaptation towards her condition that I am beginning to see in those who avoid stigma and manage well. Surprisingly, she talked very openly – something she admitted to never having done before and she seems to have appreciated the chance to do so. I did have to work very hard to contain my surprise that she has not shared news of her bowel control issues with her partner – it seems to me such an odd decision to make, but I must not place my own opinions into the interview arena, and happily, I avoided doing so on this occasion.

Interview 28: Tamsin [38, CD, *No FI, stigma*]

Tamsin and I have had quite an email conversation because she has been hospitalised and may only just make it home in time for the interview. I have given her every opportunity to

withdraw, but she insists on contributing. We had originally intended to meet at her place of work, but since she is off sick at the moment, she has invited me to her home address.

Tamsin reports no FI, but stigma related to her bowel disease, and those same issues of sense of control, support and acceptance of the illness raised their heads at interview again. I've been taking a slightly different tack too – and am simply asking people to tell me about how their IBD makes them feel. If there is any stigma in there, it will show itself naturally in the course of conversation. I'm hoping this approach will work for any participant, stigmatised or not.

Interview 30: Aileen [58, CD, FI, no stigma]

A lovely drive down through [...] to meet with Aileen. As I was a little early, I've been to the chip shop and bought some lunch, and am sitting in the car park overlooking the sea. I have a wonderful view of the Needles, off the Isle of Wight, from here. Never been to this stretch of coast, so it's a lovely treat – and the sea always lifts my spirits.

Aileen was amazing. Having survived 2 bouts of breast cancer, had a double mastectomy and all that goes with cancer treatment, her IBD causes her no concerns because in comparison, to her it is nothing. Those same three things emerged – support, control, acceptance. That's what seems to make the difference. My open starting question appears to work well – Anne feels no stigma and perhaps for the first time, I feel that the reasons for why that is the case have emerged naturally from her story, rather than being looked for by me. Progress, at last!

Interview 31: Vera [68, CD, FI, stigma]

Feeling a bit on home territory now. I did my children's nursing course in this part of the UK and it's still familiar to me. My final interview in this batch. Vera reports FI and stigma, and it will be interesting to see how my new opening prompt works here.

That was amazing: 'How does your IBD make you feel? I asked, and she responded, 'Trapped!' and then went on to describe the very many ways in which she feels trapped. This

was a wonderful interview with a strong sense of chronology, the story was told in a logical sequential manner and the links between early experiences and now are clear. It's going to be a lovely interview to analyse and at long last, I've found the way in to these peoples' stories.

Interview 33: Reggie [61, UC, FI, stigma]

Ronald reports FI and stigma. Finding him has been easy although the driving conditions are less easy – bright, low sunshine, wet, shiny roads and a lot of spray in the air. Care is needed.

I think that was one of the most difficult interviews I have ever done. I felt somehow uncomfortable, although Ron was pleasant enough. I don't know why, and I don't have a clear sense of his feelings about his IBD. I will have to wait until I have the transcript to see what's in there.

Interview 35: Janice [61, CD, FI, no stigma]

I've got plenty of time to kill between leaving the hotel and reaching Janice's house, so I've stopped in a lay-by and have the kettle on, and am making my pack-up for later, when I will have much less time between appointments and will need something to be ready. It's stopped raining, but is very cold, so I'm dressed for comfort and warmth rather than presentation. Hope that people understand.

Wow! Just when you think it's all getting a bit similar, something happens that makes you realise you've got a gem. Janice started by telling me that she never usually takes part in this sort of thing – and as we progress, I learn of her lack of confidence, her difficult past life, her low self-esteem – but she is surprising herself by talking to me very openly. There is a chronological story here, and a powerful one. She got upset at one point, but I steered her gently through it and stayed until I was sure she was okay. I hope she found it helpful.

Interview 36: Lily [30, CD, FI, no stigma]

This is useful, because Lily lives only a few miles from Janice – but at the same time not useful because after the emotional effort of the Janice’s interview, I could do with a bit more recovery time. Just have to make the best of it.

Lily reports FI and no stigma – and is so positive, feels in control and has the huge support of a wide network of family and friends. She also describes the conscious decision to ‘get on with it’ and how that links to her upbringing. She believes that successful power and control over the disease comes from having a plan in place, so that if an FI event does happen, there’s no panic about what to do - she knows what to do because she’s worked it all out beforehand.

Interview 38: Charlotte [37, CD, FI, stigma]

We’ve had quite a struggle to fit Charlotte in, as we have had to try and work in between part time school hours for her young children, but we are finally agreed on this date and time. It’s a long drive to here, and then a long drive home, but I just need to go with the flow and let things happen as they do.

Great interview; Claire is significantly hampered by her IBD and her toilet needs are such that she can no longer work. She describes concerns over what others think of her because of her inability to work, as well as because of her IBD. She had to leave to use the bathroom mid-interview, but we just carried on from where we left off, when she returned. Her biggest struggle is in trying to not let her IBD get in the way of her role as parent.

Interview 39: Juliet [52,CD, FI, no stigma]

I am on a long trip to [...] from London to interview Juliet, as we had to re-schedule her appointment. There’s snow and ice in the Home Counties, and [partner] is concerned for my safety. I’ve promised to stop overnight somewhere if the weather deteriorates on my way home.

Another wonderful interview. Juliet is intelligent, articulate, and brave enough to speak very openly about her IBD and how she manages. Again, she has support, a sense of control, and has adjusted her life to incorporate the limitations her disease presents. She says that she doesn't mind other people knowing about her IBD and FI, as long as it is not made mention of in her company. Quiet acceptance and support is what she prefers. Strangely, the journey home is quicker and safer, with better weather, than my journey up this morning.

Examples: Reflexive journal excerpts between February and October 2013.

I've chosen this portion of the reflexive journal because it covers what was a very challenging time for me. These few extracts show a path from confusion and disarray to resolve and at least a degree of certainty – this period was a real turning point for me.

28.2.13: In this excerpt, I'm reeling from a tough supervision and struggling to find the right data analysis method. Trouble is, however harsh it might have been, I know my supervisors are probably right. Already in email contact with Coralie McCormack, author of the interpretive lenses (my intended analysis method), I seek her advice:

I've been in a difficult place. At the last joint supervision, I felt like the essence of me had been shredded – both C & E [supervisors] dislike the extent of my presence in the thesis. I resolved to take myself out of it, but that left me feeling disconnected from the work, and that I was hiding myself. With no connection between me and the study, much of the rationale for the study design was gone. I've agonised about this, looking for alternatives without luck. The lit review didn't help – inconsistent and poorly described examples of data analysis. Eventually, I emailed Coralie with a long list of questions – how to manage the emotional distress? Whether to build a preliminary story? What to do about my heart being on my sleeve and therefore so very exposed? Her response was brilliant, and strengthened my resolve: 'Even in uncomfortableness there is something to learn'; 'Find a comfortable place on your sleeve for your heart to be, and keep it there;' 'Look after yourself with a thinking book.' This then, is now my thinking book.

1.3.13: By the time I made this entry, I had found a way forward:

Have emailed my supervisors. I am going to be in this thesis, but in a scholarly, academic way. I will write, where appropriate, in the first person, I will be reflexive, I will be there.

1.3.13: *Another perplexing question – Are shame and embarrassment the same thing? I asked my children last night if they could explain the difference between shame and embarrassment, and Ed (12) said: ‘Embarrassment happens in front of other people, but shame happens inside you on your own.’ Stunning – and I think he’s right.*

5.3.13: *I spent yesterday doing some data analysis, and am struck by two things – the variation in the type of data I have got, and the lack of chronological ‘story’ in many of the transcripts, especially where the storyline is weak. I fear it will be more difficult to evidence the production of themes without a clearer analysis structure to guide it. So – I think I need a framework for theme generation, and to use McCormack on those stories for which it will be effective. Currently checking out Diekelmann.*

21.3.13: *Feeling that I at last had a sense of direction. Every iteration in my writing brings new thoughts and ideas, and each version ‘feels’ better than the previous. Feel able to defend my presence in the study more effectively, and am returned to a firmer emotional state – long may it last!*

25.3.13: I had been reviewing the use of major stigma theorists within other research papers, either to define stigma, to guide analysis or to support stigma:

I think Goffman is more likely when asking ‘What is the experience of stigma ...? - rather than ‘what type of stigma, how influenced, how caused?’, especially when this is a first look

at stigma in IBD – Goffman leaves it open. I don't agree it is restrictive, I see it as simple and not so prescriptive that it blinds you to other aspects.

28.3.13: Still trying to decide on a replacement data analysis method, I ask myself the question:

Why not use Goffman or Jones as a framework for analysis? Because then I will definitely find what I think is there because that's exactly what I would be looking for. The danger is that I'll see what I think is there – what 'fits' the framework. What about the outliers? The things that don't fit? I need to look at all analysis methods used in hermeneutic phenomenology studies on stigma in health and ask 'Why Diekelmann, why not another approach?'

13.5.13: During the previous week, I had 'pitched' my rationale for adopting Diekelmann et al's (1989) hermeneutic analysis method to address my data to both my supervisors at separate supervision meetings:

Yes!! Result! Have presented a sound argument for using Diekelmann (increased structure, enhanced rigour, methodical process and increased credibility). Potential sticking point was the need for 'team analysis' – tricky business, asking two very busy professors to commit time to their student's data analysis, but they said yes. We have agreed the proportion of the data they will each review, and how to make the best of their time – I'm thrilled, without their support at this point I would not have been able to use this analysis method. Having spent some time researching it and finding it the best possible fit, it would have been a blow. I'm smiling!

17.10.13: The impact of these few months is summed up in this single entry from October 2013. I am 'in' the data analysis and considering the potential for bias:

I am acutely aware that I came to data analysis with the belief that three core themes ran through the interviews, and that there was a danger of presuming the existence of these, of making the data 'fit'. Diekelmann is proving a real help -the early stage of writing summaries (all of us) has shown that my take on things is realistic; even so, every time I find something in the data, I am making a conscious effort to ensure that it really is there, it's not me wanting it to be there for the sake of the analysis. Each time I have identified an issue, I have thought carefully about whether it really is an issue, or whether it is my interpretation, my background, making it into one.

Am about to return to three transcripts looking for evidence of issues of 'control;' locating them would mean the confirmation of a constitutive pattern – a key outcome of the analysis process – so I have to be really careful that I do not manipulate or over-interpret the text.

APPENDIX 7

Description of relational themes and constitutive patterns, with examples

RELATIONAL THEMES	Interpretation of theme in text	Related verbatim extracts from text
<p>Risk and Readiness Dealing, or not, with unpredictability; having or not having a plan; being ready, knowing what to do if an accident occurs – or not coping.</p>	<p>19. Being anywhere with good facilities is as good as being at home – means he can attend to his needs;</p> <p>26. Bowel leakages happen without warning, even when in a ‘good’ period; it can happen out of the blue</p>	<p>19. It doesn’t bother me now – I’ve got beyond that before (gastroenterologist) gave me the Questran®, which literally did transform my life, I couldn’t go anywhere without being concerned and worried, you know. I used to get up and I’d drive two or three hundred miles always knowing where I could stop and if I got to a garage where I was doing a service of a machine or something, okay, I’m okay there. It’s as good as being at home.</p> <p>26. ‘It happens out of the blue like it happened with me recently, for no apparent reason. It’s the unpredictable nature of it. If I knew that something I’d eaten was likely to cause me a problem, if I knew that whatever set of circumstances, then, you know, I would – panty liners, spare underwear carried with me, all of that. No matter how awful it might be, at least I’d be prepared. But the fact that it can happen when I’m not even going through a period of diarrhoea, when everything is as settled as ever, takes you by surprise ...’</p>
<p>Responsibility and Blame Perceptions of the public’s understanding of IBD, and of who or what they, and participants, hold responsible for illness and symptoms</p>	<p>12. Poor public knowledge of IBD; perception that surgery cures it; failure to appreciate chronic nature of IBD;</p> <p>15. She blames the contraceptive pill for causing her disease</p>	<p>12. ‘A lot of people’s perception is, when you have surgery for inflammatory bowel, more obviously Crohn’s disease, well you’re cured now. Well you’re not, you see, because you can still have problems – further surgery and things like that; I work part time, and then I do get a lot of problems at work because they all go, ‘Well, why do you work part time because you look really well?’</p> <p>15. I was so ill – my biggest concern was just being able to live again, because it really did take over my life. And then we discovered that it was the contraceptive pill that was setting it off, but it took five years to work it out.’</p>
<p>Social expectations and Norms Perceptions of acceptable social rules regarding bowels and bowel control; bowels as taboo</p>	<p>13. Bowel diseases are taboo and no-one wants to talk about them; cultural and social requirements are that bowel issues are kept private;</p> <p>21. Understands the cultural roots of stigma – messy, smelly bowels;</p>	<p>13. There’s obviously a stigma attached with Crohn’s because most people know that it’s a bowel disease and that’s about as far as it goes, and therefore nobody wants to talk about it; nobody likes to talk about bowel things. It’s one of those things that’s just not mentioned. Social rules dictate that you shouldn’t talk about urine incontinence, or bowel incontinence, or, you know, bowel problems, It’s something that is down to social rules.</p> <p>21. I can see why people would think that bowel –related problems ... I suppose there’s a stigma attached to the fact it’s a bowel problem, they’re going to be smelly or incontinent or something like that.’</p>
<p>Relational themes: descriptions, interpretations and illustrative verbatim excerpts 12, 13, 15, 19, 21 and 26 = participant / interview number</p>		

RELATIONAL THEMES	Interpretation of theme in text	Related verbatim extracts from text
<p>Impression Management Actions, symptoms or behaviours which can discredit, along with those employed to avoid discredit; covering tactics.</p> <p>Upbringing The influence of childhood on participants attitudes to their IBD as adults; ranges from openness and communication to silence about bodily functions</p>	<p>2. Not concealable: others will see; frequent toilet trips at work interpreted as shirking;</p> <p>11. Has pretended she needs to pass urine a lot to cover / hide the truth of her condition from potential partners;</p> <p>1. Socialised not to stigmatise; no stigma in house about anything; parents both blind – disability doesn't mean you can't do things;</p> <p>31. Childhood 'Victorian' – strict upbringing, bodily functions taboo, no openness;</p>	<p>2. 'It's quite an embarrassing thing if you're somewhere and you've got a wet patch at the back of your trousers – you can't sit down in a restaurant or cafe or somewhere because it leaves a mark;' 'And - I mean in places of work, somebody keep rushing to the loo all the time - it's perceived that you're actually, it's just a lazy thing, going to the loo, sitting down, or nipping out for a cigarette or something.'</p> <p>11. 'I've managed to hide it for, I'd say about three months into each relationship. And then obviously it's probably got to a point when I'm going to the toilet that much, but I always say it's a weak bladder. I say, 'God, I've been drinking loads of tea, I need to go to the toilet.'</p> <p>1. My mother was partially sighted and my father was totally blind. So we were brought up, disability doesn't mean that you have to, you can't do anything. So I've grown up with that attitude. So, if you've got something, deal with it, get on with it, get on with your life, don't let the illness dictate what you can and can't do.'</p> <p>31. 'I was brought up quite strictly, um, and I've never lost that. I'm an only child, I believe quite wanted by my mother, but not my father who was a very strict Victorian-type man. Um, and you just didn't talk openly about toilets or bathrooms or girls having periods or sex or anything. I didn't have that openness. I want openness with (my daughters). They will be open with me. But I don't say that I'm particularly, in every detail, open about myself.'</p>
<p>Relational themes: descriptions, interpretations and illustrative verbatim excerpts 1,2,4,11,14,and 31 = participant / interview number</p>		

RELATIONAL THEMES	Interpretation of theme in text	Related verbatim extracts from text
<p>Revealing IBD Whether, when, how and who to talk to about IBD; reasons for doing so, or not doing so</p>	<p>4. Tells other people about her CD when there is a need to; doesn't force conversation, but happy to explain if asked.</p> <p>14. Careful to inform people that his condition is not contagious; covers when asked if he's okay – feels others don't really want to know</p>	<p>4. I think initially it was just my family that knew. And then if it was necessary to tell friends, then I would. Up here (newly moved) we've not got a huge circle of friends but most of the villagers know us. And what happens when I tell people that I've got Crohn's is if there is a reason for me to tell them. When I've told people, it's because I've had to explain why I've not been going to do something, or if I'm going to the hospital. I don't go out and say 'I've got Crohn's, but if they say 'Well, what kind of things happen?' they're quite happy for you to discuss it with them.'</p> <p>14. 'I'm very conscious that now I've started to disseminate (information about) the condition, um, I'm very careful that I tell them it's a non-contagious one; when people ask you if you're okay, you know, out of concern, you can hardly – you don't go blurting out, 'Well, I've got an underlying condition which cases me to have severe problems,' so (my) initial reaction is, 'Yes, I'm fine,' because they don't want to hear about it.'</p>
<p>State and flux of stigma The range of stigma experiences, the fluctuating nature of these and the ability to resist or ignore others' attitudes</p>	<p>18. Expects others to think of her as a nuisance if she cannot wait for the loo;</p> <p>20. More stigmatised earlier in illness career, and in certain situations (hospitals);</p>	<p>18. 'People don't understand. They think you're being a pain and they think, 'Why can't you stand there and why can't you wait?' And you can't.'</p> <p>20. Initially, pre-op, pre-diagnosis, I felt very, very great stigma from the medical profession. I felt that it was in my head because I had difficulty in getting some members of the medical profession to listen properly to my symptoms, and apply them to a diagnosis. And I felt that even when we paid for private consultants, in some cases they were talking to my husband and not to me, and I was the patient.'</p>
<p>Resilience Aspects of the individual which promote or inhibit resilience against stigma</p>	<p>30. Having breast cancer has changed her attitude towards Crohn's – it could be worse and it's not, so it's okay;</p> <p>34. Keeps himself to himself to cover the problem; isolated and introverted;</p>	<p>30. I just think, I just found some inner strength and sort of something that told me that um, you know, life's for living and there's no point sitting around feeling upset about whatever it is, whether it's the cancer or the Crohn's, you've got to get on with it. And, and so what's the point? You're only going to make yourself feel miserable and other people feel miserable if you feel bad about it. And so that's what I did really, And so, to me, okay it's unfortunate but hey it could be worse, I could be dead with the cancer.'</p> <p>34. I prefer not to see people if it's something related with me stomach or Crohn's disease. Even going to hospital like for outpatient appointments or going for the colonoscopy, I dread asking someone to be there to pick us up when I'm slightly drowsy. And I don't like that. I'd rather just come round in me own time and then just get the bus back home.</p>
<p>Relational themes: descriptions, interpretations and illustrative verbatim excerpts 18, 20, 30, 34 = participant / interview number</p>		

CONSTITUTIVE PATTERNS	Interpretation of pattern in text	Related verbatim extracts from text
<p>Control All aspects of control or lack of it; includes physical control, and emotional / psychological control of self and of illness; includes descriptions of feeling out of control – of bowels, of illness, of life.</p> <p>Relationships and social support All representations of any type of personal or professional relationship and social support – or the lack of.</p>	<p>11. Due for stoma-forming surgery – views this positively – will restore control and privacy; stoma is predictable and controllable, FI unpredictable, no no control; loss of control = loss of life;</p> <p>17. Important to be able to leave any setting to go to loo, without having to seek permission; work with disease – manage and control it, don't let it control you;</p> <p>6. OK with those who understand – professionals, daughter, relationship with partner disrupted; wife not supportive – left when he was unable to support her financially;</p> <p>10. Help comes when people know; openness is helpful; older friends all have health problems – he's not unusual in being unwell.</p>	<p>11. 'I've just been referred for surgery so I'm going to be having a colostomy bag anyway, which actually, strangely, doesn't bother me as much as going to the toilet. I would rather have – for a number of reasons – for being ill mainly, but also for this ridiculousness of having to go to the toilet ten to fifteen times a day with diarrhoea every single day; I have my life back when I get this surgery done – it's more private to me again and it's control, and it's you know, it's emptying it into a toilet rather than running to find a toilet before I actually burst ...'</p> <p>17. 'I've had a couple of employers (who've said) 'You can't just get up, just get up and leave my meeting, and I've said 'Well alright then, but are you going to clear up after me if I have an accident?' 'I don't let it stop me, because I think if you let it stop you, you are becoming a victim again. You're letting it beat you and you are letting it take over and that's not what you – you need to be. You have got to be the other way round, you've got to work with it, and manage it and control it and not have it manage and control you.'</p> <p>6. 'It's different with a professional person, a nurse – every time I go to hospital, I'm not embarrassed to show them it, because I know they know about it, but in general, people don't even know what a stoma bag is; I've got sort of like a girlfriend, I've known her for maybe six months, but we haven't got a sexual relationship ... not that the two of us are not wanting it ... but she knows I've got all this and she doesn't want to see it; (my daughter) knows I'm ill and she's been a really good support to me'; 'It (IBD) stopped me working, and I had a house with a mortgage on it – (I) got into a financial mess - that's when my wife realised that it's time to go and have a life.'</p> <p>10. 'All my friends over the years, I've made aware of the situation. And anyone, if I go anywhere who I think should know or who would perhaps be able to assist me should I have that (urgent) need (for the toilet), I tell them – so that everyone's in the know, as it were;' 'I'm just quite open with it. If I've got a problem (with my bowels) I'll tell someone and if it's causing them a problem I will let them know what my problem is because in a way, it stops them ... it stops the embarrassed;' 'When we go out (with friends don't get your tablets mixed up for God's sake, everyone's got their own pot of tablets ... and I suppose that's friendship in that.'</p>
<p>Constitutive patterns: descriptions, interpretations and illustrative verbatim excerpts FI = faecal incontinence; 6, 10, 11, and 17 = participant / interview number</p>		

CONSTITUTIVE PATTERNS	Interpretation of pattern in text	Related verbatim extracts from text
<p>Mastery and mediation The role that experience and acceptance (or the lack of it) plays in perceptions of stigma.</p>	<p>18. Illness not accepted – doesn't want to live life like this;</p> <p>24. Accepts illnesses and what is needed to manage them; life experience puts thing in perspective for her – feels she can now cope with anything;</p>	<p>18. I think for me, because I don't have it (incontinence) all the time, because I lead my life to avoid it happening, um, when it happens, I just feel it's the end of the world. I can't explain how I feel really, I just feel so horrible, dirty, you know, that I don't want to live my life in this condition, real depressed, almost suicidal after and accident like that.'</p> <p>24. 'My whole outlook on life changed after the stroke ... (and) the asthma, the high blood pressure, high cholesterol, diabetes, all started after they said about the Crohn's, and when you go to the doctor and every day there's something else, it is a thing where you could sit there ... and really start feeling sorry for yourself. And I just thought, 'Ok God, well alright, bring it on,' you know. 'What do you want me to do?'</p>
<p>Constitutive patterns: descriptions, interpretations and illustrative verbatim excerpts 18, and 24 = participant / interview number</p>		

APPENDIX 8

Andrea's interview transcript

Andrea was 47 at the time of interview. She has Crohn's disease and had assigned herself to the *FI, stigma* subgroup. Andrea presented an interesting mix of pragmatic, intelligent, thoughtfulness – and deep humiliation and concern about her incontinence. There is a distinct difference between her doctor- patient relationship with her Consultant, and all other social relationships, including those with her partner and her close family. She hides the extent of her difficulties from her partner and family out of shame and a desire to protect them from the truth. Andrea has not discussed the incontinence with her Consultant, not because she is bothered about how he might react, but because she thinks there is no possibility of a solution. Andrea's interview emphasised the importance of cultural expectations about bowel control.

'CN' at the head of this transcript indicates that it was also coded by Professor Norton.

26 - Stigma

CN

Symptoms (could IBS)
21.8.13
Zond

Okay, so I'm here with 48?

7.

47, Crohn's Disease?

Yes.

And we were previously talking and you said you've had this really since you were 21 with a mess up of, 'Is it this, or is it something else?' and different diagnoses. But a confirmed diagnosis in 2003.

In 2003 they re-diagnosed. They undiagnosed me around 1991. And re-diagnosed in 2003.

Okay.

So 12 years more or less being led to believe it was IBS only. But like most people with Crohn's, I have IBS as well.

Yes. which... the (00.40) the picture doesn't it?

And that feels different. There's a place in my gut where my IBS lives and I can feel it when it's playing up. But that's not the same as the Crohn's and it's distinctively different.

Right, right. Okay and you also told us when you said you'd take part in this study, that you have some problems with bowel control and that's not necessarily related to being in relapse.

No, it doesn't appear to be. It's partly because I don't think I've ever actually been in remission as such.

Oh right.

That may be because my Crohn's is quite mild to moderate. So although I do have symptoms that I know the Crohn's is flaring, or what I think of as flaring, but I've never had a period of time that I am aware of where I feel like my Crohn's doesn't exist, that it's gone quiet and gone to sleep. I've always had it.

This is really interesting because what you're saying is, a relatively mild version of Crohn's, but despite that, a constant level of activity of your Crohn's Disease. And, you know, I wonder whether there is an expectation clinically that those two things don't go together.

It feels like an anomaly and, like I said to you before, I do seem to atypical in lots of ways. I don't react to drugs the way I'm supposed to. My Crohn's is not typical because I have this – and I've never actually had them confirm it's mild to moderate, but they've never told me any different. And I've said that to my consultant and he's never contradicted it. So I have what appears to be mild to moderate Crohn's but massively, to me, severe Crohn's arthropathy, whichever term you want to use – Crohn's associated spondyloarthropathy is the long version – and that is permanent and severe.

Yes.

Battered by Arthro

And absolutely chronic. Now whether that, because the two are so interrelated, that keeps the Crohn's from ever going into remission because it's tied in so closely with the arthropathy, I wouldn't have the arthropathy without the Crohn's.

No that's right.

So whether that's what keeps it going and, as you said, about connections, that's just made me think that maybe that is why, but it is a seeming contradiction to have mild to moderate Crohn's but never having had remission. It's always been there and it's always there at some point.

And so we were talking, before we started recording, we were talking about the sort of living with the unpredictable nature of the Crohn's Disease and you've described to me a recent incident that you had when visiting in hospital, an unexpected episode of incontinence. Can you tell me how that makes you feel?

*Unpredictable
episode
↓
Becky
bound
out,
discretion*

I was horrified, mortified. I'm not somebody who cries. I had, my mum's bipolar, and as a child I was always told never to show her up by crying in public. So over many years you learn not to cry. But I was bordering on tears, which is very rare for me. And I was utterly mortified because we were approaching the entrance to the hospital to visit my father-in-law, I passed wind and suddenly I was aware, not that I'd leaked a bit, but I'd leaked a lot. I was suddenly very wet. And I was horrified that other people would notice - my partner would notice, which is quite likely he'd notice the smell, but I don't know. And he certainly noticed my suddenly furtive behaviour. And, you know, the fact that it might show, that it might leak through to my trousers. I was utterly, I don't know that I have the words, I was horrified. It was horror that everybody was going to know.

And how big a thing is that issue of other people knowing?

*Less of
a person
discretion*

It's huge, it absolutely enormous. I can't stand the idea that other people would know. So, you know, I have to, it's something for me that's private. So it's something that I've never told anybody ever. I haven't - I talked to my, I'm very close to my sister and I've never told her and I don't think I ever would. Not friends and family. I've talked to the consultant about it and obviously I'm talking to you about it, but I wouldn't ever tell anybody I know. To me it makes me feel like they would view me differently, they would in some way think less of me or be concerned that they might be with me when it happens and they wouldn't know what to do or how to react. And that, you know, if you soil yourself, it's bound to smell and it's going to be embarrassing for everybody. So hence that need to keep it close and not tell anyone.

Caring

Do you think that there would be any - notwithstanding what you've just said, could there be any benefit to telling people very close to you?

*Protective
ness*

I suppose if I was able to get past my feelings about it - I think the other reason for not telling people is I know people like my sister particularly, they worry about me a lot. We worry about each other, she has her own health issues. And I think it would add to her worry. And she would feel very sorry for me, which I find difficult.

So part of not telling is about protecting you and part of it is about protecting them.

No close personal support network

Protection
 Yes the vast majority of it, 70-80% of it is about protecting me, but there is an issue of protecting them. There are things that I don't tell my family and my partner because I don't want them to worry more than I know they already do. They really do, you know, they've all, I mean he knew me - we'd been together barely a year when I was first diagnosed. So he's been through a lot of it. And people not knowing what to do and what to say or - it's mostly about protecting myself, but yes there is an element of stopping other people. I don't want to add to their - they already have this package of worry about me that they carry. I don't want to make it any heavier. But it is mostly about my own mortification really (chuckles). (Someone is shuffling around the room and there is a slight pause in the conversation). He is a good lad, he warned me before he came through the door (laughs).

You said that you don't want to change the way people think about you, and your belief is that they would think less of you.

Yes.

Why do you think that is?

Loss of control

Expectation? self-stig. active?

Well there's such an embarrassment factor involved in the fact that you are soiling yourself without being able to control it. And I know that my closest, my nearest and dearest would understand that it's something beyond my control because they know me well enough to know that if I could control it, I absolutely would. I wouldn't, you know - people who don't know you so well - they would, 'Why aren't you doing something about it? Surely you can do something about this? Surely it is manageable. There must be a way.' So to me it's, maybe it's because it horrifies me so much that I project - to me it seems natural that it would horrify other people and therefore they feel, they think a bit less of you. Or if not thinking less, it changes what they think about you, and to me that change can only be worse.

Expectation to be in control

Anticipating stig?

Right.

But it is a very emotional response. It is emotion. You know, there's the practical side of what, you know, when it happens, but the bigger side is emotion. Absolutely.

Practical + emotional implications of inc. o.

Yes because when you were talking about, previously about the episode in the hospital and one of the things that you said was, you know, your concern that surely somebody might, must know because this must smell.

Self-anticipated

Yes, yes I'd soiled myself big time. I could smell it, even before I'd got as far as the Ladies. So, and okay, there wasn't anybody standing that close and every time my partner moved closer, I stepped back from him. But it has, you know, I can't see a way that if I'd got closer to people, people wouldn't have noticed. You know, and you know how people react. I know how I react. If you are near somebody in a supermarket and you can tell that they haven't washed, it's not pleasant, it's not nice. And we don't deal with that sort of stuff well in this society. I'm sure in lots of societies, but we don't.

No.

Basically expectant on society responses / responses

We look down on people who are not taking care of their hygiene. You know, we always assume that there's something wrong with them or they're uneducated or whatever it is. It's not something to be kind of neutral about, is it?

So in comparison to having another illness, I don't know, diabetes, breast cancer – is it different?

What, the stigma or the way I feel about it?

Well do you think there's any difference in people's perceptions or understanding of...

Yes, I think understanding of because people don't talk about bowels. We don't talk about poo and people's habits, people's experiences, it's not, you know, we are still, no matter how hard we try not to be, still a terribly stiff upper lip Britain, aren't we really. Um, but it's very personal. And you'd think breast cancer would be very personal. But there's been so much known and said and campaigned about, it's become a more public thing. We haven't got there yet with IBD because it has the word 'bowel' in it for a start. Um, and we're not even at it to the point – you get adverts about sanitary wear, 'Have a happy period.' We don't talk about having a happy time when you haven't been incontinent, you know. We don't even talk about bowels in advertising. There are a few adverts to do with constipation. And they're all terribly nice and clean and – so as a society we don't talk about it, we don't go there. So breast cancer is, people talk about, most people know at least one person that's had it. Diabetes is different again. It's chronic, it continues, and if you're a Type 1, there's more known about it, I think, even though it's still not that well known, but people have a bit of an understanding. Bowels, to me, always seems as though people would still think, 'Why can't you control yourself?' *Society expects*

Oh right and I'm just wondering whether that is the key word – because with the, with the breast cancer and with diabetes, is there less fault? I'm just thinking about this.

I know what you're getting at.

I'm just thinking about this because, of course, now we're becoming aware that particular lifestyles in terms of the things that you eat and activity and that kind of stuff, increases the likelihood of...

Diabetes.

So that might not be such a good example. But, you know, something like breast cancer, you don't do something to make yourself get breast cancer.

No you're just one of the unlucky few aren't you?

Yes. But what you've talked about is this issue of control and people expecting you to be able to control, so therefore it's your fault if you can't?

I think if they understood the nature of IBD, they wouldn't say it was your fault. But as an adult - there are two times in your life when you are likely to be incontinent – when you are very young or when you are very old. And as we – there is a general societal understanding that those happen and that's age and nature when you're very old. The fact that you are old and you may be doubly incontinent, just because those people are adults, we somehow excuse that, it's not unexpected.

Yes.

*Talks
subject*

*IBD is
sanitised*

*IBD =
body or
genetic*

Body is unrelaxable

That as people age, their bodies let them down and it may happen. I'm 47, I'm not expected to soil myself periodically at my age. It's something people wouldn't expect. And I think would be horrified by. Would certainly not know how to react, wouldn't know what to say. And I think they would be mentally backing away even if not physically, to be honest. But I think it is an expectation. And I'm sure if you sat and talked to somebody and explained the nature of the disease and so on, but that's not the way you interact with the majority of people, is it? You don't sit down and tell them all this. And you wouldn't want to. So there is a case of too much information!

Expecting public to know it repulsive.

Rejecting person with pub.

Yes.

Her expectation of reg approval

But that instant reaction would be horror and surely you can control - 'I don't soil myself, so why do you?' That's how it feels to me. That's how I can picture people's reactions. How accurate that is, who knows? But that's how it feels.

Yes, and so is this expectation that people are going to view this information negatively?

Yes in the main unless they were somebody I was comfortable enough to sit and talk the wider issue of IBD through with them.

But how does it then impact on you asking for help? Have you asked for help about incontinence?

I talked to my consultant and said that I am. But it wasn't the main topic of that particular appointment, therefore we didn't really get into it very deeply. So no I haven't asked for help. There is, as far as I know, I've never had contact with an IBD nurse, I don't know if there are any at Hospital. And they may be the person that would, would, because that's more practical, you know, everyday life. I found with rheumatology that the nurses are the ones that deal with the practical, everyday matter of getting on with your life. So maybe they would. So no I haven't asked for help because having mentioned it once, it wasn't picked up on. I suppose the next time I see my consultant I could push it as an issue and say...

How difficult was it to mention it to him?

Not in the slightest, not in the slightest.

Okay.

Easy to talk to specialist

? Already exposed there, nothing to discredit.

Because it's a clinical appointment, you're there with the specialist, you know they've chosen that specialty, they're not embarrassed by people talking about poo either. You know, they spend - every three years he sticks a camera up my backside. You know, he's not going to be embarrassed by that.

Yes.

I wasn't, the impression I've had, and again I haven't gone into it in any great detail, I haven't pushed it with him and said I'm really having a major problem with this, or 'I need to talk to you and I need help,' is the impression I get is it's part and parcel of the whole thing and you just have to deal with it.

I think that's a really interesting comment and something that we found in the continence study was that, you know, where bowel control problems occur with a significant relapse, that's like, well okay, that's going to happen. But I'm not sure that there's a huge amount of appreciation that for some people this continues all the time.

Unpredictable
↳

It happens out of the blue like it happened with me recently, for no apparent reason.

Yes, you know, and having being incontinent whilst you're in relapse and you're likely to be at home because you're that ill anyway, or you're in hospital because you're that ill anyway, well okay.

Yes that's understood.

Sort of a shorter period of time and when the relapse is sorted out the incontinence goes away.

It's a bit like that's part of that particular aspect of the package isn't it?

Yes that's right and I think something that we're trying to sort of bring out is this understanding that actually for quite a few people that problem of bowel control continues regardless of their disease activity.

Unpredictability = ↓ Control

Preparedness

Yes and as we talked about earlier, it's the unpredictable nature of it. If I knew that something I'd eaten was likely to cause me a problem; if I knew that whatever set of circumstances, then, you know, I would - panty liners, spare underwear carried with me, all of that no matter how awful it might be, at least I'd be prepared. But the fact that it can happen when I'm not going through a period of having diarrhoea, when everything is as settled as it ever is, takes you by surprise and I don't think it is particularly well understood by the clinicians. I don't think - because it's practical day to day living stuff isn't it, and their focus is on, 'Are you flaring, what can we do about it? Have you got any particular issues? How have you been?' And in that ten minute appointment...

So these other, these other sort of long term things like the continence management and that gets pushed to the side because the appointment time is too short, you're there ten minutes in eight months.

Yes. And they may be picking up on how things have been or they may be following up the previous appointment may have highlighted something that's been looked into. And whatever. And so they then, that's their focus.

Right.

Even if my focus is on - you know, I know that's what we're going to check up on, how has it been since this or that or have you been okay? And, you know, it is a very short space of time and because my gut feeling, I suppose, is that this is part of the package, it's part of my package of having IBD, I don't know that, I mean I'm not aware that anything can be done about it. So you just get on with it, don't you, really. So what other choice do I have?

Well, yes.

Well, I mean, you know, you raise it with the consultant the next time, but again is he aware of anything that can be done to help or is he of the belief that this is just part of the deal?

So it's easy enough and if I've understood you correctly - it's easy enough to raise the subject of incontinence with clinical staff.

Yes.

And it's because they are clinical staff.

Yes.

It's because that's their world anyway.

Yes.

So it's not a problem.

Yes.

But it's not anywhere on your radar to talk about it with your partner or your family?

No way, no way.

Would he not be supportive to you if he knew? So that then if you were out and something happened, he could, you know, I don't know, go and get stuff for you or help you get to where you needed to be or...

Unspoken understandings? OR JOINT COVERING!

Inco undermines attractiveness. Peter provides robustness & gives illusion of everything is ok.

I mean I think the last time it happened, he was with me at the hospital because we were visiting his dad. And I think he had a rough idea. I think he knew without me having to tell him, more or less, probably not the extent of what happened. It's not unknown for me to suddenly say, 'Leave me be, I'll catch up with you, I need to go to the loo,' or whatever. That's kind of usual. And he is fantastic with the practical. If I say to him, 'Could you go and get me this? Please don't ask me any questions, just go and get this for me, bring it here, that would be fantastic.' He would do it, he wouldn't question, he would just do it. Again it goes back as well to being, you know, it's partly to do with the relationship, it's partly how you feel it affects your attractiveness. I mean we don't, as I've said to you, you know, we are currently celibate because my health has been so bad amongst other things. So, you know, how would he feel - what if he worried that during intercourse that I was going to leak? He doesn't currently know it for sure.

Yes.

*Ostrich
↑
until confirmed verbally,*

He suspects it may have happened. I'm pretty certain. But if I tell him that, it's going to be more clearly in his head, and what if he thinks that it might happen at an intimate moment and that changes everything again, you know. We're already not great in that area for all sorts of reasons. I don't want to put it into his head so that it's something that bothers him.

So again it's about protecting him more than anything else?

the problem isn't there.

*Impression
made
Views of
self*

It's protecting me. No, it's protecting me as much as him in that circumstance because again it's about how he views me. I mean he knows me, we've known each other longer, we've been together 28 years and we've known each other longer. But again it feels like it knocks another edge off my attractiveness, my - you know, when you've been together a long time - and we have apparently, according to lots of people, a partnership that people envy. But I don't want to do anything that could damage it. Or could put that picture in his head or that idea in his head, so that he's worrying about it happening wherever we may be, if we're going to be intimate or whatever, I just don't want it there. And the, if he only suspects, he can avoid thinking about it. And I would rather he did that, I'd rather I just got on and dealt with it without him knowing. And the same with the rest of my family, particularly my sister, worry so much. I don't want them to know it for that, it just adds to that doesn't it?

*Risk
avoidance*

Okay, so here's a scenario for you - what if he confronted you?

Then I would be honest and tell him. But he won't.

No.

*Describes
relationship
as honest,
yet both
avoid the
obvious
monster
that exists
between
them*

He won't unless something happens and he has to. You know, if something so - I mean he knew that I'd had, and I think he knew what had happened that time, but I dealt with it in such a way that it could stay in his head as an idea that, 'I think I know what's gone wrong here, I'm just going to let, I'm going to help her save face, be less embarrassed by just letting her deal with it the way she wants to deal with it. She'll ask me if she needs me because she knows'... I'll ask him if I need his help. If he confronted me and if it happened to such an extent that I couldn't hide it or think I was hiding it, I'm sure it's an illusion half the time - then I would be honest with him and I would explain, absolutely, because that's the nature of the relationship we have. And if he's asked the question, he deserves the answer. It's not fair to him not to answer properly and honestly. But I wouldn't tell him if he didn't ask. And I'm sure I'm not alone in that.

No I don't expect you are. I mean, like I said to you that previously before we started recording, I've now talked to hundreds of people it feels like, it's probably getting that way - and all of them have uniquenesses to their stories. And some are very, very open about, about their incontinence and feel that, you know, their life is easier if other people know because then they understand. And there are people like yourself who just don't. But the difference with you is that you, other people who don't, don't because of their own sheer embarrassment. Now you've said to me that you do find, it is embarrassing.

It is mostly that.

But...

There is the protective.

There is the protective aspect to it as well given that it is about the concern to other persons.

Yes I would say it's, it's, like I said 70-80% about my own mortification. And 20-30% about protecting friends and family, nearest and dearest from knowing that because they worry about me already. And that's just the way I deal with it.

So if there was a continence service and you could, you know, at the minute continence services are like, 'Have some pads, have some pants,' so it's about...

Yes, so you rustle while you walk.

Yes.

(Laughs).

Like you've got a packet of crisps down your knickers.

Exactly, exactly.

So it's about disaster management if you like rather than actually dealing with trying to prevent the problem. But like I said to you at some point earlier in our talking, there are interventions that are known to work in people with bowel control problems who do not have IBD. So if, speaking entirely hypothetically, you were given the opportunity to go along and try some things, would you go?

Good continuity - attend to reg. clinic is ok. Alt. cont. clinic broadcast prob. to others

Like a shot. Absolutely like a shot without a shadow of a doubt. And yes I would go initially without telling anybody what - it would be just a routine check-up as far as they were concerned, I would go like a shot because you live with the uncertainty. It's unpredictable, it can happen at any point. And as evidenced recently, I expect leakage when I'm having a period of diarrhoea. But now that it occasionally happens when I'm not, and I don't get a warning. All I suddenly feel is that my underwear is wet and I've leaked. I would go like an absolute shot, I'd be first in the queue if I could be. If I thought there was something that was worth trying, because again you're dealing with professionals who have chosen to work in this field, so therefore they're not embarrassed by it. You know, it's like when you have your colonoscopy, it pongs a bit in that operating room or whatever, procedure room, because of the nature of what's going on. You can't be embarrassed by it. They're not. They deal with... (28.29) If they see 12 patients in the day, they get it 12 times. So that wouldn't bother me.

Right.

Easier with pros. No embarrassment

Because I'm dealing with professionals who understand and who have the knowledge that I want to access, it's self serving. They know stuff that I want to know, I want them to help and I would absolutely go like a shot, no hesitation.

It's interesting because, you know, some people I speak to are, they are - everybody is embarrassed and they manage that in different ways. And for some of those people who are embarrassed, it stops them even mentioning it at clinical, gastroenterologist, nursing level, whatever, they can't even mention it there, even though that's an environment where it's the topic of the day every day.

Utterly pointless isn't it really because those people can help. Well would like to be able to help.

Yes, I know. So it's, it's quite - and, you know, my premise for this whole PhD thing is the stigma associated with bowel incontinence with IBD is preventing people from getting help. But, in fact, it's not that that's preventing you from getting help.

I don't think there is any help. Or I'm not aware of any help.

It's that there's nothing on offer that you know of.

Not that I know of. As I say I don't even know if have an IBD nurse, because certainly
nobody has ever mentioned it.

I don't know.

I don't know that they have. And it's not, I mean I think that my gastroenterologist is fabulous, he's been really good and, you know, we get on well and I mean even some of his staff, if I've seen one of his other team, they've picked up things. They discovered, because I was having, I can't remember what symptoms I was having, and they did a screening and my vitamin D level was on the floor.

Ah right.

So, you know...

It would probably...yes, makes sense.

That's not good because it's also been directly through studies connected with chronic pain in women. So, you know, I have faith in him and the people he works with. But nobody has mentioned anything to do with incontinence. And actually after this I will probably ask when I see him next now, because I've always assumed that nobody has mentioned it because there isn't anything.

There's nothing there.

There's no help available or we don't have that access to it, other hospitals do. And I suppose there's an element of the fact that my Crohn's is mild to moderate that makes me think maybe it's the more severe people that need it more than I do. I don't know.

Right, so not being able to ask for help is about there being nothing to ask for.

That's how it seems at this moment.

That's how it feels.

But I will, actually, you know, when I next go, I will ask because I wasn't aware – nobody's ever mentioned it. And I have mentioned it kind of in passing that I'm having trouble with leakage and nobody has ever reacted to that as in, 'Well we have this service,' or, 'We can look into this, let's book another appointment to discuss it further,' or anything. Nobody has reacted.

And even if they don't have that service there, you can be referred to, like you can be referred to St Marks where they have got that service.

Yes.

Handwritten note:
How
service to
be offered
to prove that
the exist

You know, so there's options there. But I was just remembering what you were saying about, you know, maybe your - because you're quite mild with your Crohn's, and maybe it's more severe - but what I'm sitting here, what that made me think instantly was whether actually success is more likely in milder cases than in more serious.

Yes, yes.

I don't know, because it's never - you know, it's never been tried.

I mean that's why, you know, I think maybe if there is help available, do they only offer it to the people who have very severe Crohn's or worse than mine - because everybody knows that the arthropathy pain is my biggest issue. Maybe I should have jumped up and down about it a bit more. I don't know, but I will ask definitely because, like I said I've always assumed it's part of the problem and you just have to live with it.

Accepts personal responsibility for lack of progress help

Well what Professor Norton says, who is my boss, is that even at St Marks, which is the UK specialist hospital for IBD, where they have got biofeedback services and, you know, specialist interventions for people with bowel incontinence, and they hardly ever see people with IBD. Now that's not because people with IBD don't have bowel problems, it's because they're not being referred.

Directed.

And they're not being directed there.

Passive acceptance of problem

And maybe like me they all think this is part of what you get with IBD and you just have to live with it, horrible though it is.

But just imagine, just assume that, you know, often you have a bit of biofeedback or whatever, and the problem is cured, what difference is that going to make to you?

Huge. A lot of it's tied up with self esteem. You start to see yourself differently. You start to feel a bit more confident and you can go out somewhere without potentially soiling yourself. And it doesn't happen that, it's not like it happens that often. But the problem for me is the fact that it's so unpredictable. And therefore the day it happened recently, I wasn't even carrying my little makeup bag with my spare undies in, because I wasn't going through one of those phases. So it would be - an element of my condition would be transformed, you know. Yes my biggest problem is living with the pain of the arthropathy. That's - the fatigue I get with Crohn's and the fatigue that I get with the arthropathy - so I get double fatigue - is a huge part of my day to day. The bowel incontinence on top just makes everything so much worse.

Preparations - good enough all the time

Yes.

And it would take an element away that I could think, 'Brilliant, I will never have to go through that again.' So it would be fabulous. Almost you can't quite think that it might be possible, you know. So yes it would be fabulous. And like I said, I'd go for it like a shot if I could. And it makes me think why haven't I asked more definitely in the past.

Hardly dare hope that problem could be solved

Well I suppose because you take your cues from the people there, don't you? And if there's no mention of anything...

Absolutely, if they don't react, if they just kind of treat it as if this is part of the IBD and, 'Sorry sunshine but you have just got to live with it.' They don't say that, but that's kind of the impression you get. Then I suppose – but I will, I will ask, especially now that it seems to have happened more unpredictably recently because it does make you worry. I mean I, in some ways I'm fortunate that I work from home. But I work from home because of the nature of my condition. I can't hold down a full time job. You know, even part time supply teaching, I do a day in school and then the next day is guaranteed that I'm going to be really ill and have an awful day. But to be able to go confidently knowing you weren't going to have an accident somewhere would, would make things – it's not always forefront of my mind – but it's peaks and troughs. When it happens, it's forefront of your mind for a long time, and then if you have a period of time when you don't have it for ages, it dies back, it recedes into the background a bit more. But then if I flare a bit and I've got diarrhoea, then I know that that worry is always there. It's permanently niggling away in my brain. But to lose that would just take a slice off the whole having this condition. And make it, I suppose if the analogy is in terms of weight, it's a little less weight to carry.

Yes, yes.

Which would be amazing. And then I might tell him if there was a chance of it going away. So, I don't know. But yes that would be, ooh I can't even, I can't even let my brain go there actually because it's too...

Well that's right. I mean like I...

It's not a known possibility at the moment.

At the moment, and like I said to you previously, you know, nobody has tested these things on people with IBD. And it's something that we plan to do.

I'd be a guinea pig quite happily.

But, you know, nobody has so nobody knows. And that may be one of the reasons why it hasn't been suggested as a, you know...

Because there's no history of it being used.

No, no.

Thank goodness for your research.

Well we try. We try.

Somebody who is brave enough to do it.

Right, just to sum up then, because I have the feeling that we're at that kind of point, that this unpredictable behaving bowel, unpredictably behaving, misbehaving bowel of yours, causes you to feel very embarrassed, causes you to be concerned that if other people, as in social and family acquaintances, knew about it, they would think less well of you.

26 – Al Stigma

If I don't know I can only imagine and I have a very overactive imagination because I am artistic and that just goes down in a really nasty place. So the more I know the better.

Yes and that's a really, I mean that's a really interesting thing. It ties up with an issue, sort of a theme of control that comes out over and over again – not just physical control, because clearly that's what the problem is, but if people feel that they are in control, even if they're not, but if they feel that they are in control, they generally cope better.

Manage better, yes.

Yes.

And for me knowledge is power all the time, always, even if, you know, I mean there's been health scares with members of my family and, you know, okay well let's find out. The worst thing is not knowing. If it is the worst scenario, then we know how to deal with it. We know what to expect, we know how to deal with it and we get on with it. But not knowing is the worst place to be, for me.

Yes, yes.

So now I can go and ask. I'm fed up with this. I'm going to be pushy for a change instead of – I mean I'm always, 'for a change' is probably wrong actually but my, my gastro appointments are always very uneventful. He checks up on me and we agree that yes life's a bit crappy but 'Don't give in,' he says. And I say, 'I never do.' And that's that really. So to have something very definite to pursue is also very useful for me, it does make me feel psychologically better about it, that there's some, an avenue to pursue. I had a pain in my left side for over a year. And he started it off, 'Because of course it could have been gut,' and then it went through various bits of investigation and it ended up at pain management and it turned out to be the nerve in the facet joint in my spine. I've now had a denervation done and it's died right down to manageable proportions. And again it was knowing, that year of not knowing what it was...

Helps her
to be
proactive
rather than
passive

Yes awful.

It was horrible. But you can pursue things once you know. And there are options. And that is such, it's like light at the end of the tunnel if there is an option. And if there's more than one, that's even better because you try one thing and it doesn't work, there's several other things you can try. And it's fabulous. For me that's where it matters such a lot. And I know it's not true of everybody, but I think there are a lot of people who feel better when they understand at least. So thank you for that.

Well thank you.

I've learnt stuff, that's always good.

(END OF INTERVIEW)

APPENDIX 9

Carl's interview transcript

Carl was 54 at the time of interview. He has Crohn's disease and assigned himself to the *FI, stigma* subgroup. He has an ileostomy which he desperately hopes is temporary, but has already had one failed reversal attempt and may be left with the stoma permanently. His illness has cost him his livelihood and his marriage, and he is struggling psychologically to cope with the stoma. He is not bothered by the stoma, but by what it produces. This very visible and forced interaction with his bodily waste goes against his expectations, learnt in childhood, to be clean. He suggests that dirt is only troublesome in some situations – in public, amongst strangers – whilst it is no problem at all in hospital because there it is the norm. Carl does not understand why he is in this situation when others with the disease seem worse, and we agree together that events have taken away his sense of control not just of his body, but of his life and his future plans.

6- Stigma

www.
1st interp story
2nd

Okay, so I'm here with _____, how old are you now?

. You've got two first names.

(Laughs).

, how old are you now?

I'm 54.

Okay.

22nd of the 2nd '58.

That's it. And you were telling me before we started recording that you were diagnosed with Crohn's disease about five years ago?

Yes, that's when it was, September, this coming, this – so it's nearly five years.

It's nearly five years.

They didn't actually diagnose me with Crohn's until a year or two after that.

Right, okay, but you were first aware of problems about five years ago.

Yes, that's right.

Okay and when you completed our online survey, you said that you were interested in taking part in the Stigma Study, which is why we're here now. Um, and that you did, had, at the time, had some problems with incontinence, but you've currently got a stoma.

Yes.

Okay, but, so starting from any point that you feel is the place to start, tell me about the way that your bowel disease or your previous incontinence or the stoma or whatever, makes you feel, thinking particularly about the stigma and/or other things.

1st symptoms

Right. When I first took it, it was slight diarrhoea, running to the toilet and it was embarrassing going about twenty times a day to the toilet. So then I had to contact the doctor and from there got sent to the hospital.

Sorry to interrupt, were you living on your own then?

No, no I had two kids with me and my wife. Um...

So was it embarrassing because they were in the house?

Always in the house

Well yes, um, yes we were staying in our house and we only had one toilet and I was in the toilet a lot, for hours in the morning and it was a fight to get in the toilet. So that was

Tried to
change work
but lost
jobs

Past tense: -
has lost
friends?

It is shameful
Breaches rules
of his
upbringing.

Losing
control is
a big
problem

Control
NOT lost

embarrassing yes, and eventually I just couldn't go to work and I was in the house all day. The tiredness was a lot to do with it as well, just through the disease. Um, but I was a builder by trade and I gave my job up at building and I'd done taxis years ago, so I tried to do that again. But I was getting caught in the car, got caught short in the car. So I remember a couple of times I had to run into McDonald's and that and so trying to clean yourself in these places is really embarrassing. There's no bins in McDonald's to put anything in. You know, (chuckles), to leave stuff in. So it's really embarrassing. It's embarrassing to your friends that you knew, you know, it's not the nicest thing to talk about. So it has been embarrassing for the years I had before the stoma, a lot of times.

~~Is this embarrassment actually shame, cos occurs~~
Right, and is that, do you know why it is that you feel so embarrassed?

Just because of the way I was brought up, I was always clean and my mum was, you know, I was, I had to be clean and just from the smell or something - if you've had an accident you just feel really embarrassed and it's not the way to be, you know...

No, so for you it was because it's dirty.

It's dirty, yes. I never looked at poo before (laughs), you know. You know, you never look in the toilet pan, you just do it and walk away, you know.

Yes.

Um, so this all became a new thing, you know, you were seeing it all the time, sort of thing and running, it's in your pants or whatever if you've had an accident, it's just disgusting to me, it was. Not natural, not natural, just not meant to do it. You don't even think of it if you don't have these problems.

No.

So um that's really, it's embarrassing.

You were saying before we started recording about also having some urinary problems.

What?

Having some wee problems as well.

Yes, yes.

Is that as embarrassing?

Well no, no because I wasn't leaking there, it's just problems doing it. Um, every time I had an operation, I would have to get a catheter in and after that it takes a couple of months before it's back to normal.

Right.

So that, that's not so embarrassing. That's just, to me that's, if you're in hospital and got a catheter, it's different, it's maybe different if you can't control it if you're outside, but I can control it. The problem was not doing it.

knows I
will know
about
hairs to
throw
away

embarrassed laugh

heathh lap-r-r

Dirk out of place.
OK to be out of control in hosp. cos it's

~~Okay to be~~

6- Stigma

So if you have problems with control when you're in hospital, that's not so bad.

*pooh
the more place
laughing is
worse*

Yes, everybody knows you're in there and there's something wrong, but if you're in the street and um, you've got to get to the toilet to do a poo or something like that, you build up, you get into a sweat and a panic, just in case, you know, it does happen and you don't there in time. And if you don't get there in time, as in you're in the toilet and trying to clean it up, it's really embarrassing. I ended up - I used to carry stuff with me, and wipes and spare pants and things. *Would be alone in loo, so is this shame?*

So was your concern, apart from the difficulties in cleaning up because there's no space or anything to do it with, are you bothered about what other people might think?

Yes.

Tell me a bit about that.

Self-conscious

is this about the risk of discovery
It's just, I don't know, you think everybody's, um, if you have an accident, you think everybody's watching you. They're probably not even thinking about you, but you've got this feeling that they are.

That they are.

*Worried that
people will
know.
Discreetly*

Yes. And it's the same with the stoma bag, I keep thinking everybody can see it and that, but they probably don't even know, but it's just on your mind that it's not right. So I have really got a problem with that.

Well given that you were saying ...

*OK with
those who
understand*

hitt
It's different for a professional person, a nurse - that every time I go to hospital, I'm not embarrassed to show them it, because I know they know about it, but in general, people don't even know what a stoma bag is.

No.

You know, unless they've had it they know someone who's had it.

Yes.

So most people don't really think about it, but when you're having it, it's like a ... *disability* (06.34) to me, if you know - just...

Do you tell anybody? - *this is me trying to determine whether he can see support in other's hands.*

I do yes, depends who they are, you know.

*Share info
about his
IBD -
depend
who they are*

Right.

People in the flat here ... (06.46) they knew I was in hospital for a week, my daughter told them and, 'How's ...?' and ... said, 'Oh he's having to go through major operations, he's not well,' and when I came out I said I had Crohn's disease, you know, they don't know

6 - Stigma

Problem is with strangers.
Shows with clenching

Okay with close friends.
Risk of discovery

what it is. And I say it's the bowel and I've got a colostomy bag on and, you know, if I was friendly enough to talk to them, so they would know. It's not as if I'm hiding it, but as to people that you can talk to you about it, it's just people you don't know that's walking down the street, that you don't feel - for some reason, you know, if the shirt blew off or something and they saw it, they would be shocked. That's, it's trying to hide it. But yet I'm not really embarrassed talking about it to someone if it was like yourself, one to one or anybody. It's just the thing I've got to have, and if I've got to have it, I've got to have it. It's just the people you don't know that you're worried about, I think. *- Uncertain response.*

Why do you think that is?

Doesn't want to be thought badly of.

I don't know, I just, I don't know what that is, I don't know, it's just you feel as if everybody is watching you, I don't know, it's just a sort of embarrassing thing, I don't know how to explain it (sighs). Yet if you actually get to talk to someone, I don't mind explaining it, but if you're not talking to people, that's when I find that's the worst, you know. (Pause). Going anywhere, you know, I was, I always wear a shirt over my t-shirt or something so that people don't see things. I've been at the hospital and I have people all waiting in the queue, they're all waiting to see the same nurse as me, and obviously, you know, they've got a bag. And you're looking to see if you can see it, and you can't really see it. So you wouldn't know and strangely you keep thinking to yourself, 'Everybody can see mine, but you can't see anybody else's,' (chuckles), sort of thing. *Imp. Dan*

Feels exposed.

Do you feel like you've got a sign above your head?

Yes, yes that's it.

That says, 'I've got a stoma bag.'

Yes, but it's not there (chuckles). Yes that's right. So...

How do you think people would react, how do you think strangers would react if they did find out?

It would be embarrassing for me. I don't know if it would be embarrassing for them. I don't think they'd actually bother, you know, if you explain to them that you have problems with diarrhoea and I did that to collect it, so... I don't think they would be embarrassed, it would be me at the start, but once you explain it...

So your concern is that if other people, other people find out, that causes you a great deal of embarrassment. *Risk of discovery.*

Yes.

Right, okay. And is it the same with this, you were talking first of all when, before you had the stoma, um, and the difficulties with bowel control - now that you've got the stoma, do you still feel the same or is it a different kind of thing?

It's a different thing. It's, I have had a couple come off, a couple over the year. But I'm 90% confidence that the bags that I use won't come off.

Right.

Lesley Dibley/PhD/Stigma/do 4

Because I've got a bag that fits and it's the safest type of bag. It's not the comfortablest of bags, it's quite hard, but I've got a softer one to use in the house because I'm not certain that they won't come off. So when I go out I know I'm okay. And it's just when it fills up, you know, it's usually I stop and I'll like change it. But I'm actually - it's alright going out with the bag as long as I know I'm covered, you know.

And given what you were saying earlier about, you know, your mum brought you up to be clean.

Yes.

How do you get on managing the stoma and changing the bag and having to see the poo that you normally wouldn't be looking at?

poos smell disgusting but stoma ok

Um, poo is just disgusting to me. Seeing a cut, or inside your body is alright to me and I can watch surgery on the telly or anything, operating there and watch it. Seeing a car accident and people, I think that wouldn't really, it's the smell and you know it's waste, and it's just that bit that's disgusting to me. It's just - the stoma doesn't bother me, I know it's part of me. But the toilet stuff isn't part of you if you know what I mean, it's just waste, it's...

I don't know if you know, but you can get, or you can have - some people can have to have a bag for wee.

Yes, yes, I do know that.

Right, so it's called a urostomy, because it has urine in it.

Right.

Would that be as bad, do you think?

Aha.

It would be as bad.

Yes, having a bag is just bad to me.

Just, right.

Abnormal by having to have stoma bag

Yes, just knowing I'm not right, just, um - before I had the bag, when I, when I was running to the toilet, once I'd been to the toilet I'd feel normal again, once I'd cleared up from the day and I was finding in the afternoon I would feel okay for the - for six or eight hours, I was alright. But having the bag all the time, it feels as if I'm not alright all the time.

So it's like a constant reminder to you.

Aye, that something is wrong.

That something is not...

Agrees together that the bag serves to remind him of his (dirty) disease

Yes it's just not right. So they've been through this with me in the hospital, 'You have to have it forever,' so if I have to have it, I have to have it. It's either life or death sort of thing.

Well obviously...

You know, if I don't go and get ... (12.44) life and death at the end - and then we can then decide.

Yes, if it does it again, every time - if every time they try and reverse it, you have that same problem of leakage at the - it's called the anastomosis site...

Yes that's right, yes that's right.

... um, you know, then there's bound to be a point that they say...

Verbalises his biggest fear!

'We can't do it again.'

Yes.

Yes I was just wondering, they moved it from the big bowel to the wee bowel, so I mean it's, I'm thinking if that's easier to put back together, no? *Asks my advice*

I don't know, I don't know. It seems...

Right, I don't know, they haven't told me that much.

It seems there's all sorts of different options but a lot depends on, you know, the state of disease and where it's sited and all that kind of stuff.

Whether it's the small bowel or...

But um...

Feels uninformed - ? = out of control.

They've not really explained it before I went to hospital about what can happen, leakages and things, it's just like you're getting a stoma bag, we'll just bring your stoma and then reversing is just as simple as sewing it back ... (13.44)...

Yes joining it up again, yes.

Feels he's ended up in this situation not of his choice. Control

So going in for three or four days, join it together, whether they did it with clips or sewed, and that's me back out. And then when something happens like that, if they'd explained all that all the way back at the start, I might have thought twice, you know, that - because it's the one thing I didn't want to be left with a stoma.

Yes.

Had no choice due to severity of situation

The last operation when they said they was putting me back on the stoma, I said I'm not signing for it, and they said, 'Well you've got about an hour to live if you don't.' So I said, 'Right give me the paper and I'll sign' (*chuckles*). And you've got a life and death situation, that's different, if you've got to have it, then you've got to have it.

Disgust

So did that, would that help, does thinking about that, the, you know, 'If I don't have this stoma bag, then I'm seriously going to be ill and I may well not survive'? If you can bring that to the forefront of your mind and remind yourself, 'Well that's why the bag is there,' I wonder if that's able to help you feel any differently about it, to view it in a more positive light because it actually saved your life.

Unable to accept stigma, despite the fact it saved his life.

Well if the surgeon is standing there and said they couldn't reverse it, I would have to leave it and still be as if it shouldn't be there. It's not natural, it's not - it may be different if I had it since day one or since I was young, you know, but to have that at this stage of life, and suddenly... (15.26) you don't know about it, it's like a new world, it's just a new thing that - I'd never heard of Crohn's disease before, five years ago... (15.39). You've got this and you've got that and just suddenly come on and...

Altering his sense of identity?

How much of a part do you think that the Crohn's had to play in the breakup of your marriage?

Unable to support wife financially. Wife left!

Um, quite a lot actually because it stopped me working and I had a house with a mortgage on it, and I wasn't working. And the money side of things, got into a financial mess and that's when my wife realised that it's time to go, sort of thing, and have a life. And she used to go out with pals on a Friday night and I used to sit in because I just didn't feel like going out. So that's probably a lot to do with it. But, you know, it could have ended this way anyway, you know, you don't know. Um, she wasn't really bothered after the couple of years. I'd been in hospital a few times and my daughter had to say, 'You have to see your husband,' you know. So it's quite a change - we were 28 years together, so...

Yes. Is it difficult for you not being able to work?

WORK a big part of who he was.

I felt I'd never stop working in my life, I didn't plan to stop working until I was 60 anyway, you know. So at least ten years before I planned things, all the plans went out the window, you know. Financially as well, my pension fund was zero and I cashed it in when I took ill when I was 50 and took... (17.33). But I've gradually got used to not working because I'm not fit enough to work, I'm not, I'm usually asleep most of the - it's hard to get to sleep at night and then when I get to sleep, I can't get up. Some days I sleep for 12 hours, just tiredness.

The fatigue with it, yes.

With the illness.

Yes.

I went through really bad times with that and sweating and I would be lying in the bed soaking. So I'd love to, I'd love to have just carried on the way I was, you know. Um, but now I've got used to being in the situation of not working because you just don't feel like working. I've still, my mind is still going to try and do things, but the body's just not, just not wanting to do it.

So you're having to find other things to do.

Yes. I'm managing to find things to do. The days seem to fly, and, you know, it's lunchtime before you know it. I never thought I could actually sit in all day. I've never sat in the whole

WORK
delighted
him.
He's lost his

day in my life, I don't think, because I was at work, I'd work seven days a week most of the time actually, and...yes, between two jobs. I was doing the building and I was doing taxiing at the weekend and I could do eighty hours a week, no bother. So, and um, all my life I got up at 6 in the morning, on the site for 8 o'clock in the morning, without any bother. I used to drive for two hours sometimes. And um, I couldn't get out now to a set time. The alarm goes and I put it off now. I never used to do that. I used to just wake up and...so things have all changed that way.

And do you think that's also part of upbringing? We were talking about your mum and, you know, being clean and that was very important and of course now we live in a world where everything is supposed to be super, super clean. Um, and is that work ethic part of your upbringing as well?

My mum and dad, well my mum was off for years when we were kids, but my mum and dad both worked. Dad was a teacher and he worked at night in a night school as well and he just worked and that was the way things were.

Yes.

Everybody was working in those days. And my mum went back to work when I was 12 and she worked until they were older and that was just the way I was brought up. My brother worked as well and we've all worked. Some families don't work and some families do work, but it's the way you're brought up. And, my daughter works, my son works, so they've all got the genes in them to work.

Yes, yes. So how do you feel, surrounded by a family that works, when you're not able to?

Bothered that
others will
think he's
shirking.

Well it's annoying that I can't get out there and make all the money any more. People see you about all the time, 'He's not working,' and they don't know if I'm ill or what. So they don't really know. They think I'm retired or whatever, but yes...it is quite frustrating that you can't go to work. Work was a big part of my life. Most of my friends were work friends, you know.

Do you still have contact with them?

Some of them, yes, two or three of them, yes.

And have you talked to them about this?

They knew, yes they know, yes. Well I worked with them, most of them, and they knew I was on the toilet loads and I explained. They keep thinking I'm going back to work (laughs), and I say I wish I could.

Yes.

How he
delighted
himself

Yes, and the building trade was my life, it was absolutely fantastic, I loved working, just the challenge of building a house or anything, you know. It was a fantastic challenge. Weekends, I used to do extensions and ... (21.42) and things, you know, and just seeing something getting, a structure getting built - I've probably never seen the end job yet, because I was a bricklayer and ... (21.55) or something, you know, but just knowing these people were getting their house extended or whatever, or built, it's the satisfaction. And I

Animator talking about
something he is proud of

really loved that part of it. And the challenge was, I would take on anything, I would take on building a full block, a block of flat myself sort of thing, if you know what I mean, and you always got there – it was just an aim to keep going, to keep going and you'll get there in the end, and you always did get there. So that's just a challenge in life, and now I don't have that challenge, it's, it's just destroying, it's just – it makes your life – it would have been different if I'd planned in retiring earlier and I had a load of money in the bank and went round the world, but that never will happen. You get limited resource money wise and it's not always easy to do things. It's psychological, I think it's all psychological, just writing your... (22.58) off for years.

No purpose
Not his choice.
Not his control.

So what, what do you think you could do to help yourself cope better psychologically if you do end up with that stoma permanently?

Big PAUSE
(Pause). I don't know (chuckles). I thought about, I've never done office work, I have been a foreman and things in my life and I've thought about that going back in the building trade, maybe to do clerk of the works and things and do that that type of foreman's job and things like that. But by the time I trained for that, there's no work about now anyway, in the building, so I don't know if I'd be wasting my time, even the challenge to – I'm meant to be going on a computer course shortly, just the challenge of maybe getting a certificate or something at the end of it, it could open up other things. But um ...

Amn't my question.
So I ask it again.

But how could you, how could you deal with the, the way that you feel about the stoma, on the poo and the whole thing?

Others see this like this

Well it's kind of... (24.28) if you have it forever, you know, when you get older, how are you going to empty it and change it and clean yourself, your shower and your sort of – you're going to have to rely on someone to help you. That's a worry. Um, I don't think I'll ever change my mind about that, I've got it and it is disgusting. And the way it is just now, the wee bowel is all watery and, you know, if you've ate a Chinese, you know the next day you go to the toilet, it's got different smells and it's different...

disc: future

Texture?

Texture, yes, different thicknesses and textures and things. It's disgusting seeing that coming out. It's amazing how it does, you know. They said to me don't eat onions and things like that, and if I eat an onion, I chop it finely and eat it, but it still manages – I wonder how it pushed through the really tiny hole, but it does, it comes out. Tomato skins and anything, they all come out. And you wonder how the body copes with all these things.

Well, of course, normally that would be in there for longer.

Yes.

So it goes through...

Yes it's through the large bowel.

Yes.

Yes.

6 - Stigma

And so, you know, you get a different product at the end.

Yes it's dried up.

Normally, than you do from the ileostomy, it's always going to be more liquid and up there. And the smell is different.

Yes. And the – when you wake up in the morning and it's got all air in it, so it doesn't come out, then everything comes out.

Yes, yes.

And the bag was blown up this morning and it was full as well.

Yes, yes.

Dirk
Thurs

And you've got to empty that and it's absolutely disgusting in the morning. The morning is the worst smell because it's so built up, it's just been lying there. Um, I don't know, before I had the bag ^{blown} up the back, and I was going to the toilet, I was actually being sick when I was going to the toilet and it was running out constantly, just I'm useless if I smell sickness.

Right.

I'm one of these people, that I can look at things, but the smell's just – and the toilet was exactly the same ... (26.45) and I was actually vomiting. Yes it was making me sick, but I think the sickness was part of the disease as well, but it was just actually making me sick. At one point I went through the smell of food was making me sick. I don't know if it was all to do with the bag, you know, I don't know, it's just some things – smells have a lot to do with it because I feel this sick feeling in my throat all the time, especially in the mornings. And that's the worst time. It's like sometimes I'm not sick but I'm hoping if, you know, it's a dry sickness thing. So the smells are... (27.33) I will just have to cope with... (27.36). I don't know, maybe it's what's making me keep – is thinking that it's going to be reversed. The surgeon did say, 'We'll talk about your surgical options when you come back,' the end of last month. So there must be something they're going to do – (chuckles). So (sighs) if I do get it reversed, I don't know what problems I'm going to have either. It's a 22 thing, a catch 22.

It is, it is. ^{hopeful.}

Catch 22;
Rent + deep

You know, you have a bag or you're running to the toilet, it's one or the other isn't it?
^{blue sea. No choice. No control.}
Yes.

And you just keep thinking it's going to heal up, but maybe it won't.

I suppose the only um, thing is, if you, when you get to that situation, you will have experienced both, you will know what it's like to have your bowel intact, but keep running to the toilet all the time. And you will know what it's like to have a stoma bag. So there's no, there's no wondering, is there?

No.

There's no like, 'Oh well, you know, if I don't have this done, what is it going to be like?'

That's right.

You know, and it's not to say that if it is reversed that you will be running to the toilet all the time, but that's the trouble, nobody can tell you.

Yes, no. There is a... (28.59) ^{write new drug out} a test drug that's come out, I've read, they're doing it in one of the doctors has got access to it - I was going to ask the consultant that if you didn't react... (29.14) ^{Hydrolyse} this was another thing you could try. So if that's what happened to me, then I'll ask if I can go on that, because it's actually the consultant in the Royal, he said to me, 'Even if you go to get the stoma temporary, you're not getting your bowel taken away. There's still a chance with new things coming about and you can't get it reversed.' That's before I knew they were having problems with it joining. So I still have got it in my mind, I'm hoping that things do eventually get back to normal.

Having on to the hope of a reversal.

It would make life a lot better for you emotionally as well, wouldn't it?

Leads bag as doesn't see it as permanent

Yes. Yes I suppose if you just knew the decisions, if you just knew what was going to be in the future. If you're going to have the bag forever, then you can maybe get your mind round about it and talk to people, you know, psychologists and things and get your mindset that it's going to be there, you have to have it, then I might think of it differently. And if you're going to try new drugs and things, you're always thinking, 'What is going to happen?' but if you just knew what was happening, then you might be, I might be more settled.

Yes. And, of course, nobody can predict. nobody can - because, you know, it is individual.

That's right, yes but it's different to people you've talked to before.

You know, and I've talked to people who resisted and resisted and resisted having the stoma, because um, for all the reasons that you've already described, and then they get to the point where there's been no choice and they've had to, and they've not looked back, you know. For them, they're saying things to me like, 'I wish I'd done this ten years ago,' but other people like yourself who find it extremely difficult to...

Context. In this girl

I've been in hospital and in the same ward there was a young girl and she was 23, 24 and she had ulcerative colitis and she got a stoma bag and she said, 'That's me, that's me for good. I can't go through that running to the toilet.' But she had the option to go back and get an internal pouch. 'Oh no, no, that's me, finished now, that will do me. I'm quite safe now and happy.' And I'm listening to her thinking (*chuckles*) 'Well I'm not happy, I'm not, you know,' I don't know. I don't know if my mind will change and there's a lot of people that are glad to have it. She shared a flat with other girls and getting to the toilet was a nightmare. Yes, so I think there must be different thinking about the way...

And it must be influenced by personality and by upbringing and, you know, all that sort of stuff as well, that - and I'm not for one minute suggesting that any reaction is right or wrong or better or worse than any other. It is what it is, you know, people respond in the way that they do because of who they are, I think. And that's what I'm, also what I'm trying to get to, so we can, we can, you know, bring that information out and show that to the people who need to know - the IBD nurses and the stoma nurses, and, you know, make it, make it apparent how very different everybody is. And even, if it gives you better

control, which it clearly does, doesn't necessarily mean that you're going to be happy with it.

Yes, that's true, yes.

Whereas, you know, from the nursing point of view, you might – a nurse might sit and think, 'Well if you've got some poor sod who's running to the loo 20 or 30 times a day, and um, they can't do anything, they can't go anywhere because of that, and they're very, very sore because they keep going to the toilet.'

Yes that's a problem.

You know, form the colostomy because you need to for whatever reason, that's got to be better. You know, that would be, that would be the sort of the medical/nursing way of looking at it because of the control and the apparently better quality of life.

But it's not for me.

But obviously not necessarily the case.

No.

Is it?

Has control freedom, but not how he wants it. Control has been achieved

It does get, the bag does give me freedom, I can go out at any time I want, I don't need to worry about the toilet, but it's just having the bag, it's just knowing that there's poo in it and I'm walking about with a bag of poo and it's just, no although you've got that freedom and everything, it's still not the answer to me, it's just not, *(sighs)* I don't know, I keep going to the toilet to empty it as often as I can, as soon as there's anything in it, just because I know there's, it's there, it's just dirty and it shouldn't be there. It's like... (34.18) *(chuckles)* It's a mess, you just know it's there, a lump of mess.

In a messy way
Yes.

Lack of control. Getting the bag makes no sense to him.

So it's really, I don't know, it's just my mind thinking, it's not everybody knows it's there, it's just me thinking. But it would have been easier – one of the nurses actually said to me, 'If you were in a car accident and something, your stomach was ripped, and you woke up after an operation and you had a stoma bag, you might have took it a lot easier because you haven't thought about it for so long and you've had to have it, your stomach has been ripped or something and you've had, you've got to have it, you're lucky you're alive and you've survived a car accident,' but when you've talked about for a year or two before it came about and I hadn't had *(sighs)* an operation for Crohn's or anything before the stoma bag, and I kept thinking to myself, 'I'm not the worst who has Crohn's disease,' because I was talking to people in the hospital. They were giving me all sorts of stories *(chuckles)* really bad stories that through their life they've had Crohn's and they've had 20 operations and bits of their howel taken away. And I said well I've not had that. And then suddenly I am meant get this wee simple thing, I have a bag put on for six months and taken off, it's like, to me it's like they would have clipped it on and clipped it off *(chuckles)*, because the operation to me is not, it's a big thing, but it's not, I'm not frightened of it. So it's, oh it's a bag clipped on and clipped off and then you go to get it reversed - and then, an emergency operation and you're cut wide open, that's when you think. well is it because of the Crohn's

Doesn't understand why he is in this situation

or what's wrong with the tubes and - nobody actually sits there and explains. Consultants have maybe half an hour or maybe quarter of an hour, they don't sit and explain exactly all that can happen. They don't tell you about things.

I completely appreciate what you're saying, but they can't predict everything that can happen.

No, no but they could say this, no I know. I think that was just unlucky that that happened to me. I did look on the internet and things and I just stopped going there, because that gives you the worst, worst things.

Oh you always get the horrors, don't you?

Yes, yes, you do.

You rarely get really good stories on, you know, the easy ones and the things that went very, very well.

And they said that the last resort was these HUMIRA injections and they would, if it wasn't working, the other stuff, that would work. And you could be on them for life, and I thought well that's fine, I think I can inject myself if I have to, that's okay. But after a year of trying them, I said, 'It's miserable, take me off them because it's not working.'

It's not working, yes.

And that was another hope that I had for a year.

Yes, yes.

hookish always to resolve his feelings about stoma

So I don't know the answer.

Yes.

It's not... (37.29) I've got so many appointments for different things and um, after the, I got the first stoma, I did see a psychologist in the hospital, to talk about it.

Did it help?

Yes it did a bit, yes.

Would you go back? Or go to another person?

Yes well she said...

Or whatever.

She said to me, after we found out what was happening again, if I'd got to go, if I need her she's there, just get the consultant... (38.08) and make an appointment. And also I did... (38.18) all different things in my body, I was fine five years ago, but I get pains in all my joints and things, and...

Yes it's all part of the Crohn's.

Yes, aye, they just say it's wear and tear throughout my life and my knees are really sore and a couple of days ago I had to go to the doctor and I'm on different medicines for these things, you know, ... (38.37) to get me ... (38.44) I've got a problem, a sexual problem – I can't get an erection and it takes ages, it's forever, and I've got sort of like a girlfriend, I've known her for maybe six months. But we haven't got a sexual relationship, she's just a friend. Not that the two of us are not wanting to do it, but we would tomorrow probably if I was okay. But she knows that I've got all this, but she doesn't want to see it, she's one of these sort of squeamish people that just – 'Oh I don't know... (39.18).' She came to see me when I was actually getting reversed and that. She met my daughter and everything is fine, you know, but just the sexual part of it. I'd probably be embarrassed as well, she'd probably be embarrassed as much as me. I've been going to urology for that as well, and they were talking about, I think there's a clinic somewhere here for sexual diseases and things, but they also have a psychologist or a person that can talk about body image. And you think they're going to find out about this person, someone that can get you these appointments, because I have the bag, you know, they could maybe talk to me about it.

Stoma
disrupts
sex life

So you're thinking, is your feeling that it's the, that the impotence is related to how you feel about yourself because of the bag?

I don't know if it's just – my body feels dead, I don't know if it's Crohn's disease that's making me feel tired and everything is just not working right. Or if maybe it is in the mind, you know. But wanting to do things and doing thing is a different thing. I also have a wee tiny hole here and you can fold it up and it's quite wee and all the rest of it, but it's just having it and coping with it. I just know my body's not right.

Yes.

I don't know what stuff goes on inside your body, I'm not a specialist in these things, but I've been through a whole lot of different things. I've never had any problems before, just since Crohn's disease – sweating and headaches and I've just been through months at a time with these blocks of different things that have happened to me.

Yes.

And even when I broke up with my wife, before we moved, just when we moved down here, that's a year ago, um, I begged her to stay with me and everything, you know, because we were together that long. And didn't think it would ever come to that. And obviously her thoughts were different from mine and, it was quite a bad thing then. My daughter has been a real support. If I didn't have my daughter when I was in hospital, I don't know how I would have survived it, I'd have had to have helped from somewhere, you know, I came home and I was in here for four weeks, I was in hospital for four weeks and then in here for four weeks.

And how does she feel about the stoma?

She's fine, she just knows that I'm not well and I've got a stoma and she's seen it and she's quite okay with things. She knows I'm ill. And 'You took ill dad and you just need to battle on and get there,' and she's been a really good support to me. She's 23 and she's quite wise, you know, she works in the... (42.29). But (sighs) she doesn't talk to her mum now either because, she didn't talk to her mum before she'd left because she wasn't going to see

Daughter
okay with
stoma

Has resolved
loss of wife.
CD exposed
the cracks

me in the hospital, you know, visits and things, and she could have been there, but she was more interested in her pals and, yes, so *(sighs)*. I don't know what would have happened if I didn't have Crohn's, but then I'm looking at it in another way, like if I didn't take ill, I'm been through my life with somebody that didn't want to be with me anyway. So trying to look at it, this is actually, it's actually better, it's peaceful and there's no arguing, there's no nothing. And *(sighs)*, I don't have to put with, 'I'm going out on Friday night,' so I feel actually better, you know, when she's not here. It's good actually.

And you've now got somebody who is, accepts you as you are.

Yes.

It takes a lot of stresses away doesn't it?

Yes, and she has a lot of problems of her own, her daughter is not well, she's down in London. That's where she has to stay and she works full time and she's got, she's got use of her car now, and she works, she's been, not single, but on her own for 8 or 9 years, I think, now. ... (43.56) she's kept her house and just kept going. So, and um, yes we get on fine, we don't argue or anything, you know. It's the way life should be, you know.

Yes.

I don't think I'd ever move in with her now anyway, *(chuckles)*, it's just, I think she doesn't want that either, you know, it's complicated when you've got kids and...

Yes.

But I think it's the way people my age are thinking, once you've split up, you want your own space and, maybe that's what my wife is thinking too, you know, my ex.

Yes.

But I've actually, people say, 'How are you?' and I say, 'I feel great,' because my mind feels okay. But I maybe ill, but I'm not lonely and I'm not closed in here. I know I've got a car and I can go out any time I want and I could drive anywhere, go anywhere. I haven't been abroad for five years because I've been ill. I used to go abroad quite a lot, I'm all for seeing different culture. But I'm fine in my mind, if you know what I mean, it's just this feeling like somebody who can still go out, you know, I wouldn't bother, just a weekend in maybe and I feel great, it's just having the, it's just the worry of the future, that's the big thing.

Yes, the unknown.

The unknown.

And I suppose really, for all of us, the future is unknown, isn't it?

Yes, it is, you could get up tomorrow and get hit by a bus.

Well...

You know, you can have a heart attack.

Coping
with
everything
except
the stomach

Re giving some of myself back to him

Well, you just sort of, you just don't know, do you? You know, I mean exactly as you were saying, you had your plans and in the same way, you know, I've got my plans for how long I think I'm working for.

Of course you have, yes.

And what we're going to do when we retire and, you know, when the kids have left home and all that kind of stuff, you just do.

Yes.

But I wonder whether it's when things get taken out of your hands, you know, when it's not your - although you don't know, although you don't know what your future holds, you kind of are influencing it by the choices that you make and the decisions that you make.

Your life's held all together by what you think of.

Yes.

The future, sort of thing.

Loss of control is the problem

Yes, so when something happens that throws that and then it's not your choice any more.

That's it, I think that's it.

I don't know if that's it, I don't know. Are you okay?

He sums up.

Yes. Yes. I had a plan to do things and working and (sighs) and carrying on and just having my life. But... (46.38) and five years ago... (46.41) I bought that to sell it, but things went, the market went all crazy then. So I sold that and moved to a bungalow on... (46.57) just up the road and renovated that... (47.00). I renovated (sighs) um, I was going to, but I did most of that myself, but I wasn't well. I was running to the toilet and I was being sick and I thought I should have done it in a year or two, but it was four years. And that caused financial problems. I didn't think I was going to have to pay the mortgage for four years. I thought a year and that would have made me a bit of money and moved on. But I was lucky, I pulled through it and got there with the help of some of my friends, financially as well. I've got some good friends. You get two or three people in life who are really good, just normal people who are really good. I've helped them and so they've helped me and things, you know. So I managed to pull through it all but I planned to do another two or three houses if the market kept going and then earn some money, because as the kids were growing up, I gave them, you know, bought them a car and things, got them settled in life sort of thing. My daughter is still about and still here, she's got her own life. She's hardly ever here, she's just back on holidays and so (sighs). So you've done everything you can for your kids and you think this is the stage of life where it's your turn, but it's not going to be my turn, (chuckles) if you know what I mean. This is what... (48.29) and I put it away, that's what... money and I'd be able to save and do this and do that for the next ten years, when I was 50 to 60. That's when I should have been making my bigger pension thing, you know what I mean.

Yes, yes.

But it's just not worked out. But you look all over the country and you think it's not working for loads of people.

Yes, for all sorts of reasons.

Implies alcoholic is to blame for situation or junkie

For all sorts of reasons. And I'm not the only person. And I don't feel really guilty about going to hospital or anything. I took ill and it's not my fault I took ill. It's not that I'm an alcoholic or anything like that.

No.

have to be

Or drugs. When I took ill, just took ill, nobody knows how. So if I'm going to hospital all that time, I have paid my national insurance and tax all my life, so I think I'm entitled to it. I was made to pay it, if you know what I mean, made to pay things like that, but you're made to pay them, so, at the end of the day I don't feel guilty taking any of the services or anything. I thought about all these things, and I'm never away from this, I've always got an appointment for something, and I think district nurses came here after the hospital for two or three weeks, two nurses and they were... (49.48) but I think the cost of that is phenomenal. The health service, I get these bags and, they must cost a fortune. But I've got to have them, I've got to do it. It's just great that there is a health service.

Yes.

If it was private, you know.

Yes, yes.

Terrible. So I have had plenty of time to think over the last year and so on, being down here and, yes - and the HIMURA injections were £200 a time. That's why I said to them, 'Try them on someone else because they're not doing me any good,' and they said, well they were just giving me the option to say that. I said, 'No that's...' but there are other things that drug companies have got out, and they have to pay for these things too. I have been an expense to them (chuckles).

Yes.

So the health service is a thing that is a necessary thing.

Yes.

It's probably just gone way over the budgets and things.

Well they, to provide a really, really good service costs more than the budget that they're given and, you know, I mean they have to - they have to be, um, not economical, that's the wrong word, they have to make the best use of the money that they've got, but if they're consistently overspent, it would suggest that they're not getting enough money in the first place.

That's right, yes.

But there we are. Okay. Alright then?

Yes fine yes.

Great.

(END OF INTERVIEW)