



The
University
Of
Sheffield.

EVERYDAY LIFE WITH IRRITABLE BOWEL SYNDROME

Lauren White

*A THESIS SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE
DEGREE OF DOCTOR OF PHILOSOPHY*

UNIVERSITY OF SHEFFIELD

DEPARTMENT OF SOCIOLOGICAL STUDIES

FACULTY OF SOCIAL SCIENCES

DECEMBER 2019

ABSTRACT

This study offers an exploration into the everyday experience of living with the health condition Irritable Bowel Syndrome (IBS). IBS is a common condition, involving many symptoms such as pain, changing bowel habits, wind, and urgency to go to the toilet. Despite its commonality, however, sociological research has yet to fully explore the social experience of living with IBS. This thesis draws upon empirical research using diaries and follow on in-depth interviews with 25 participants, all identifying as living with IBS. The research aims to explore the ways in which participants navigate their daily lives, told through the places they go and the routines of their day. In doing so it seeks to capture the hidden yet significant encounters that those with IBS experience in their everyday lives. The analysis focusses on key issues including: the social experiences of food and its consequences, (re)organisations of routines, how privacy is located in places and objects, and navigating toilet access in ‘private’ and ‘public’ spheres. Throughout these everyday encounters of living with IBS, the research identifies feelings of (il)legitimacy, (in)visibility, and (in)accessibility. It also reveals the steps taken by participants to locate certainty in the face of contestation. I suggest that the sociology of everyday life facilitates an enlivenment of understandings of IBS. This is achieved precisely because of the status that IBS occupies as a common but underestimated health condition. The study offers a contribution into conceptualisations of health through the lens of the everyday.

ACKNOWLEDGEMENTS

First and foremost, thank you to all of the twenty-five individuals that offered their time and shared their experiences of living with IBS. I must also thank the Economic and Social Research Council for funding this research. I would like to acknowledge the work of The National Charity for IBS, The IBS Network and to Dr Vicky Grant who has been a constant source of support, knowledge and ally in researching IBS.

I would also like to give a special thank you to my exceptional supervisors, Professor Kate Reed and Dr Kate Weiner. I have been incredibly lucky to have your insights, time and guidance throughout the course of this thesis.

Thank you to my critical friends and academic colleagues. In particular, Dr Mel Hall, Dr Julie Ellis, Dr Ros Williams and Dr Katherine Davies who have always been supportive and have offered a listening ear. A thank you also goes to my fellow doctoral researchers, Ruth, Dawn, Laura, Natalie and Winona in particular for their daily support and for indulging me in a cup of tea and a chat.

I would also like to acknowledge the support that my disability support mentor Sarah has given me. Sarah has been with me since I arrived at the University of Sheffield as an undergraduate. The regular reminders of ‘Well done you!’ have carried me through – thank you.

Last but certainly not least, I would like to thank my family - my mum, dad and sister for all of their care and support that has got me to this point. Thank you to my mum for all the Sunday dinners and help with my washing when things got busy. Thanks to my dad who also read frequent drafts - ‘None of it made sense’ was useful advice. Finally,

thank you to my partner Will, who probably knows this thesis just about as well as I do.

I, Lauren White, confirm that the Thesis is my own work. I am aware of the University's Guidance on the Use of Unfair Means (www.sheffield.ac.uk/ssid/unfair-means). This work has not been previously been presented for an award at this, or any other, university.

A handwritten signature in black ink, appearing to read 'Lauren White', with a stylized flourish at the end.

TABLE OF CONTENTS

ABSTRACT	2
ACKNOWLEDGEMENTS	3
CHAPTER ONE	8
INTRODUCTION	8
1.2 INTRODUCTION	8
1.2 WHAT IS IRRITABLE BOWEL SYNDROME (IBS)?	9
1.3 BACKGROUND TO THE RESEARCH.....	13
1.4 THE STUDY	17
1.5 THE PRESENTATION OF THE THESIS.....	19
CHAPTER TWO	24
‘PROBABLY IBS’: PEN PORTRAITS OF THE PARTICIPANTS	24
INTRODUCTION	24
CONCLUSION.....	40
CHAPTER THREE	42
BRINGING THE BOWEL TO THE FORE IN THE SOCIOLOGY OF HEALTH AND ILLNESS	42
3.1 INTRODUCTION	42
3.2 THE (DYS)APPEARING <i>BOWEL</i> IN HEALTH AND ILLNESS	44
3.3 STIGMA AND THE S(P)OILED IDENTITY	46
3.4 HEALTH NARRATIVES AND MEDICALLY UNEXPLAINED SYMPTOMS (MUS)	49
3.6 CONCLUSION	52
CHAPTER FOUR	55
CONCEPTUALISING THE EVERYDAY	55
4.1 INTRODUCTION	55
4.2 TAKING THE MUNDANE SERIOUSLY: SOCIOLOGIES OF THE EVERYDAY.....	57
4.3 RHYTHMS AND RECONSTRUCTIONS: SOCIOLOGIES OF TIME.....	59
4.4. EVERYDAY PLACES AND SPACES: PRIVATE HOMES AND PUBLIC TOILETS	62
<i>No Place Like Home?</i>	64
<i>A Sociology of Toilets</i>	65
4.5 FROM TOILETS TO CAN’T WAIT CARDS: THE SOCIAL LIFE OF THINGS.....	67
4.6 CONCLUSION	70
CHAPTER FIVE	73
METHODOLOGY	73
5.1 INTRODUCTION	73
5.2 RESEARCH APPROACH	74
5.3 ACCESS AND LIAISON.....	74
5.4 DIARIES: CAPTURING LIFE ‘AS IT IS LIVED’	78
5.4.1 <i>Diary as Biography</i>	80
5.4.2 <i>Diary as Monitoring</i>	81
5.4.3 <i>Diary as Temporal: A Record for Time Keeping</i>	84
5.4.4 <i>Diary as Reflections on Public and Private Life</i>	85
5.5 THE INTERVIEWS: A PROCESS OF EXPANSION	86
5.5.1 <i>‘You need a big handbag when you’ve got IBS’ Reflections on Materialities in the Interview Setting</i>	90
5.6 JOURNEYS THROUGH ANALYSIS	92
5.7 ETHICAL CONSIDERATIONS	95
5.8 ABOUT ME	97
5.9 DIARIES AS RELEASE AND REALISATION.....	99
5.10 MY DEAR DIARIES: THE MATERIALITY OF ‘KEEPING DIARIES AS A RESEARCHER.....	100

5.11 CONCLUSION.....	101
CHAPTER SIX	103
FOOD AS A SOCIAL LENS: CARING FOR THE LEGITIMATE CONSEQUENCES.....	103
6.1 INTRODUCTION	103
6.2 ACCOMMODATION(S) AND ACKNOWLEDGING CONSEQUENCE	105
6.3 EXCLUSION(S) OF FOODS	110
6.4 'I'LL TAKE THE HEARTACHE': MOMENTS OF RESISTANCE	117
6.5 CONCLUSION.....	123
CHAPTER SEVEN.....	126
'LIKE CLOCKWORK': REORGANISING DAILY ROUTINE(S)	126
7.1 INTRODUCTION	126
7.2 WEEKLY ROUTINES AND THE PERIODICITY OF SYMPTOMS.....	128
7.3 EARLY MORNINGS AND THE ELEVEN O'CLOCK RULE	133
7.4 ALLOCATING TIME	139
7.5 CONCLUSION.....	144
CHAPTER EIGHT	147
FROM THE HOME TO THE (HAND)BAG: NEGOTIATING INTIMACY AND PRIVACY.....	147
8.1 INTRODUCTION	147
8.2 GEOGRAPHIES OF HOME AND SHARING	149
8.3 INTIMATE BELONGINGS	156
8.4 PRIVATE MOMENTS IN PUBLIC.....	162
8.5 CONCLUSION.....	167
CHAPTER NINE.....	170
"I HAVE TO KNOW WHERE I CAN GO": NEGOTIATIONS OF TOILET ACCESS AND MOBILITIES	170
9.1 INTRODUCTION	170
9.2 MAPPING OUT SPACE: TOILET MAPPING.....	172
9.3 MOVING THROUGH SPACE: TRAVELLING VIA PLANES AND TRAINS.....	178
9.4 BOUNDED SPACES: IN/ACCESSIBILITY	183
9.5 CONCLUSION.....	190
CHAPTER TEN.....	193
CONCLUSION	193
10.1 INTRODUCTION	193
10.2 THESIS STORY	195
10.3 INFORMING PRACTICE.....	203
10.4 LIMITATIONS	205
10.5 FUTURE RESEARCH	206
10.6 CONCLUDING THOUGHTS AND CONTRIBUTIONS	208
REFERENCES	210
APPENDICES	223
EVERYDAY LIFE WITH IRRITABLE BOWEL SYNDROME: INFORMATION SHEET	223
CONSENT FORM.....	226
DIARY GUIDANCE	227

“My husband’s got normal bowels, just a’ lately he’s gone off a little bit for what reason we don’t know, he had a bad bout of flu last year, he was poorly for a good four or five weeks...Whether or not that’s it, I don’t know. He has said, ‘Oh I haven’t been to the loo today’. Now to me that’s normal, but to him, it isn’t. He’s up ten minutes and ‘Ohhh’ you know. Deary me, I wish I could be like that.”
(Brenda’s interview)

“What is ordinary and mundane to one person might be quite extra-ordinary for another.” (Scott, 2009: 2)

CHAPTER ONE

INTRODUCTION

Imagine it's Christmas time and you're off to stay with your extended family.
You are up an extra hour earlier than normal, just in case.
You miss breakfast today.
You take a couple of tablets, just in case.
You figure out the toilet stops on the motorway.
Your bag is packed with tissues and toiletries, just in case.
You arrive and you skip the downstairs toilet in preference for the upstairs one.
You feel awkward at the family meal because you avoid the vegetables, just in case.
You get anxious on what should be the therapeutic family walk to the countryside.
You try the toilet just before you set off, just in case.
It's 'just' that you have IBS, a bit of stomach ache, but nothing of significance.
But for you, there is nothing *just* about it.

1.2 INTRODUCTION

The account above is a fictional one, written to inspire a sociological imagination about the daily life of someone with irritable bowel syndrome (IBS). The intention is to tell a story of the everyday strategies whilst simultaneously giving weight to the taken-for-granted nature of the condition. This thesis offers a sociological analysis of everyday life with IBS. In particular, it seeks to explore the ways in which the condition is negotiated in relation to the places people can or cannot go, the routines or reorganisations of their day, and the people and material objects that matter. Utilising solicited diaries and follow on semi-structured interviews with twenty-five participants,

the thesis aims to provide insight into the daily experiences of living with this common health condition. The participant diaries facilitate an understanding of everyday life through capturing the personal accounts of experiences of IBS and facilitating the often hidden, but incredibly common strategies employed in navigating symptoms. From the train to work to the weekend walk with the dog, the accounts in this thesis engage with the minutiae of daily life and the ‘ordinary’ activities that IBS complicates and brings to the fore. By framing experiences of IBS through the lens of the everyday, we see the daily navigations of living with a common yet contested condition, where the severity of symptoms often stands as unnoticed. By conceptualising the experiences of IBS in this way, there is an appreciation of how we might notice the minutiae of everyday life that those without IBS may take for granted, and simultaneously gives weight to the condition in its own right. It is through the negotiations of IBS that daily encounters become noticeable. The study aims to contribute to the sociology of health and illness by framing the empirical work with the sociology of everyday life. This introductory chapter aims to familiarise the reader with the condition of IBS. I will then trace an outline of the background of the study and the sociological issues that are at play. These will begin to build a picture for the foundations for this research. Finally, I will provide a plan of the thesis.

1.2 WHAT IS IRRITABLE BOWEL SYNDROME (IBS)?

Irritable bowel syndrome (also known and abbreviated as IBS) is a common health condition. The symptoms include abdominal pain, bloating, constipation and/or diarrhoea, urgency to go to the toilet, and a felt need but inability to go. However, symptoms also go beyond the digestive tract, with individuals experiencing fatigue, urinary problems, back pain, anxiety and depression. The severity of the symptoms can vary from person to person, as can the collection of symptoms that are experienced at one time. Symptoms are wide-ranging, and this is in part due to the difficulty in

classifying the condition¹. IBS is said to affect up to 20% of the UK population². It is twice as likely to be diagnosed in women than in men³. It is experienced at all stages of the life course, although we shall see later that the symptoms are often present from an early age but only diagnosed as IBS when a person enters into adulthood.

The process of *diagnosis* is important when it comes to IBS. The condition can only be diagnosed when all other associated conditions have been excluded. These include Bowel Cancer, Inflammatory Bowel Disease⁴ (abbreviated as IBD which includes the conditions of Crohn's Disease and Ulcerative Colitis) and Coeliac Disease⁵. These conditions are often labelled as serious, and the symptoms that separate them from IBS are considered 'red flag'⁶. These include unintentional weight loss, rectal bleeding, and a family history of cancer of the bowel or ovaries. The diagnosis of IBS tends to take place in the GP surgery, and there is not always a referral to a specialist gastroenterologist. Individuals may also self-diagnose IBS based on their knowledge and experience of their collection of symptoms and commonality.

There is no known cause of IBS and at present, it is a poorly understood condition. As it is a syndrome, IBS is a *collection of symptoms* that has no biomarker or medical test that can identify and definitively diagnose the condition. Current knowledge suggests that there are associations with the motility of the gut, nerve sensitivity, stress, and family history⁷. An onset of IBS can also occur following a bout of food poisoning or

¹ For a full list of symptoms associated with IBS, see the symptom page on The National Charity for IBS: <https://www.theibsnetwork.org/have-i-got-ibs/what-is-ibs/>

² See NICE guidelines for further information on diagnosis and prevalence: <https://www.nice.org.uk/guidance/cg61>

³ The gendered aspects of IBS could stand further scrutiny (see Bjorkman, 2014; Dixon-Wood and Critchley, 2000). One might also consider the gendered nature of health seeking behaviour in relation to getting a diagnosis from visiting the GP (see Annandale, 2014). See also studies into women's experiences of living with contested, unexplainable illness (See Malterud, 2000)

⁴ For more information on IBD please see: <https://www.nhs.uk/conditions/inflammatory-bowel-disease/>

⁵ Coeliac disease is a life-long condition in the small bowel caused by a reaction to gluten that is found in wheat, barley and rye (NICE, 2015)

⁶ See section 1.1.1.2 for description of red flag symptoms <https://www.nice.org.uk/guidance/cg61/chapter/1-recommendations>

⁷ See NICE guidance on treatments for IBS: <https://www.nice.org.uk/guidance/cg61/chapter/1-Recommendations#dietary-and-lifestyle-advice>

gastroenteritis. Consequently, this process of diagnosis by exclusion means that the label of IBS is often a diagnosis of *dismissal* for individuals (Bertram *et al.*, 2001; Stenner *et al.*, 2000). Despite the fact that the symptoms of IBS can also be present in conditions that are considered ‘serious’, the diagnostic category of IBS means that there is often a failure to appreciate the effect that these symptoms can have on people’s everyday lives. This exclusion and dismissal can leave a feeling of ‘*epistemic invalidation*’ - that the experiences of those living with IBS are often invisible to the scientific, objective, and observable knowledge un/seen in the clinic (Bjorkman *et al.*, 2016: 2974). Dancy and Rutter (2005: 8-12) refer to the diagnosis as a ‘*dustbin*’ one, where any unexplained symptoms of the bowel get thrown into the category of IBS.

The current treatments to manage symptoms typically surround moderations in diet, medications, and lifestyle changes. NICE guidelines⁹ offer first-line advice in the management of IBS, which include physical activity, relaxation strategies, dietary advice and probiotics¹⁰. Following this process, patients can then be referred to a dietician and follow a low-fodmap diet¹¹. Doctors can also prescribe medications such as laxatives¹², antispasmodics¹³, loperamide¹⁴ and in some cases, antidepressants. Sometimes, hypnotherapy¹⁵ and cognitive behavioural therapy (CBT¹⁶) are also drawn upon. These numerous treatments reflect the lack of a universal and successful way to manage symptoms, and that individuals find their own ways of negotiating them. This will become evident in the course of this thesis.

⁸ NHS Choices makes references to some of the potential causes of IBS. See:

<https://www.nhs.uk/conditions/irritable-bowel-syndrome-ibs/>

⁹ For more info on NICE guidelines into IBS see:

<https://www.nice.org.uk/process/pmg20/chapter/introduction-and-overview>

¹⁰ Probiotics are food supplements containing bacteria or yeasts that may be a health benefit (NICE, 2015)

¹¹ For more information on the low-fodmap diet please see:

<https://www.webmd.com/ibs/guide/what-is-fodmap#1>

¹² Laxatives are medications designed at loosening the contents of the bowel or stimulating a bowel movement

¹³ Antispasmodics are a type of medication aimed at relaxing gastrointestinal muscles

¹⁴ Loperamide is an antidiarrheal medication

¹⁵ Hypnotherapy is a therapy that works to create subconscious change in a person’s attitude, approach or behaviour (NICE, 2015)

¹⁶ Cognitive behavioural therapy (CBT) is a talking therapy aimed at challenging ways of thinking and behaviours (NICE, 2015)

Together with these medical understandings of IBS, the next chapter ‘Probably IBS’ will feature important narratives of the participants’ experiences. These include coming to be diagnosed with IBS, how they make sense of and manage the condition, and the things that matter in their everyday lives as they negotiate symptoms daily. First, however, I will provide some background to the thesis, by discussing current studies on IBS, the absence of the ‘social’, and why this paves the way for my sociological research.

1.3 BACKGROUND TO THE RESEARCH

As we have seen in the previous section, IBS is still somewhat of a medical mystery. Given how common it is, one would expect a wealth of research into the condition. However, there has been little research into IBS. Studies to date tend to focus on biomedical knowledge or the placing of IBS within psychosomatic realms. When we turn to the few studies that explore the ‘*social*’ experiences of IBS, we capture only a glimpse of what it means to have the condition. For example, there are a number of studies that have acknowledged the effects that IBS can have on health-related quality of life, albeit from a medicalised perspective (see for example, Amouretti *et al.*, 2006; McCormick *et al.*, 2012; Monnikes, 2011; Penny and Smith, 2012). Current literature has also acknowledged the problematic healthcare encounters and the lack of support or negative treatment experienced by those living with IBS (Bertram *et al.*, 2001; Bjorkman *et al.*, 2016). Bjorkman *et al.* (2016) explore patients’ experiences of negative healthcare encounters through a narrative and feminist lens, arguing that those living with IBS strive to portray a positive identity in the presence of trivialisation by healthcare professionals. Håkanson *et al.* (2009) have also explored how living with IBS can mean a struggle with an unfamiliar and unreliable body, leading to altered self-image, shame, tiredness, and distrust. Rønnevig *et al.* (2009) echo similar findings stressing the pressing nature of unpredictability in the lives of those with IBS. Håkanson *et al.* (2010) further explore unsupportive healthcare encounters that demonstrate how those with IBS faced disbelief, humiliation, and feelings of abandonment. As a result, they suggest that those with IBS lose trust in their own experience and have an unfamiliar sense of being in the world. The research captures two key points. First, that there is a poor experience of healthcare due to the lack of recognition of IBS. Second, there is a related loss of trust in individuals’ own experiences precisely because this certainty is not established within the clinic.

While the research mentioned above privileges narrative experiences of people living with IBS, studies continue to be undertaken by healthcare professionals, which take place within healthcare settings. This does not allow for the necessary extension into the in-depth everyday experiences *beyond* the clinic. This is particularly important precisely because of the rejection IBS faces when a diagnosis is reached. Moreover, it is important again when we consider how the dominant treatments fall into categories

of diet, lifestyle and stress management. Herein lies the gap in studying IBS, where research fails to go beyond experiences within healthcare. It does not acknowledge the *everyday* experiences of living with the condition, despite its limited involvement in treatment, management and to some extent, diagnosis. What happens in the lives of those with IBS once the diagnosis is given and the doctor's door is closed? How might we give attention to the condition that is trivialised and managed through 'lifestyle'? It is this gap that this thesis seeks to fill. It traces how individuals negotiate their IBS within the tasks of everyday life, locating the condition in the places, routines, relations and objects that bring it to light. When negotiating IBS becomes the undertaking of people's everyday lives, research should follow and locate it in such. So how might we get at a health condition that is taboo, trivialised, and the severity of symptoms taken-for-granted, but tells an important tale about the lived experiences of so many? My argument is that this can be aided by the sociology of everyday life.

Turning to the Sociology of Everyday Life

Thus far, I have sought to demonstrate the commonality of IBS as a condition; its diagnostic process, and the context to this research that tells us how the condition is negatively experienced due to its ambiguous status. I have reflected upon the potential for thinking beyond the boundaries of the clinic at the point of diagnosis, given that the options for managing the condition are so often grounded in 'lifestyle'. With this in mind, I turn to the sociology of everyday life as the conceptual basis for this thesis. The rationale for this is that it gives weight to the dismissed, the glossed over and the minutiae of daily life, that tell a broader story of how we live the way we do. Neal and Murji (2015: 812) suggest that focusing on the everyday involves an immersion in the '*seemingly unremarkable, routine relationships and interactions with others, things, contexts and environments*'. These seemingly unremarkable things are important: attending to them is what those with IBS require in order to validate their social experiences. As I will show, the intertwined encounters and facets of the everyday are very much at the heart of this thesis, and of the lives of those with IBS. I now want to introduce why the sociology of everyday life is useful for studying IBS, and why the case of IBS offers something to the study of the everyday.

So why is the sociology of everyday life useful for understanding the experiences of IBS? My argument is that there is something to learn and appreciate as the conceptual task of the everyday is to take the seemingly unremarkable, pay explicit attention and *listen* to it. As Neal and Murji (2015: 812) argue, the everyday involves an engagement with the '*unremarkable*'. My argument is that symptoms of IBS, at present, fit within this category as they are not seen as serious in line with other illnesses. Moreover, the sociology of everyday life, in its everything and nothingness, facilitates a contribution to an inclusive conceptualisation of health and illness. There is a limitation within the current realm of sociologies of health and illness even in the presence of illness narratives and medically unexplained symptoms. It is important to acknowledge how illness goes beyond disruption and the medical realm, made apparent in the case of IBS. It is not only a matter for medics, but for broader, common-sense understandings. The sociology of everyday life is further significant in the exploration of IBS because of its position as a common illness, but where its symptoms are taken-for-granted and reportedly dismissed by medicine as an institution in terms of their severity. As previously stated, IBS is an extremely common condition, known about, and present in a substantial minority of the population. However, it is also rarely articulated and made visible, precisely due to the 'taboo' nature of the condition. In '*Making Sense of Everyday Life*', Susie Scott (2009: 2) posits that our everyday lives are simultaneously private and personal. This is a distinction ever more valuable when considering the private nature of IBS symptoms, together with a public landscape of how commonplace the condition is, and a universal need to go to the toilet. The accounts later in this thesis will illuminate the everyday nature of the symptoms of IBS. Moreover, many of the participants tell a story of how IBS is *normal* for them and has always been present in their life, even if it has been granted little attention by both the general public and the medical community.

The sociology of everyday life also encourages the facilitation of hopefulness and continuity, even in times of chaos and disruption. I seek to address the balance of giving weight to the severity of IBS whilst simultaneously not portraying a picture of sole desperation. Les Back (2015: 821) stresses that in taking the mundane seriously we ask, '*what is at stake?*' in our daily encounters. In particular, I will stress how the taken for granted assumptions about daily life are illuminated, disrupted, and routines *reimagined*

through the everyday experiences of people with IBS. Studying everyday life also means we consider life as a whole, from the moments of despair and desperation through to the ordinary triumphs of *getting by* (Miller, 2008). As we will see from the participants in this study who live with IBS, they are not simply accounts of struggle, desperation and chaos, but of resourcefulness in the management of doing everyday things and getting on in spite of symptoms. Routines are created; family members care and accommodate; neighbours jump in at the supermarket when someone has to rush home to the loo. These events and practices are also an important part of the picture.

The case study of IBS offers something more to the sociology of everyday life too. Illness, disability, and the body (explicitly its *products*) are not clearly seen within the study of everyday life, though it is not only the responsibility of those within the sociology of health and illness or disability studies to appreciate these. Health, illness and disability span more than that. The sociology of the everyday allows us to go beyond illness as disruption and it facilitates an *inclusivity* of illness or health conditions to fit within the realm of the *ordinary*. This is something achieved in Nettleton and Watson's (1998: 1) edited collection *'The Body in Everyday Life'* in their argument that *'we all have a body'*. However, with IBS it is not only the body, but rather its *products* that matter. In viewing IBS through the lens of everyday life, we see the symmetries and asymmetries of health and illness. The status of IBS offers a particularly useful connection point in what we consider illness and what we do not. This proposition is not offered to add to this contestation, but rather to highlight how this very status offers a particular distance between health and between illness. To some extent we all think about the right time to go to the toilet, or we question whether eating certain foods might give us a stomach ache. We know our bodily rhythms, even if we might not be immediately conscious of them. We may feel unease at defecating in a domestic toilet that is not our own and we might weigh up whether we should drink that coffee before embarking on a lengthy motorway journey. And yet, these matters of everyday life are brought to attention only through the case of IBS. Otherwise, they are the unspeakables of everyday life, despite being commonplace. The case of IBS uncovers a very human part of everyday life by showing the mundane experiences of our morning routines, our social experiences of sharing public toilets, of packing up our bags for the day trip out, and of eating together. This is important because this conceptualisation enables an

empathetic understanding through the everyday encounters of IBS, that are not as distant or extreme as we might initially think.

I have set up a justification for the sociology of everyday life as important in the study of IBS, and what IBS offers for understanding everyday life. In the sociology of everyday life's focus on illuminating what is passed over as insignificant, there is an opportunity to conceptually approach the daily experiences of those living with IBS in the same way. Doing this allows for an appreciation of symptoms and the demand for attention in the face of unpredictability, illegitimacy and inaccessibility. However, this is by no means exceptional, but simply an illumination of how the small details of everyday life become important in broader understandings. IBS also offers something to the sociology of everyday life too. It facilitates an understanding, and more importantly an inclusion, of health and illness and their place within the minutiae. This is facilitated by a consideration of IBS not as a distinctly disruptive condition, but as one that occupies a liminal space that allows this to come to the fore.

1.4 THE STUDY

The thesis builds upon my own research journey of studying IBS sociologically. I began with my undergraduate dissertation which explored women's experiences of living with IBS (White, 2016a). This research introduced me to the importance of toilets for people living with IBS. Consequently, my master's dissertation explored the processes of toilet mapping with the use of mobile methods (White, 2016b). Engaging with toilet mapping sensitised me to spatial, temporal, and relational ways that IBS comes to be experienced by those with the condition. These accumulations of knowledge and my developing sociological curiosities have structured the questions of this thesis. Thus far, I have sought to introduce a brief description of what IBS is, and the current understandings of the illness trajectory and its treatment. I have introduced academic literature on IBS and demonstrated how this has typically focussed on negative encounters within the healthcare system. My argument is that, in the main, experiences of IBS are not within the realm of the clinic, but within the minutiae of everyday life. This point is further supported by the fact that IBS is not granted status within medicine, and symptoms experienced may be glossed over or seen as insignificant. Due to this ambiguity, I

suggest that the sociology of everyday life conceptually guides the study of IBS. This is because of the weight given to what is glossed over as unremarkable, and the ways people get by in spite of disruption. Further, the study of IBS has the potential to contribute to the sociology of everyday life, by considering the taken-for-granted practices of our bodies, of health, illness, and disability. IBS offers a useful case to do this because of its status as a common but glossed over health condition. The task of the thesis is to shift focus to the day-to-day practices of negotiating the symptoms that characterise IBS. Therefore, the thesis asks the question, ‘*How do people negotiate IBS in their everyday lives?*’ Engaging with this further, I pose the following research questions:

- How are symptoms of IBS experienced in *mundane everyday spaces*? How are these symptoms negotiated as people *move between* these *places* of the *home*, the *workplace* or the *dinner table*?
- What are the *daily routines* and navigations of *time* for those living with IBS? How might these routines be disrupted, (re)organised and (re)imagined?
- What *social* and *material* relations are at play for those with IBS? How might these relations play out in ‘*public*’ and ‘*private*’ life?

These questions come in part from my earlier research that attuned me to the spatial, temporal, relational, and material ways in which IBS is navigated. However, the thesis develops these issues in both depth and scope. It addresses how symptoms are experienced in the home and in the workplace and the spaces in between. It asks where people with IBS feel they can go, and the places they feel they cannot. It explores the routines of daily life, from getting up in the morning and the commute to work, to the time we allocate to the things we do and how these meet or come into conflict with the temporal rhythms of the clock of the bowel. It explores the material things that matter, from the presence of toilets to the carrying of medications in handbags and gloveboxes, to see how the hidden and quiet presences of these things become heightened and important, even if we might not necessarily see them. More broadly, the thesis seeks to explore the shifts between public and private worlds. It asks about the ways in which IBS is articulated and, more importantly, called into question in the face of invisibility and legitimacy. These sit within a broader insight into the negotiations of daily practices when living with IBS. The daily diaries and follow on interviews capture the hidden

aspects of life with IBS. The participant accounts of where they go, the routines of their day, and the items of importance, show a condition seeking out legitimacy, accessibility, and certainty in the face of unpredictability. These are important to notice in light of IBS being a condition that is glossed over, contested and seen as an unimportant health condition. As such, this thesis works at bringing these aspects of this condition to light.

1.5 THE PRESENTATION OF THE THESIS

This thesis is divided into ten chapters. Following this introduction, the thesis follows with chapter two, '*Probably IBS*'. This chapter provides twenty-five pen portraits of the individuals that took part in the study. These accounts introduce the background of the participants and their arrival in this research. Placing these biographical narratives at the fore of this thesis is a deliberate attempt to prioritise the backgrounds of the participants, as well as giving weight to the processes of IBS being worthy of attention. In beginning with these portraits, I also keep in mind the research process and how the biographical accounts often became the first words written down in the diaries and spoken in the interviews. Similarly, the analytical process required this biographical base to give weight and meaning to the everyday experiences conceptualised in subsequent chapters. In listing every participant's biographical fragment here, I aspire to include a small account of each individual that may not be present in later empirical chapters, and as a way of being egalitarian. This section does not include an overt theorisation of illness narratives, nor does it include the processes of diagnoses. Through these portraits, I emphasise the participants' voices, their experiences of IBS, and the ways in which IBS fits into their everyday lives.

The literature review of the thesis is in two parts. Part one, chapter three, reviews some of the relevant literature within the sociology of health and illness. This includes studies that have attended to the bowel in times of health and illness, reflecting upon how these contributions have neglected IBS. I argue that this further demonstrates the status of IBS as both a *taboo* and *taken-for-granted* illness. As part of this, I reflect upon stigma as an important backdrop in terms of the unboundedness of bodily products and the stigma of not having what is perceived as a legitimate health condition. As such, the

final section of part 1 engages with narratives of health and illness that have explored everyday experiences of health conditions. I then bring to attention the role of literature exploring medically unexplained symptoms and the role of diagnosis. Literature within the sociology of health and illness explores stigmatised health conditions and those that are medically unexplained. However, IBS is missing from these debates. I suggest that this is due to IBS being both contested *and* taboo, and reflect upon the status of IBS as common but denied attention due to these factors. With this in mind, I argue that the status of IBS as a medically unexplained but ignored condition, benefits from the conceptual approach of the sociology of everyday life that uncovers and gives explicit attention to the '*seemingly unremarkable*' (Neal and Murji, 2015: 812). As such, part two sets the conceptual framework for the thesis by exploring some of the literature within the sociology of everyday life. In line with the research questions, it delves into everyday notions of time, space, and materiality. I conclude the review of the literature by establishing a contribution to the sociology of health and illness and the sociology of everyday life, suggesting that IBS bridges these two bodies of literature together through the status it occupies as a common, but glossed over health condition. It further establishes a gap within the sociology of everyday life, facilitating the inclusion of health and illness achieved through this work.

Chapter five provides a detailed description of the methods utilised in this research. I explore the background and biographical foundations underpinning this research, the anticipation and preparation for doing the research and justification for utilising the diary and interview method (Zimmerman and Weider, 1977). Second, I explore the data collection process, offering reflections on the nuances of diary methods and follow-up interviews. I tease out themes that include monitoring food, time, and private aspects of life. These themes lend themselves to the production of the empirical chapters that follow and engage with the theorisations of everyday life. I offer brief reflections on the ethnographic elements of the interview process that include the materials that were made present. Then, I reflect on the analytical process and how this forms part of the structuring and storytelling of this thesis. Finally, I reflect on the more personal and ethical encounters of my research journey.

Chapters six to nine detail the everyday negotiations of living with IBS. These chapters explicitly engage with fragments of the everyday, connecting the sociology of everyday

life with the daily experiences of those with IBS. I do this in conversation with the pen portraits that will be seen shortly, setting up the complexities of IBS as a contested illness and how the symptoms are made to be real and experienced in daily practice. I do this to show how the ambiguous, contested, and often denied experience of IBS sits against the realities of everyday life. More specifically, I attend to the daily experiences of food, routines, navigations of privacy and intimate worlds, and finally, the places one can or cannot go based on toilet access and the mobilities of everyday life.

Chapter six explores *food* as a social lens on life with IBS. I start with this as the first empirical chapter as a response to the overwhelming presence of food in the accounts of living with IBS. Drawing upon the sociological theorisations of food, this chapter seeks to unpack notions of inclusion, exclusion, and resistance. I do this through Murcott's (1993) understanding of the consequential nature of food that includes excretion, and through Nettleton *et al.*'s (2010) ideas concerning the '*moral threat*' of food intolerances. To achieve this, I document how food is made inclusive within relationships and the processes by which others accommodate with 'consequence' in mind. Second, accounts are presented on the experiences of exclusion. This includes social exclusions in terms of sociality. However, it also explores the complete avoidance of food in social life due to the complexities of communicating the *legitimacy* of food intolerances, together with the declaration of the *consequential* nature of food. Finally, situated within the complexity of the IBS diet and the pleasures of and efforts to strive for social participation, accounts of resistance to an IBS friendly diet are uncovered. This chapter ties together scholarship on food intolerances and on the consequential nature of eating to include excretion. In doing this, the chapter illuminates how those with IBS navigate social experiences of food with the undertone not only of a questionable and contested diet, but one that also involves the potential consequences of IBS symptoms.

As an additional way of demonstrating how IBS is negotiated, chapter seven moves onto the rhythms of the everyday. The chapter '*like clockwork*' explores how time is (re)negotiated when living with IBS. It draws upon theorisations of everyday routines and time. There is a deliberate reflection on the temporal calculations of the body. I extend temporal concepts related to the body (Adam, 2004) to the digestive system after participants referred to their rhythmic bowels as '*like clockwork*'. First, there is an

exploration into weekly routines and the periodisation of symptoms. This periodicity demands a recognition of regularity and disruption. Second, there is an acknowledgement that participants often go through a process of (re)organising their daily routines. Here I focus upon how morning routines offer an important lens on how social structures meet the individual and how participants rework their lives to *pace* or *slow* these down. Finally, there is an exploration of how the timing of everyday tasks meets the demands of those we interact with and the places we need to be. This chapter considers the body in time, extending ideas of the body or biological clock to include the bowel as '*like clockwork*'. Specifically, it considers how the biological clock of the bowel meets and comes into conflict with the social, through the pressures of time that is *squeezed* or *disrupted*. The chapter stresses the processes of accommodation, pacing, and (re)organisation.

Chapter eight '*From the Home to the Handbag*' examines how participants negotiate privacy when experiencing or expecting IBS symptoms. Drawing upon Twigg's (1999) '*ordering of privacy*', I map the intimate ways in which participants establish privacy in domestic spheres and the move to locate privacy in public realms. Here, I highlight that whilst there is a preference for managing IBS symptoms at home, there are also intimate geographies within the home. These are told through the *sharing* or *spatial orderings* of domestic toilets. Second, I move from the home to the material ways in which participants carry items to ensure privacy. I analyse the way intimate belongings work at achieving privacy and '*ontological security*' (Giddens, 1991) in managing IBS symptoms, building upon Buse and Twigg's (2014) work on handbags. Finally, I explore how privacy is navigated in public and how there is often a return to the home as part of this. The paths to obtaining privacy are illuminated as symptoms move from the home to the handbag, and through to the public sphere. This chapter engages with the sharing and intimate geographies of space and the role of material objects as a way of securing privacy.

The move from chapter eight to nine attempts to capture the move from 'private troubles' to 'public issues' (Mills, 1959) in the changing landscape from private domesticities to public domains. The final data chapter explores the negotiations of toilet access and broader questions of mobilities. It engages with the question of where one can *go* when toilets become a priority. Chapter nine begins with the importance of

understanding space and place as ‘central’ to sociology (Urry, 2001: 3) and draws upon previous literature relating to toilets and mobilities. First, I discuss the processes of toilet mapping whereby individuals come to know of toilet locations, the time it takes to get to the toilet, and how their material makeup is central to establishing certainty. Second, I consider the ‘*emotional geographies*’ (Sheller, 2004) of travel and how this extends to IBS symptoms. Accounts of train travel, routes to work and experiences of flying bring to light IBS as a condition thought about ‘on the move’. Acquired knowledge of toilet locations and the issue of getting to them lead up to the final issue of toilet accessibility. I address both physical accessibility and the felt experiences of what a sensorially appropriate bathroom is. I illustrate how disabled toilets are negotiated, contested, and how the experiences of IBS as an *invisible* and *contested* condition leads to processes in which individuals work to ‘pass’ as having an alternative ‘legitimate’ illness.

Finally, chapter ten concludes this thesis. I retrace my steps into the research process and the importance of IBS as a topic worthy of sociological exploration, and why the sociology of everyday life provides an important framework. Thus, I work to fill an important gap in the theorisation of the experiences of IBS as a condition. I consider the broader threads that tie the themes of food, time, privacy and mobilities together. These important facets of everyday life work to provide meaning to the experiences of living with IBS. I offer broader implications for the study, suggesting how this knowledge and understanding may be of use for those working with IBS and those experiencing it. I offer sociological contributions into key substantive areas and reflect on the road to future research.

CHAPTER TWO

‘PROBABLY IBS’: PEN PORTRAITS OF THE PARTICIPANTS

INTRODUCTION

The aim of this chapter is to introduce the participants of this study. These portraits work by offering a ‘background’ to each of the participants, and also provide a narrative into their experience of IBS as a diagnostic process and label. Pen portraits or short biographies¹⁷ are often placed briefly in the methodology or referred to in appendices. Whilst this may be appropriate in some cases, I felt that it was necessary to start with the person. This personal feeling was reiterated by the fact that these biographical notes were often the first stories written in the diaries or spoken in the interviews. These accounts were given *before* the minutiae of everyday life came to be revealed. As such, I look to reflect this ordering in the structure of this thesis. Much of the portraiture work is directly taken from the diary and interview accounts themselves or paraphrased from the data. Moreover, whilst not all of the participants accounts will be discussed in the later chapters, it felt important to ensure that their diverse biographies were still placed within the thesis to capture the experiences of IBS and the ways in which it comes to be known. Similarly, this chapter engages with the argument that Les Back (2007: 17) makes as he says, ‘*quotation is not portraiture and it is the task of sociological writing to bring to life the people we work with and listen to*’. The quotes in later chapters cannot live without the biographical accounts presented in this chapter.

This chapter also works in some way as a provocation. As seen in the introduction, IBS is an illness that is contested, and poorly understood, and the trajectory of the illness and its management is not clear cut. These pen portraits aim to throw a heavy weight on to the narrative of IBS as a condition that is underestimated, and often not taken very seriously. These pen portraits and the ‘*probably IBS*’ work that is made visible is a

¹⁷ I will use pen portraits and biographies interchangeably throughout the chapter and thesis

prompt for the later conversations on the daily experiences of IBS, told through the places people go, the routines of their day, and the social and material relations made important in private worlds and public spheres. These pen portraits also do important work in demonstrating what is at stake when living with IBS. First, the portraits help to show the processes of diagnosis and how the experience and biographical facets people attribute to this, such as the family histories of illness they find themselves within. Second, these biographical accounts work at underscoring the difficulty of diagnosis, and of living with a medically ambiguous and neglected condition. Third and finally, the individual narrations show the everyday work performed by living with the condition *precisely* because of the diagnostic processes and failure to legitimise the experiences of living with IBS and the severities it can carry. These social processes result in individuals finding their own path to navigating the symptoms they experience in the absence of universal and successful treatment, and thus pave the way for later chapters in this thesis.

Kelly¹⁸

Kelly is a 48-year-old woman who works within an administrative team in a university. She lives with her husband, who is a chef, and has no children. Kelly has lived with IBS for the past 8 years, and believes her onset was when she was around 40 years old. She has had food intolerances for longer, having headaches from foods such as cheese, chocolate and oranges. Kelly associates her symptoms of IBS with both food and stress. Kelly uses a herbalist for her migraines and periods, and has tried using herbal remedies for her IBS. She has often questioned whether or not she has endometriosis¹⁹. When first diagnosed, Kelly '*massively modified*'²⁰ her diet. She saw a dietician and took their advice on board. Kelly explained that she knows what she '*can and can't have*'. However, Kelly also recalls having conversations with her alternative therapists about the role of stress and IBS. As a result, she employs mindfulness and breathing techniques from Yoga and Tai Chi, but feels it takes a '*lifetime of practice to master it*'. Despite this, Kelly explains that she '*struggles with IBS all the time [which] shows*

¹⁸ These names are pseudonyms for each of the participants and will be referred to throughout the thesis.

¹⁹ The symptoms of endometriosis are similar to those of irritable bowel syndrome (see <https://www.endometriosis-uk.org/endometriosis-and-bowel>)

²⁰ Italicised quotes are borrowed from participants written thoughts or spoken words

how difficult it is to control'. For Kelly, her IBS *'can feel overwhelming and all encompassing, like your whole life is dedicated to managing this condition'*. Kelly described negotiating her IBS as *'masquerading as a normal person'* whilst not wanting others to find out.

Shaun

Shaun is a 44-year-old man who works as a freelance sports journalist. Alongside this, he is a full-time carer for his mother, whom he lives with alongside his father. Shaun changed career around 7 years ago to care for his mother and cited a lot less stress since. Despite this, Shaun thinks his IBS is *'quite prevalent now'* and feels it *'dominates day to day activities'*. Shaun has lived with IBS for a few years but believes he can trace his symptoms back to being much younger. Shaun explained that he probably had IBS at university as he remembers *'incidents then that he didn't think much of at the time'* and reflected on the role of alcohol. Shaun is not sure what triggers his IBS and cannot easily pinpoint the causes. Shaun wondered if he is *'secretly stressed'* but does not believe he is. He puts his IBS down to a *'bad tummy...gone bad, an everyday bad tummy'*. The main symptom of his IBS is bloating. Shaun recalled seeing a doctor two years ago, worrying that it could be something *'more sinister'* but he had a colonoscopy which he felt he was *'desperate for'* as he *'wanted to know'*. He described the doctor identifying a *'raw area'* from which his pain emanates. However, the doctors referred him back to his GP, said it was IBS and *'that was that'*. Since then, Shaun has not been back to the doctor.

Stacy

Stacy recently gave up a job in the public sector to return to university. Alongside being a student, Stacy works part time supporting disabled children. Stacy is currently living with her partner at her parents' house. She recalls having IBS for approximately 3 years, with the onset of symptoms beginning at the start of her old job. Stacy stated that she ignored her symptoms at the start as it was often pain after a rich meal but *'never anything prolonged'*. Stacy remembers having a conversation with her mum about whether her new job was a contributory factor for the onset of her IBS, but Stacy felt it was just a coincidence. Stacy said that she is a *'logical'* person and IBS is something that *'you can't find any logic to'*. She explained how completing the diary for this research showed her how good days and bad days are not indicative of something she

did or did not do. For her, the lack of clarity is the most frustrating thing about IBS. For Stacy, her main symptoms of IBS are pain and discomfort. Stacy was not sure if this was better or worse than having '*constant*' constipation or '*regular*' diarrhoea, but the pain, which she feels is less severe and intense, is also more constant and underlying than other symptoms.

Deborah

Deborah is a 67-year-old retired woman who has two daughters, grandchildren, and lives at home with her husband. Deborah explained that she has lived with IBS since she was approximately 50 years old. In the back of her mind, Deborah explained, she thought about her mum who had bowel cancer. In the year 2000, she had a colonoscopy which was 'ok' and Deborah was then prescribed Buscopan²¹ and Imodium, which she was already taking. She discussed IBS with her GP, initially thinking that IBS meant constipation, and not the diarrhoea that she was experiencing. During this time, Deborah described not being able to go out due to the extent of her symptoms. Later down the line, a doctor encouraged her to '*speak to someone*', leading to her having Cognitive Behavioural Therapy (CBT). Deborah explained her anxiety of waiting in the doctors' surgery and needing the toilet, alongside her experiences of anxiety with bus journeys. The CBT therapist encouraged Deborah to go on a bus ride every day whilst living with her symptoms. Deborah explained that she '*relies*' on Imodium and discussed how the CBT therapist has encouraged her to challenge this when going out. Deborah explained she has also a prolapsed bowel which she had surgery for.

Dean

Dean is a 58-year-old man, who lives alone and retired two years ago due to ill health. Dean has lived with IBS for around 18 years, citing the beginnings of it around the age of 40. He believes it is due to a combination of '*middle age and the bigger factor - stress*'. Dean recounted the experiences at this time, namely his demanding work as a financial director and living with his father who was elderly, became ill, and passed away. Around this time, Dean noticed that he needed to go to the toilet urgently with '*considerable wind*' 2 or 3 times a day, meaning that knowledge of toilet locations was important, but describes this as having '*little impact*' on his daily life at that time. Dean

²¹ Buscopan is a medication used to treat abdominal cramping

recalled having various tests to which the doctor said, '*it's probably IBS, a name we give to a range of conditions when we don't know the cause*'. This diagnosis followed what Dean said was a '*do your best*', '*try this, try that*' scenario, none of which having long term lasting success. Dean recalled his mother having similar problems, '*but they didn't diagnose in those days*'. He remembered during his school days his mother telling him to hurry up in the bathroom as she ran up the stairs and stood at the top shouting, '*hurry up, hurry up*'. Dean believes this is like his experiences now.

Dean had finger prick tests which identified intolerance to wheat and dairy, and by cutting these out, he had an '*instant improvement*' for a few years. However, over the years he has become increasingly intolerant to '*many foods*'. He currently sticks to meat, vegetables, and bananas, but still has symptoms. Dean explained he has always been thin and has been tube fed for his weight in the past, which is monitored by the hospital. For Dean, he believes his restricted diet has also led to other health problems such as gastritis, acid reflux, and reactions from his immune system. Dean has a regular routine of four meals a day at 8am, 11am, 2pm, and 7pm with similar foods each day. He also explains that he has '*off*' days where he has energy to do little. After some toilet visits, he is left feeling '*off*' and '*wiped out*'. Despite only having a toilet visit once in a morning, Dean explained that he has chronic wind which he feels is '*highly unsociable*'. This has led to a decline in social activities due to the unpredictability of his wind. He no longer goes to pubs and has lost touch with some friends. When Dean does go out, he ensures this is a place that he can '*safely release*' his wind without others being aware. One of the places that this is the case is where he volunteers: the railway centre. Here, Dean does the gardening and takes care of the flower beds. Dean also shares a holiday home by the coast with his sister, which he regularly visits and occasionally spends time with her there.

Caroline

Caroline is a 41-year-old woman who works in a full-time office-based job. She was diagnosed with IBS around 5 or 6 years ago, after having a period after Christmas where she felt unwell. After consulting a doctor, they explained that it was '*probably a bug that will go off*'. But for Caroline, the chronic indigestion she was feeling remained. Following another visit to the GP, she was told it was '*probably IBS*' until she was referred for a colonoscopy 3 or 4 years later which '*confirmed*' it. Caroline has a brother

who has Coeliac Disease, so she was also tested for the condition and it came back negative. After this, Caroline felt it was *'down to her'* and not with the support of the doctors. For Caroline, she described IBS as *'people think it's tummy issues, but it is so much more than that. It affects every ounce of a person's soul and living with it can be very hard'*. Caroline has felt very unwell at points and has attended A&E due to the pain she has experienced. Over the past year, Caroline has visited a dietician and followed the low-fodmap diet. She also seeks advice and support from social media groups. Caroline finds travelling to work difficult as her commute is one hour long each way which aggravates her IBS and the trains having no toilets make her panic.

Carl

Carl is a 33-year-old man who currently works as a bus driver and a driving instructor. Carl is married, and lives at home with his wife and two children. Prior to his current job, he served in the army. In terms of his IBS, he recalls it starting in his role as a bus driver, when he got *'caught short'* one morning on a bus route, citing this as a trigger ever since. Carl says that the doctors who diagnosed his IBS after some tests have also stated that his IBS could be anxiety related. This is because his IBS affects him whilst being *'out on the road'*. In terms of his symptoms, Carl describes his IBS as a similar feeling to butterflies in your stomach, accompanied with wind, which he sometimes finds embarrassing because of the smell. Carl also experiences cramps where he is *'doubled over'* with pain, which is often followed by a bout of diarrhoea. As a result of this, Carl is conscious of his IBS when he is out. This is a factor for his work as a driver and the routes that he takes, but he takes Imodium to *'stop [him] going whilst out on the road'*.

Rosie

Rosie is a 30-year-old woman who works in an environmental role. She lives with her boyfriend. Rosie traces the beginnings of her IBS back to the year 2005. She explained that her symptoms appeared to begin when she was eating her favourite food, Chinese sweet and sour chicken. Rosie recalled having pain in her stomach, but said she thought that it was something that most people got when eating takeaways and *'didn't really think much of it'*. She remembered having the same meal again in 2008 and recalled her boyfriend having to almost ring an ambulance, because, as she described, she *'really, really, felt like something was happening...'*. Her pain then resulted in a toilet trip which

relieved her symptoms, but also encouraged her to visit the doctors. The doctors said, *'so we think you have IBS'*. Following this, Rosie told me, *'that was it, pretty much'*. She described the process lasting 6 or 7 years before any tests were done to confirm her diagnosis. Rosie also explained that Ulcerative Colitis was a concern in the process of receiving a diagnosis, as her grandad has the condition, which led to him having a stoma²².

Ellie

Ellie is a 28-year-old woman, who works as a secondary school teacher. She currently lives alone but is soon to move in with her partner. She described having a sensitivity to 'dairy' and 'cereal'. This became particularly noticeable at university where she was *'eating a lot of pizza'*. Ellie told me that her mum also lives with IBS. Ellie went to the doctors who *'did all the tests to rule out Crohn's and something else'*. Ellie explained that she became used to her symptoms flaring up three or four times a week she felt she didn't know what was normal for her stomach. For Ellie, having an upset stomach becomes *'normality'*. As Ellie said that she had sensitivity to milk, I asked her if she was lactose intolerant, and she explained that she *'can eat stuff like chocolate'* but not *'heavy dairy'*. She tells people she is lactose intolerant to cut out any confusion. Ellie told me she was placed on the low-fodmap diet and various medications following a colonoscopy examination and hydrogen breath test that did not detect other conditions. She explained *'I don't know why they didn't do those before they put cameras inside me'*.

Molly

Molly is a 72-year-old 'retired' carer who volunteers throughout the week at her local community centre. She recalled having IBS for the past ten years or so. This began with *'niggling pains'* and a sudden urge to *'go to the toilet'*, having to rush home and struggling to make it. Molly recalled having a colonoscopy and had polyps²³ removed.

²² A stoma is an opening on the abdomen that can be connected to either your digestive or urinary system to allow waste (urine or faeces) to be diverted out of your body. (see <https://www.bladderandbowel.org/bowel/stoma/what-is-a-stoma/>)

²³ Bowel polyps are small growths on the inner lining of the large intestine (colon) or rectum. See <https://www.nhs.uk/conditions/bowel-polyps/>

She also had a test for coeliac disease, but was diagnosed with *'just IBS, a put up with it sort of thing'*. Molly explained that she had no follow ups, but simply a diet sheet to send her on her way, and was not referred to a dietician. For Molly, finding out she had IBS was finding out why she was *'going through severe stomach ache, cramps and the immediate need for a toilet'*. This led to a *'fear of not finding a toilet, a fear of eating before going out and eating whilst out'*. Molly has tried to find out if anything triggers her IBS. She tries to avoid a high concentration of fat and sometimes milk. However, Molly said that she has ruled out certain foods and *'tried to eat a fair diet'* but sometimes things she thinks are *'safe'* can set her IBS off. Because of this, Molly mostly opts for eating what she wants but does not forget the consequences of doing so. She recalled a time at her daughters where it was *'only half an hour'* before dinner had an effect on her, leading her to *'rush to the toilet'*. As part of her voluntary work, she goes on regular day trips to the seaside. For Molly, these trips are troublesome, and she often avoids eating all day, so as to avoid toilet trips (and the potential for pain and diarrhoea) whilst travelling.

Tony

Tony is a 34-year-old man who works as a gas engineer and lives with his partner. He first experienced symptoms of IBS following a parasite infection whilst on holiday (often known and categorised as post-infectious IBS). Tony explained that environmental health were the first people at his door, and he had to recall the past nine months. At first, Tony attributed it to *'a bad stomach'*, as his job role often required him to eat out in hotels where food was *'not always the best'*. Tony had symptoms for 9 months before seeking treatment, and he feels this did *'long term damage'*. Tony had various tests and, having ruled out other conditions and found *'nothing physical'*, the consultant gave Tony a sheet for the low-fodmap diet. Tony explained that he was not given the full information on the diet and so he excluded foods without reintroducing²⁴. When he finally saw a dietician, Tony had become *'super intolerant to everything because [he'd] cut it out for so long'*. Tony explained IBS feels like a *'knife slashing your stomach...24 hours a day'*. However, the low-fodmap diet has made the pain easier to manage and is now a *'dull ache'*. Tony described how, when having bad cramps, he

²⁴ Dieticians who support the low-fodmap diet encourage a three-stage process which includes reintroducing foods as an importance process of identifying intolerances. See: <https://www.monashfodmap.com/blog/3-phases-low-fodmap-diet/>

has to pull over from driving due to the pain and consequent diarrhoea. He says that having IBS has changed his attitude to life and feels he now approaches life with a '*fuck it*' mentality. He places importance on his happiness, and that of his wife, as the main things in life. For Tony, the diagnosis given was '*chronic IBS*'.

Brenda

Brenda is in her 70's and is a retired shop assistant, married with three children and lives with her husband. Brenda plays bowls regularly as her main hobby. She recalled living with IBS for the past forty years, with it being diagnosed at the hospital. Brenda explained that they '*didn't seem to bother then, go and live with it.*' Brenda reflected on her mum and dad's experiences of bowel health and how they were both '*fine*' apart from her mother who '*did blow up a bit*' when she got older. Brenda spoke of the tests and investigations, including being asked if there were '*strings*'²⁵ in her stool, which she found: '*what did I see in the pan? two linked together with string*'. Upon returning to the doctor, they '*didn't want to know*'. Brenda also recalled times where she would cry to her mother as she '*couldn't go to the loo*' and her mother would make her sit on a bucket of hot water that often eased her symptoms. However, this occurred in waves that she '*outgrew*', her symptoms waned, and she was later diagnosed with IBS.

Keith

Keith is a 51-year-old man, married with three children, who works in manufacturing and trains for marathons as a hobby. Keith's recalls his IBS occurring slowly through his lifetime. He assumed his toilet trips were '*normal*' until he was in the office one day and two colleagues pointed out and joked about his frequent trips to the toilet. This led him to visit the doctors, have tests, and left him examining his diet. Since noticing his symptoms, Keith began changing his lifestyle and diet. Keith excludes gluten, which changed things '*overnight*' for him. Keith attributed his symptoms to '*unhealthy*' living over the years, recalling a life history of growing up eating the '*wrong foods*' and '*too many Weetabix*'.

James

James is a 21-year-old student currently doing a science degree. At present, he works full time on a placement as part of his degree programme. James lives in a shared house with six other students. James described having symptoms of IBS for '*as long as [he] could remember*'. Between the ages of around 8 and 10 years old, James recalls having

²⁵ Strings in the stool can be a sign of digestive ill health. This can be a result of a low-fibre diet or may be an indicator of the presence of an infection. For more info: <https://www.medicalnewstoday.com/articles/322502.php>

to *'lie on the sofa and rub [his] belly for a bit'* due to bloating after a meal. For James, he feels that his diet has changed growing up, and cites a more balanced diet now in comparison to his younger years where he used to eat *'pasta and pizza'*, which is something he considers when managing his IBS. James has visited the doctors three times with his IBS, who recommended trialling the low-fodmap diet alongside a prescription of antispasmodic medication. However, he has never had any tests to confirm the diagnosis and exclude other conditions. James feels that gassy drinks, eating too much or too quickly all trigger his IBS, which he relates as a matter of *'self-discipline'*. James explains that he uses humour to discuss the effects of his IBS. This is particularly the case with his fellow housemates, although he notices the lack of humour from his female housemates.

Julie

Julie is a 66-year-old woman, who recently retired as a civil servant. She has been married for more than 40 years, has no children and *'few relatives'*. Julie recounts how her IBS started following an attack of gastric flu one Christmas more than 10 years ago. Julie has had many tests and medical procedures that concluded she has IBS in the *'absence of any other evidence'*. She explained that she had *'no guidance, basically you're on your own'*. Julie's partner knows about her IBS and its effects. He has helped her manage her *'attacks'*, working together to narrow down her triggers to gluten, fat and stress. Julie explained that friends and colleagues' knowledge of her IBS is limited to *'I have IBS and avoid certain foods'*. Since retiring, Julie states that she is stressed only when going on a journey or travelling when toilet stops need to be identified. She plans for *'what if'* scenarios, leading to careful practices of what she eats and when, and having supplies of medication, tissues, wipes, her *'Can't Wait'* card and radar keys (present in both cars). Julie states her meal times are regular with small portions and her food is plain. Julie describes her ongoing research into IBS and now takes Kefir (fermented goat's milk) which she believes is helping her IBS symptoms. In terms of her daily routine, Julie cites mornings as the worst time for her IBS as it can wake her early with sweats. However, since retiring, she knows there is no *'deadline'* to be out of the house and tends to schedule any morning appointments for 11am onwards. This helps her to relax and reduce her IBS symptoms. For Julie, flatulence is a worry as she finds it difficult to differentiate between needing to go to the toilet and pass wind. This often leads to frequent toilet visits, which she finds embarrassing and *'difficult to*

explain' when in company. Alongside this, Julie finds that she often needs time to sit quietly after toilet visits to *'settle her insides back down'*.

Martin

Martin is a 40-year-old man, who currently lives alone and works in communications for a football club. Martin said the beginnings of his IBS was a while back but recalled his IBS symptoms coming to prominence when transitioning from home life to university life. For Martin, this involved *'probably eating and drinking properly to living a lifestyle that's not so balanced'*, but also feels that his IBS has been *'lingering in the background'*. Martin described going to the doctors at the end of university after *'trying to ignore it, you don't think it's anything serious and eventually you think it's worth getting checked to see what it is'*. Martin described the doctors doing the *'usual thing'* of eliminating Crohn's and Colitis and they narrowed it down to IBS. For Martin, dietary advice was offered, alongside working out over time what works and does not work for him. Martin described his IBS as frustrating, recalling a period of trying diets and things doctors suggest you try but it not necessarily changing anything for his symptoms. Following this, Martin felt that he should not miss out on foods he enjoyed if it didn't make *'enough of a difference to stop eating them'* but described it as more of a *'level of tolerance'* and *'finding a place you're comfortable with'*.

Amy

Amy is a 25-year-old woman who works in an administrative role. Amy is married and lives with her partner. In terms of her IBS, she recounts living with it since approximately the age of 18. At this point in her life, she stated she was *'becoming more independent, doing more things on my own, eating out more with friends'*. Amy started to notice that her stomach *'wasn't acting the same'*. She would have a *'really bad stomach upset'* or would *'not be able to go to the toilet for over a week'* which she explains can be worse now but felt *'dramatic'* compared to how she had previously been before the onset. Amy's dad is a GP and told Amy that it could be IBS, but she went to her own GP and over the past few years has had various tests (including blood tests, food intolerance tests, scans on her ovaries, x-rays on her bowel) as well as trying medications. She was *'signed off as being unfortunately IBS'* and that she should *'watch what [she] eats, watch for trigger foods'*. Amy has not found a direct cause for

her IBS, as it is different every day. From then on, Amy began to re-adapt her life. I asked Amy what she thought led to the onset of her IBS, and she reflected on how her IBS began as her parents were getting divorced. However, the intersection of the two life events was not something she had given much thought to in the past.

Carly

Carly is a 36-year old woman who is currently a student at university and lives with her partner of nine years and their two cats. Carly has both IBS (Irritable Bowel Syndrome) and IBD (Inflammatory Bowel Disease – specifically Crohn’s disease). Carly’s Crohn’s Disease was diagnosed at the age of 16, but she had experienced symptoms from being 9 years of age. When her inflammatory markers²⁶ are decreased in relation to her IBD and she is considered ‘*in remission*’, Carly still sometimes experiences symptoms. Her IBD nurse and GP attributed this to ‘IBS’, and told her to ‘*try peppermint capsules and relaxing*’. Carly said she was left to ‘*get on with it*’. She takes Buscopan daily, drinks peppermint tea, and finds ‘*pooing is an issue*’. Looking where the toilets are is an automatic part of daily life.

Katie

Katie is a 29-year-old woman who works for the NHS, and lives with her partner. Katie described having sickness as a young child which she now attributes to IBS. Her IBS ‘*properly*’ started around the age of 14. At that time, Katie had doctors’ appointments in which they said, ‘*there’s nothing wrong with you, it’s just IBS*’. Katie also explained that her mum works in endoscopy²⁷ where she sees IBS diagnosed frequently and thus reiterated her diagnosis. Due to her IBS symptoms, Katie described being ‘*obsessed*’ with taking Imodium. Katie explained she feels nervous at the thought of having to use the toilet in another person’s house. This avoidance of using other people’s toilets once lead to a difficult coach journey with school when she was a child, and has resulted in her dislike for travelling. Katie explained her dad also has ‘*issues with his stomach*’ and ‘*gets very anxious about travelling as well*’ but has never sought a diagnosis.

²⁶ For more information regarding inflammatory markers in monitoring IBD, see: <https://www.crohnsandcolitis.org.uk/about-inflammatory-bowel-disease/publications/tests-and-investigations-for-ibd>

²⁷ An endoscopy is a procedure where the inside of your body is examined using an instrument called an endoscope. See: <https://www.nhs.uk/conditions/endoscopy/>

Gina

Gina is in her thirties, lives with her partner and works freelance. Gina is into fitness and likes to do bike rides, iron man triathlons, and goes to the gym regularly. Gina recalled her IBS as something she *'always remember[s] having, not necessarily badly, but there in the background'* and something that became more apparent as she began to get into fitness and eating more. Gina also explained that in her teenage years and early twenties she lived with an eating disorder, which *'might not have helped as there wasn't much to process in the body'*, and when her eating patterns *'were back to normal, that was when a lot of the IBS was triggered'*. She has a certificate in nutrition, which she explained helped her to think about her food and *'figure out on her own'* the low-fodmap diet to manage her IBS symptoms.

Sharon

Sharon is a 50-year-old woman, who works in an admin role and lives alone. Before talking about her IBS, Sharon discussed how her menopause was affecting her. Sharon stated that she has had IBS for a while, but it has worsened over the past two years, and is something she thinks may intersect with her experience of menopause. Sharon explained that she took photographs of her bloated stomach and took them as evidence to her GI consultant. For her *'it was like it was going to burst, you'd think I was pregnant'*. Sharon explained that he looked at it *'like it was nothing'*. Sharon recorded the dates of the flare ups in her diary, and the nature of her symptoms. She described her IBS as involving a broad range of symptoms and feelings, which include:

- *Fat*
- *Gut gurgles (worse at night)*
- *Loads of flatulence (and associated pain that makes her want to lie down with a hot water bottle)*
- *Back pain*
- *Some days are very 'clumsy' – bumping into and dropping things and having poor concentration (brain feels foggy)*
- *Very rare to feel 'empty' even after passing motions and straining to go to the toilet without medication*
- *Clothes are tight*
- *Not sociable – cancelling friends as feeling so uncomfortable, pained, and irritable with bloating*

- *Irritable*
- *No energy and sleeping much more*
- *Anxious when out going to the toilet (at work and in general public toilets) and can spend 'ages' trying to go, or sometimes going and it being loose, which causes a worry of the odour (Sharon's Diary)*

Sharon listed the tests involved in her diagnosis of IBS including a negative H Pylori²⁸ test, a negative Coeliac test, and an IBD stool analysis that '*showed 'slight inflammation' but nothing to be concerned about*'. Sharon explained she has 2 yearly endoscopies and colonoscopies as she has a cancer gene (called Lynch Syndrome²⁹) and is at increased risk of stomach, bowel, and ovarian cancer. She had a total hysterectomy a few years ago for prevention. In her diary, Sharon listed the medications she has tried for her IBS, including their effectiveness and the dates she began taking them. These included a range of laxatives, antispasmodics, antidepressants, vitamin D tablets, the low-fodmap diet, syrup of figs, and Yakult.

Sharon reflected upon how stress is understood as a factor for IBS. However, she stated that '*the past 4 years have been stressful, but [her] life is a constant stress, it's major big things...part and parcel of my life...I don't think IBS is linked to stress.*' Sharon explained that she had been going to the gym three times a week, swimming twice a month, and had begun mindfulness and meditation. She explained, '*you go to the gym, you eat healthy, you drink loads of water, and nothing helps...it makes you angry...what more can I do?*' Sharon also explained her experiences of IBS at work, where people could see that she was ill and explained that it was her IBS. For Sharon '*[it] feels as though people look at you like 'what's that? It's nothing' you feel as if you're being a...not a hypochondriac but it's like, it's nothing.*'

Terry

²⁸ Helicobacter pylori (H. pylori) is a type of bacteria. These germs can enter your body and live in your digestive tract. See: <https://www.webmd.com/digestive-disorders/h-pylori-helicobacter-pylori>

²⁹ Lynch syndrome is a condition that can run in families. It increases the risk of developing some cancers. See: <https://www.macmillan.org.uk/information-and-support/diagnosing/causes-and-risk-factors/genetic-testing-and-counselling/lynch-syndrome.html>

Terry is a retired social worker, who is married with two children and has a dog. Terry recalled that up to the age of 26-27 years of age, he was *'normal as anybody...one bowel movement a day, first thing in a morning, that was it'*. Terry recalled two events. First, he began running marathons and saw the onset of symptoms after a long training run. Second, Terry reported that his IBS symptoms also coincided with the process of getting a divorce from his first wife. Terry explained that between stress and running, he was not sure what triggered his IBS, but that it has got progressively worse. For Terry, he has never experienced pain with his IBS that he perceives others to have, but he has loose bowel movements, and *'unpredictability has always been an issue'*. Terry was not officially diagnosed with IBS in the early stages but experienced some pain which led to a colonoscopy. He was diagnosed with *'probably IBS'*, as well as polyps that were pre-cancerous and therefore has regular colonoscopies. Terry explained that his father had colitis, and his daughter, Sophie, also has IBS.

Joyce

Joyce is a 75-year-old woman, who is married and lives with her partner. She has a son and a daughter, and several grandchildren. Joyce worked as a biomedical scientist until retirement aged 65. She has been a dancer all of her life and continues to perform. Joyce spoke of her childhood firstly in her diary and in our conversation. As a child she recalls being *'force fed 'syrup of figs' which [she] spat out most of the time'* shortly followed by *'pink pills' 'all because her bowel movements weren't 'regular' and [she] had a fear of vomiting'*. Joyce believes her childhood experiences may have played a part in her IBS later in life. Joyce explained that she has tried Neurolinguistic Programming (NLP)³⁰, cognitive behavioural therapy (CBT), mindfulness meditation, alternative medicines, and 'modern' medicine. She said that has had every investigation that has been available over the past 50 years. Joyce feels her IBS is worse than ever, but over the years, people are *'more accepting of IBS'* as more people have it. She explained how she thinks that medics still do not know how to treat or manage IBS and a lot more research is needed.

Sophie

³⁰ Neurolinguistic Programming (NLP) is a pseudoscientific approach to communication, personal development and psychotherapy. See: <http://www.nlp.com/what-is-nlp/>

Sophie is a 32-year-old woman who works as a makeup artist in a salon, and sometimes travels as part of her work. She lives alone but is in the early stages of a new relationship. Sophie talked about her IBS as something that has progressed over time, starting in her late teens and early twenties. Both her parents have IBS and Sophie recalled memories of growing up, and IBS as a part of it. Sophie discussed having counselling and hypnotherapy for her IBS, as she feels anxiety and past experiences are linked. However, she also feels that there are some foods that she cannot eat. These include beans, spicy foods and pulses which give her bloating, wind, and pain. Sophie described her diet when she was younger and how it was quite different to her diet now. Despite becoming healthier in terms of her diet, Sophie feels her IBS is worse. Sophie diagnosed her own IBS as she felt she '*already knew*', had tracked her symptoms and identified what was '*setting it off*'. She now tries to establish a '*balance*' with everything.

Lucas

Lucas lives with his partner and is currently studying in higher education. He is from South America but moved to the UK to study. Lucas recalled '*some key moments*' which prompted treatment for his IBS, namely travelling and accessing toilets.. He describes his IBS and what he knows about the condition as '*a nervous illness [rather] than a physiological one, a nervous illness with physiological implications*'. Lucas explained that conversation with his doctor positioned IBS as a condition whereby '*it won't kill you, but it won't let you live your life*', placing the management of the condition on '*curing yourself*'. In response to this, Lucas stated '*stress was a natural state*' for him, even though he knew that this should not be the case. If his stress is not manifesting in his IBS, it manifests in his eczema. When diagnosed, Lucas was advised by his doctor to reduce his coffee, alcohol, spicy food, and cigarettes, and to make '*smart choices...to make life happier*'. He reflected on his daily practice and how it was not in line with this. Lucas also reflected on the importance of managing his IBS in terms of the '*possibility of having a bathroom at hand*'.

CONCLUSION

'If you are going to get at the humanity of people, you can't just have a bunch of disembodied thoughts that come out of subject's mouths in interviews without ever developing characters and trying to show people as full human beings. In order to do that it is useful to have a character that lives in the text...' (Duneier, 2006: 554)

As Duneier (2006) argues, it is necessary to develop characters in sociological work in order to make it meaningful beyond thoughts and quotes, and to work at creating human beings that *'live in the text'*. This chapter of portraiture works to do this right at the start of this thesis. Drawing these accounts to a close, from Kelly's account right through Lucas', we have seen the ways in which IBS comes to be experienced and known in the twenty-five participants' biographical accounts. As well as the methodological significance of these being the first accounts revealed, these portraits have illuminated a particular story regarding the social processes of an IBS diagnosis. First, the portraits have sought to witness the trajectory of coming to be diagnosed with IBS and how this diagnosis intersects with the biographies and histories of people's everyday lives. Second, these narratives have reiterated the problematic diagnosis of IBS and what it means to live with a medically contested condition that is often not taken very seriously. Third and finally, these biographical fragments show how this diagnostic process together with contestation shapes the move away from medicine and the turn to individual practices within their everyday worlds. Keeping these illness narratives and forms of contested illness in mind, I will now move to the relevant sociological contributions to discuss why and how they are important in understanding the lived experience of IBS. Moreover, in light of this contested nature, which results in individuals finding their own way to navigate their symptoms in daily life, I introduce the sociology of everyday life and its important facets, to conceptually situate the later accounts of the everyday lives of those with irritable bowel syndrome.

CHAPTER THREE

BRINGING THE BOWEL TO THE FORE IN THE SOCIOLOGY OF HEALTH AND ILLNESS

3.1 INTRODUCTION

The literature review for this thesis is organised into two chapters. Chapter three considers the substantive contributions within the field of the sociology of health and illness, and how these are complimentary to the study of IBS. This highlights the absence of IBS within sociological literature and draws attention to the ways in which the bowels and associated illnesses have been studied. In particular, I illustrate how sociologies of health and illness have studied inflammatory bowel disease (IBD) and coeliac disease (CD). Through relevant texts and theorisations, I reflect upon the ways in which their presence, and the absence of IBS, is perhaps indicative of IBS as a bowel condition, with its attendant issues of legitimacy and severity. I argue that the paucity of research is reflective of the position and hierarchy of bowel conditions, and specifically IBS, and I argue that there has been a (dys)appearance of the bowel (Leder, 1990). Namely, the bowel is only attended to in times of *serious* illness, disruption, or particular polarisations in the life course. In reviewing literature concerned with matters of the bowel, I also reflect upon the ways in which they are theorised. These include anthropological understandings such as '*matter out of place*' (Douglas, 1966) and relatedly, matters of stigma.

This chapter then explores literature on the sociology of stigma. I reflect upon the traditional understandings of Goffman's (1963) concept of stigma and the importance of '*passing*'. I then consider contributions post Goffman, particularly within health and illness, and evaluate why this is significant to the study of IBS. I utilise the sociological theorisations of stigma as a *backdrop* to the work, but also as an implicit undertone to some of the accounts presented by participants later in this thesis. Here, stigma operates not only on matters of the bowel, but on the status of the illness itself. However, this thesis moves beyond theorising the bowel solely as relating to stigmatising experiences, suggesting that a focus on dirt and stigma may not be entirely conducive to appreciating everyday experiences. This comes in part from my wish to consider how we might

contemplate excretions or leakiness as somewhat ordinary, ‘mundane’, and part of the fabric of everyday life, despite their hidden nature.

Third, it is necessary to position this work within the context of broader health narratives. As such, I explore the well-established body of literature of health narratives, as a way to engage with how sociologists have understood everyday experiences of illness within the context of people’s lives and biographies. This encompasses a range of scholars who have explored the meaning and work of living with chronic illness, including landmark studies of Bury (1982) on biographical disruption, and Williams’ (1984) theorisations of narrative reconstructions. I attend to this literature as a way of engaging with the field of sociology of health and illness and the ways *everyday experiences* of illness have been approached. However, I echo Lawton’s (2003) call for attending to the ‘*mundane*’ matters of everyday experiences of health and illness. Whilst she focuses on the body, my attention, in line with the experiences of IBS, extends this to the *bowel* and the *body’s products*. This thesis attends to the *minutiae* of everyday experiences, and what we can learn from the *daily encounters* that give weight to and make a health condition noticeable.

Fourth and finally, since IBS is hard to diagnose, and its symptoms are unexplained, it is relevant to utilise the sociological literature that explores experiences of having a medically unexplainable condition and collection of symptoms. Sociologists of health and illness have recently taken an interest in the phenomenon of ‘medically unexplained symptoms (MUS)’ and an appreciation for the role of diagnosis in the experiences of health and illness. Literature on MUS suggests the need for certainty and legitimacy in people’s experiences. This is pertinent since symptoms disrupt or reshape daily lives while lacking a medical categorisation and thus, support or treatment. The earlier part of the literature review, which attends to sociological literature on bowel conditions, argues that IBS has been left behind because it has not achieved a status as a legitimate health condition. It would stand to reason that the sociological interest in medically unexplained symptoms would fill this gap, given that IBS is a common illness that is medically unsolved. And yet, studies have not explicitly explored IBS from a sociological perspective in terms of its diagnostic process. Thus, I argue that that the limited degree of attention given to IBS - in both everyday life and academic scrutiny - is indicative of both its lack of legitimacy and the stigma associated with it being a

bowel condition. These matters combined have rendered the condition neglected in research and is thus where I look to fill the gap, while not exploring the condition solely through these issues. The explorations of medically unexplained symptoms, and the ways in which symptoms can be dismissed, provides a useful juncture point to the conceptual lens of this thesis. My argument is that within the realm of the medically unexplained health conditions, there is a presence of everyday experiences that are denied attention, glossed over, and taken-for-granted. Taking the mundane and the minutiae seriously has been the remit of everyday sociologists and this is the intention of the present study.

3.2 THE (DYS)APPEARING *BOWEL* IN HEALTH AND ILLNESS

As I have demonstrated in the introduction to this thesis, IBS has failed to establish itself within scholarly literature, particularly within sociological studies. Academic research into IBS within the field of nursing and healthcare research to date has focused on the difficulties associated with the condition, particularly in terms of its legitimacy and negative healthcare experiences as a product of this (Bjorkman *et al.*, 2016; Håkanson *et al.*, 2010). Work that is perhaps most useful considers the quality of life and ways in which IBS comes to be known and experienced (Bertram *et al.*, 2001; Dancey and Backhouse, 1993; Håkanson *et al.*, 2009, 2010; McCormick *et al.*, 2012). However, IBS has fallen under the radar in *sociological* studies, with the exception of Lewis' (2015) methodological piece that utilises questionnaire data from those living with IBS, offering suggestions of how we might interpret such data. There is therefore a gap in work that locates IBS within the field of sociology.

Scholars that have argued for the body to be theorised seriously have historically noted the '*absent presence*' of the body within sociological literature (Shilling, 2003). IBS of course happens within the body, and one might suggest that there has been a similar absent presence of the bowel in particular. To take this one step further, Leder (1990) talks about the (dys)appearing body, explaining that an awareness of the body only happens when the body forces us to notice it and tune in when something is wrong, such as when experiencing illness and/or disability. On a broader level, conversations around the bowel and its products have been theorised with work on the *body* (Twigg, 2006), body products as '*matter out of place*' (Douglas, 1966), or how body waste

becomes *unbounded* (Lawton, 2008), in the face of illness, dying and/or disability. Engaging with this literature encourages a reflection on the framing of bowels and their excretions thus far. Yet, one might ask what we do with this theorisation when matters of the bowel are not adjoined with a legitimate illness, or with a view of rupture or decline. In fact, the very nature of IBS as a condition sits somewhere between extraordinary disruption, and mundane, even familiar, experiences.

My argument is that what we see in the field is what we might call the (dys)appearing bowel. This is because much of the literature to date within the field of health and illness often tells a story of bowels in times of extraordinary and disruptive circumstances. The attention is not always on the regular, the routine, or the common, taken-for-granted illnesses or toiletry routines that fall under the radar. In particular, attention to matters of the bowel within the sociology of health and illness has typically been given to conditions such as bowel cancer, inflammatory bowel disease (IBD), coeliac disease (CD), and living with a stoma. For example, Kelly's (1992) seminal work '*Colitis*,' explored life with IBD, describing the social and psychological experiences surrounding the condition covering the onset of illness, living with the condition, and consequent surgery that results in a stoma. Ogden (2010) also explored life with IBD from the perspective of children living with it, advocating for a narrative based approach to understanding such experiences. Similarly, Saunders (2014, 2017) has also explored experiences of IBD, theorising it in relation to '*recurrent biographical disruption*' due to the relapsing/remission status of IBD as a condition. Thompson's (2013) work takes a symbolic interactionist approach to the experiences of IBD by studying the conversations had by those with IBD in a support group, signalling that those with bowel conditions are often wary of giving too much away for fear of stigmatisation. Turning to studies on Coeliac Disease (CD) as another associated condition with similar symptoms, studies draw attention to the dietary changes (see for example Veen *et al.*, 2012; Gregory, 2005). This is useful in capturing the multiple directions of experiencing a condition that affects the bowel and suggests an incorporation of seeing the bowel as part of everyday life and the things it affects, such as daily dietary practices.

I do not at any point want to suggest that we should discredit or deny the severity of illnesses such as IBD or CD. However, I want to stress the legitimacy of and the rights

that these conditions allow, including the *'sick role'* (Parsons, 1951), in comparison to the liminal and contested status of IBS. As I have explained earlier, the diagnosis of IBS is an exclusionary process, where conditions such as IBD and CD are attended to first, and arguably this hierarchy seeps into academic study. These distinctions are important in the experiences of IBS, particularly the comparison of IBS and IBD; those with IBS feel that they are not taken seriously, and they are diagnostically separated from the severity of IBD. Likewise, those with IBD are often frustrated when their condition is mistaken for IBS in everyday discourse, precisely because of its taken-for-granted, dismissive nature. As a result, the lack of understanding and an appreciation of the everyday experiences of symptoms results in frustrations for *both* conditions. I wish to tread carefully in utilising and reflecting upon the sociological work into IBD whilst studying IBS, due to the hierarchy that the illnesses sit within. However, there are commonalities as well as distinct differences in how the diagnoses and illnesses are experienced. The literature is also a useful reflection point because it is not uncommon for those initially diagnosed with IBS to receive a later diagnosis of CD or IBD. As such, I argue that there is more in common than there is difference. In consolidating the literature on the *'absent presence'* (Shilling, 2003) of the bowel and how this comes to be known and theorised in times of *'serious'* illness or rupture, one must also reflect on the processes of stigma brought to attention in previous studies of bowel conditions. Theorisations of IBD draw upon stigma, but in the case of IBS, work is also to be done in thinking not only about the stigma of a bowel's unboundedness, but also of the diagnostic label categorisation and consequent struggles for legitimacy.

3.3 STIGMA AND THE S(P)OILED IDENTITY

The previous section has touched upon the study of the body and its products, focusing on how they have often been theorised as *'matter out of place'* (Douglas, 1966). In particular, this often comes to be known in times of serious illness, disability, or dying, with what we might call the *(dys)appearing bowel* (Leder, 1990). Studies into IBD have reflected on the role of stigma associated with having a bowel condition. To date, there are some accounts of IBS that have been theorised in the same way, although not in sociological studies. In particular, Taft *et al.* (2016; 2011) explored the role of stigma in both IBS and IBD, studying them together, albeit from a medical perspective. They found that stigma was greater in those with IBS, compared to those with IBD. Despite

this being a study from the lens of medics and their preferred quantitative methodologies, there is nevertheless an important recognition from Taft *et al.* (2016; 2011) of the stigma in IBS. My own sociological work into IBS (White, 2016a) started with stigma as an important point of theorisation, alongside what Koutroulis (2001) coins the '*soiled identity*', applied in the context of menstruation. I will now revisit the sociological foundations of stigma to consider why it is valuable and how we might appreciate the backdrop of stigma in the study of IBS. However, I look to move beyond a reduction of the theorisation of IBS to the task of stigma, towards the context of understanding everyday life with the condition.

Stigma has been widely explored within sociological literature, particularly in relation to health and illness, with a variety of contributions. Goffman pioneered the exploration of stigma in his work '*Stigma: Notes on the Management of Spoiled Identity*'. Goffman (1963: 13) defined stigma as '*an attribute that is deeply discrediting*', with the definition originating in an individual who was blemished, polluted, and was to be publicly avoided (Goffman, 1963: 11). In understanding stigma, Goffman (1963) suggested that there are three types; one of the body, one of character, and one associated with social collectivities. Goffman (1963) made four pressing points in his exploration of stigma. First, that stigma is a perspective that is generated in social situations (1963: 138). Second, that those '*possessing*' a stigma learn to manage the potential effects of this social experience by paying attention to particular strategies of identity management such as passing and concealment. Third, that stigma is historically specific in the way in which it manifests, and fourth, that it functions as a '*means of social control*' (p.139). There are important considerations here when we think about IBS. First, the sensory management employed in the attempts to contain symptoms to avoid them being seen, heard or even smelt. Second, Goffman's notion of passing is also an important backdrop to the study of IBS. The condition troubles the notion of the need to pass as '*normal*' for two reasons. First, due to its invisible nature, the condition cannot necessarily be *seen*. Second, the very nature of the diagnostic category demands a rethink of striving not necessarily for '*normal*', but for '*legitimate*', as we shall see later in this thesis. Sociological work on '*passing*' is important here, where there is an exploration of the distinct and flexible work in negotiating identities (Jenkins, 2014). Wendell (1996) reflects on Goffman's work on passing and suggests the importance of

how those who feel, or experience stigma are placed within hierarchies of value. This hierarchy is important to note not only in the distinction between those who have IBS and those that do not, but in distinctions between conditions that are legitimate and illegitimate, visible and invisible.

Since Goffman's defining work, scholars have grappled with the sociological concept of stigma. This is particularly the case within the field of the sociology of health and illness, where the concept has been applied in a multitude of conditions, including the case of IBD mentioned earlier. For example, Scambler and Hopkins (1986) explored stigma in the context of epilepsy and Scambler has continuously engaged with the concept and a move towards understanding the role of blame and shame, increasingly drawing attention to the broader social, cultural, and economic contexts that facilitate such processes (see for example, Scambler, 2006; 2009). Similarly, Tyler and Slater (2018: 721) recently reflected on the processes of stigma in the context of '*ending the stigma on mental health*'. They argue that stigma works as part of cultural and political economy, calling into focus the performance of stigma as a form of *power*. Wendell (1996: 57) also highlights how Goffman fails to appreciate the social '*norms*' that stigmatise people with disabilities, important when we think about the '*nonconformity*' of the defecating body (Thompson, 2013) and the '*civilising process*' that Elias (1994 [1939]) traces, and what this means for those who do not meet them, if indeed any of us do. As Wendell (1996) suggests, it is important to consider how these social norms stigmatise those with disabilities and how we might reimagine and be inclusive of different norms. With these matters in mind, it is important to think about stigma as an important backdrop that is perhaps implicit in the accounts I will present in this thesis.

Whilst this thesis is not approaching the experiences of IBS through the lens of stigma, it is important to keep in mind where this stigma may operate in *everyday encounters*. For example, more recent work on stigma has explored stigma in *place* (see special issue on rethinking the sociology of stigma by Tyler and Slater, 2018). This is an important consideration when we ask where do those with IBS go, and where does their IBS come to be known, or more importantly, in what spaces do uncertainty, passing, and contestation arise? What about the socio-political issues of toilet access that further perpetuate the stigma and social ordering of those with IBS? The way that IBS is managed in everyday life, with a particular view to how symptoms are negotiated in

temporal, spatial, social and material ways, are *inseparable*, and *underpinned* by stigma. Stigma is implicit throughout the study, but not overtly theorised as a way to try to change the course of thinking. One of the things that makes IBS stigmatising is the label of the condition itself. As stated by Jones *et al.* (2009) those diagnosed with IBS reported that they felt that their illness was stigmatised by both their symptoms and the lack of understanding from others. IBS is a condition that often fails to gain legitimacy, with individuals living with IBS often told it is '*all in their head*' (Chelvanayagam, 2016: 19; Leston and Dancey, 1996). With this in mind, it is important to consider how such stigma links up with the narratives of illness experience, and a particular focus on illness that is contested or unexplained.

3.4 HEALTH NARRATIVES AND MEDICALLY UNEXPLAINED SYMPTOMS (MUS)

Thus far, I have sought to review bodies of literature that provide an important backdrop to the study of IBS, including theorisations of the bowel, stigma and their useful contributions. I now turn to contributions in the understandings of health narratives. Health narratives capture the stories and trajectories of illness experience which in many ways line up to the epistemological aims of this work into the lives of those with IBS. An acknowledgement of the narratives of health speaks to the methods of this thesis, made visible by the pen portraits of each participant and the narratives presented of their journey with having IBS. There have been a number of studies that have delved into experiences of illness and how they are made sense of (Corbin and Strauss, 1987; Lawton, 2003; Pierret, 2003; Williams, 2000; Conrad and Bury, 1997; Bury, 1991). More specifically, Kelly's (1992) account of colitis highlighted earlier provides an important account of the everyday experiences of living with IBD, touching upon everyday encounters that are also made present later in this thesis. Lawton (2003) maps the contributions of lay experiences of health and illness, and the particular ways mundane matters have been neglected somewhat. Usefully, she draws upon Kelly and Field's (1996) concern that 'mundane' aspects of living with illness have not been given sufficient attention. In particular, Kelly and Field (1996: 247) state, '*physical aspects of living such as eating, bathing and going to the toilet are the prime focus of experience of chronic illness, because above all else coping with chronic illness involves coping with bodies*'. The themes they identify provide a useful platform for the contributions

of this thesis. Contributions that are useful in illuminating the epistemological foundations of experiences of illness, founded upon experience of those who are living with it. I also wish to extend Lawton's (2003) call that stresses an appreciation of the '*mundane*' matters when it comes to experiences of health and illness.

Health narratives also capture the temporal trajectories of illness, both macro and micro, macro being what we might call biographical disruption (Bury, 1982), to more micro analyses such as Charmaz's (1991) '*good days, bad days*', and these understandings of time, and particularly of routine, are important for my current study. Scholars in the sociology of health and illness and specifically in chronic illness have acknowledged how long-term illnesses can define and redefine or restructure the everyday lives (Lawton, 2003; Pierret, 2003; Strauss *et al.*, 1984), the 'good' or 'bad' days, the pacing, (Charmaz, 1991), and the '*biographical disruption*' (Bury, 1982). For instance, Bury's (1982) concept of '*biographical disruption*' had three elements. First, he explores the things we *take for granted* in the absence of illness. In the context of IBS, this could be the biological rhythms of our bodies, eating food without query, the locations of toilets being absent from our consciousness, as well as the lightweight (hand)bag free of materials necessary to manage symptoms. Second, is the disruption to sense of self and biography, and third, is a mobilisation of resources in response to such disruption. Literature following Bury's (1982) concept of biographical disruption have unpicked trajectories of illness. This includes Williams' (2000) understanding of illnesses reconstructing narratives. In particular, consequent literature reflects upon the context of broader daily routines, and the normality of illness as expected and part of the lifecourse (see for example, Williams, 1984; Williams, 2000; Pound *et al.*, 1998; Faircloth *et al.*, 2004; Sanders *et al.*, 2002). Bury (1982) also explored the experiences of *uncertainty* of the future in times of illness, and the ways in which this may manifest. In the case of IBS, this uncertainty is particularly pertinent in the experience of health and illness, when symptoms can be medically unexplained and contested. I look to demonstrate throughout this thesis how this uncertainty manifests in *everyday* ways.

Health narratives are important because they relate to the illness trajectory of IBS, and the literature that follows on medically unexplained symptoms. Going back to studies on health narratives, Frank (1995) talks about three types of illness narratives: restitution, quest, and chaos. Restitution involves a functional process in which health

can be somewhat restored. The quest narrative understands illness as an experience of discovery. In comparison, the chaos narrative shows how illness can offer a difficult trajectory where the weight and complexity of it is brought to the fore. What is important to bring to attention here, is what happens when matters of illness and the diagnosis of such are not so clear-cut and thus affect the narrative of the expected course of illness. Nettleton (2013: 76) explains how some medically unexplained symptoms may secure a label, as with myalgic encephalomyelitis (ME) (Brown *et al.*, 2017; Cooper, 1997), or repetitive strain injury (RSI) (Arksey, 1998; Turner, 1995), but some diagnoses remain *contested*. Jutel (2014) explores the significant process of '*putting a name to it*', with the process of medical diagnoses being significant and worthy of academic scrutiny. For those with bowel symptoms that cannot be attributed to a medical condition such as IBD, cancer or coeliac disease, these medically unexplained symptoms become the diagnosis of IBS. Nettleton's work into medically unexplained symptoms (MUS) (2006) suggest that these patients fit into Frank's (1995) chaos narrative. This is because experiences of MUS are bound up with uncertainty, due to the lack of knowledge and a clear trajectory of the course of illness and a consequent resolution. For Nettleton (2006), this uncertainty means that there are questions for those with MUS for being '*successfully ill*'. For people with IBS, this ambiguity is also present in the management of other MUS, often in the form of food intolerances (Nettleton *et al.*, 2010), as these are seen as less legitimate than food allergies which are medically certified. Dumit (2006: 578) states that there are '*illnesses you have to fight to get*' featuring debilitating symptoms, but no '*known*' scientific aetiology. IBS fits within this category. The narratives of IBS, including the tricky terrain of receiving a diagnosis and the consequent experience of illegitimacy, make this literature significant in the study of IBS. As explained in the introduction to this thesis and detailed in the accounts directly from the participants in chapter two, the stories of coming to live with IBS are complicated and contested. We see how the condition of IBS is taken-for-granted, glossed over, and how individuals with the condition fight for their everyday experiences of the symptoms to be taken seriously. It is within this point that I wish to establish my link with the theoretical body of the sociology of everyday life, as I now turn to explore how we take the mundane *seriously*, and why studying IBS, allows us to do this in the context of health.

3.6 CONCLUSION

The first part of this literature review has set out to explore existing contributions within the field of the sociology of health and illness that are complementary to understanding IBS. The aim of this chapter has been to explore the substantive contributions within the field, reflect upon the dominant theorisations and consider how these assist with the study of IBS. Initially, I attended to what I coined the '(dys)appearing bowel' in studies of health and illness. Here, I argued that the current studies into illnesses associated with the bowel reflect how it only comes to be studied in times of disruptive illness, disability, or polarisations of the life course. The problem here is that IBS does not neatly fit into these categories due to its status as a somewhat liminal health condition. Furthermore, I traced literature that has studied the bowel and highlighted how conditions such as inflammatory bowel disease and coeliac disease have received attention within medical sociology. Whilst such research is important, their presence, accompanied by the lack of studies into IBS, reflects the hierarchies of bowel conditions. IBS occupies a status as an unexplained condition, often denied legitimacy and an appreciation of its potential severity. Consequently, IBS is absent from academic conversation not only as a condition of the bowel, but as a condition not taken seriously. It is here that this study contributes to the field through its study of IBS. There is also more we can learn from the study of current literature into bowel conditions. I have argued that studies into the bowel tend to theorise in one of two ways: first, in relation to matters of the body and second, in relation to stigma. Whilst these are useful, the thesis seeks to refocus conceptual approaches to IBS. This means not merely viewing it through the lens of the body and the ways in which it can be stigmatised (and IBS has a double stigma of being a condition associated with the bowel, as well as being a questionable one). Instead, this thesis works to incorporate the everyday encounters that tell a story of how IBS fits in with the broader minutiae of everyday life.

Nevertheless, this chapter has attended to stigma in a direct response to its role in previous theorisations of the bowel. I have turned to the sociology of stigma as it is an established lens used to theorise the bowel and its products. I returned to Goffman's (1963) conceptualisation of stigma and identity management, paying particular attention to matters of concealment and passing. I provided a whistle stop tour of sociological literature since Goffman's original work, and outlined the task of

extending the concept. Whilst stigma is not the central theoretical lens for this thesis, its place in this literature review provides an important backdrop for the implicit experiences of stigma in the lives of those with IBS, especially related to visibility of IBS as an illness, and the feelings of legitimacy associated with it. These matters, together with the sociological concept of *'passing'*, become particularly pertinent in the public matters of toilet access in my analysis. These latter points are useful in understanding IBS and I thus work at providing an extension to these. My argument is that theorisations of stigma are useful particularly due to IBS being a condition stigmatised due to its excretions, but further exemplified due to its lack of legitimacy. However, I wish to move beyond this theorisation for fear of reducing the experiences of IBS to stigma alone. As I will hopefully show, sociologies of everyday life offer something new to appreciating experiences of illness, showing not only the ways in which encounters can be disruptive and stigmatising, but also how people get by and find ways of negotiating their health condition.

I have explored the well-established literature that explores the experiences of health and illness within medical sociology. These include the dominant literature of Bury's (1982) *'biographical disruption'* and Williams' (2000) *'narrative reconstruction'*. I reflect upon the contributions of such bodies of literature in their deliberate attention to everyday experiences. However, it is my intention to extend Lawton's (2003) call for an attentiveness to the 'mundane' matters of illness experience. Literature within narratives of health tend to focus on the somewhat macro nature of biography and the ways in which this can be disrupted or reimagined. Whilst these are useful and are present within this thesis, I look more readily to the minutiae of everyday life. In particular, my work pays particular attention to the seemingly small encounters very much situated in daily practice, rather than an attention to the trajectories of illness. This is especially important because IBS does not occupy a clear-cut trajectory due to its liminal status as a condition where the diagnosis can shift. Therefore, an attentiveness to the symptoms rather than the status is increasingly important.

Finally, I explored literature within sociologies of health and illness that have explored medically unexplained symptoms (MUS) and the role of diagnosis. This leads on from narratives of health and illness but is a direct response to the uncertainty of the status of IBS. This section attended to the theorisations of MUS and the social importance of

diagnosis. Here I reflect upon the contributions that highlight the significance of diagnosis and a label for consequent navigations of managing illness '*successfully*'. Moreover, it is important to acknowledge the absence again of IBS from this literature. I have argued that this is due to the double bind of illegitimacy and stigma and is thus where this thesis fills the gap by giving IBS serious sociological attention. Within the literature of medically unexplained symptoms, there is an acknowledgement and an attentiveness to the ambiguity and underestimated experiences of symptoms situated within people's lives. This is an important crux that will lead on to the conceptual framework of this thesis.

This section has sought to establish that the presence of experiences of the bowel that are not reduced to serious illness or stigmatisation, nor as biographical disruption. I have sought to illuminate the role of both bowels and legitimacy and how we might become attuned to them in the study of IBS. However, in exploring the ways in which medically unexplained symptoms can be appreciated and highlighting experiences of symptoms that are glossed over, I argue that the conceptual basis of everyday life can assist with this process. As such, this thesis extends theorisations of health and illness by arguing for a conceptual conversation and engagement with the sociology of everyday life. This can happen *precisely* because of the nature of IBS as an illness and/or collection of symptoms. My thesis is a forum for this conversation and a relevant juncture to connect my two bodies of literature, *with the study of IBS*, precisely because of the underestimated and glossed over nature of the condition.

CHAPTER FOUR

CONCEPTUALISING THE EVERYDAY

4.1 INTRODUCTION

This chapter is the second part of the literature review, but specifically looks to conceptually frame this thesis. The previous chapter has mapped some of the substantive contributions within the sociology of health and illness that are complementary to understanding the lived experiences of IBS. In doing so, I have built up a picture of what we might call the (dys)appearing (Leder, 1990) bowel in the sociology of health and illness. This requires a consideration into how serious bowel conditions are studied and theorised, acknowledging the tendency for IBS to be left behind for lack of what we might call *'extremities'*. I have explored substantive literatures around the narratives of health and importantly what this means when illness is unexplained, and diagnosis is uncertain. With these in mind, I argue that the ways in which IBS has been missed from the sociological agenda is telling of both its lack of legitimacy and its relationship to the stigmatisation of the bowel. I argue that the medically unexplained, yet common status of IBS, and its failure to be noticed can be studied through the sociology of everyday life. This is because the task of the sociology of everyday life is to take the daily experiences and minutiae seriously.

Together with an introduction into IBS and the pen portraits of people living with IBS, I hope to have begun to illustrate its ambiguous nature, and how this meets with the necessary work required to appreciate and take seriously the experiences of living with the condition. Les Back (2015) argues that the sociology of everyday life is about *'cultivating a sociological sensibility [that] allows us to remark on what is otherwise passed over as unremarkable'*. In developing an argument that suggests that IBS is common, known about, but passed over as insignificant, there is a sharing of this sociological sensibility. As such, studying IBS through the conceptual lens of everyday life works at giving these fleeting encounters and everyday experiences credence. Narratives of health and illness have of course focused in on matters of everyday experience, and this is certainly useful to the matter at hand, however, IBS is not only a story of biographical trajectories. In fact, given its diagnostic uncertainties, changing

symptoms, and its delicate position as a ‘common’ health condition, it is more complex than solely biography. So, a focus on the minutiae, combined with the biographical, is important in understanding experiences of living with IBS. This conceptual chapter frames the argument of this thesis. That is, I argue that IBS as condition demands that literatures between health and everyday are bridged. This means that in using the sociology of everyday life, we take the mundane seriously (Back, 2007) and this is applicable to the medically unexplained where symptoms are passed over, as is the case with IBS. I begin this chapter by exploring the ways in which everyday life has been thought about by sociologists. This includes the particularities of understanding the extraordinary and the mundane and the blurring between such boundaries. Just as in the experience of being sat in a café wondering where the toilet is, right through to the desperation of begging the barista to let you use their facilities despite not being a customer, there is a simplicity and an extremity to be found within the same everyday place. My broader intention is that the lens of everyday life allows us to capture the mundane encounters and the extreme situations.

Furthermore, as part of exploring IBS through this lens, this conceptual chapter explores a number of literatures to construct an image of the dimensions of everyday life. In particular, I explore the everyday theories of time, space and socio-material relations. First, I turn my attention to the temporal rhythms of the everyday. The previous chapter explored notions of illness narratives that captures temporality in one sense, but I shift attention here to the temporal *minutiae* of everyday life. In particular, I stress the importance of clock time (Adam, 2004) and the ‘*private calendar*’ (Sacks, 1987) that negotiations of IBS might fall into. Second, I introduce everyday notions of space and place that allow us to understand the places people go in the context of their everyday negotiations of IBS. With IBS in mind, I examine the everyday spaces and places of the home and the toilet. In particular, I flag up the sociological significance of toilets as everyday spaces worthy of paying attention to, and thus an important material constitution of our social worlds. This has been a neglected area within sociological studies which I look to contribute to. My final strand of conceptualising the everyday is materiality. I explore some of the sociological foundations of materiality, looking to capture the things that matter in people’s everyday worlds, and how we should take these objects seriously. This has been conceptualised as the ‘*material turn*’ (Hicks, 2010). The literature review calls for a recognition for the

materiality of the everyday, extending this work to the domesticities of material life within the context of health as well as the mobilities of mundane objects. Through the lens of everyday life, its temporalities, spaces and places, and daily objects that come to matter, this chapter sets an agenda for understanding and exploring IBS. Most significantly, this agenda is set between experiences of health and illness and sociologies of the everyday, made possible through the category of IBS. This framing offers a contribution to studies of health and illness, particularly common illnesses that do not always receive attention. It offers a vitality into the everyday experiences of common illnesses and the ways these come to affect, and matter. For everyday life, it offers a contribution by including health and illness as part of everyday social worlds that are simultaneously ordinary but incredibly worthy of being included and receiving attention.

4.2 TAKING THE MUNDANE SERIOUSLY: SOCIOLOGIES OF THE EVERYDAY

Chapter three offered a glance into the current theorisations of bowel conditions and broader narratives of living with illness, particularly those that are contested. I then reflected upon narratives of health where many scholars have grounded their work within everyday experiences of what it is like to live with a health condition or chronic illness. Bates' (2019) work, *Vital Bodies* offers a useful connection as she explores the daily rhythms of bodies whilst living with chronic illness, utilising visual methods and diaries designed at capturing these everyday experiences of the body. Thomas and Latimer (2015) have also bridged this gap of seeing traditional matters of health and illness told through the lens of the everyday in their studies of in/exclusions in the clinic and the ethics of medical work. These studies provide useful groundings for theorising IBS through the lens of everyday life. However, what I hope to do with this thesis is to demonstrate how IBS as a condition provides a particularly useful juncture between sociologies of health and illness and the sociology of everyday life. This is because IBS occupies a space as a common condition that is rarely discussed or given much attention, due to its ambiguous and taboo nature, and as such, has an affinity with the explorations of everyday life in the ways in which they are both passed over as seemingly insignificant. In order to challenge this absence, this thesis looks at the

mundane encounters that happen in the lives of those with IBS, using these encounters to take serious notice and ground IBS experientially.

I began this thesis by laying the foundations of what studying everyday life entails. This lens is not particularly new, and insights into the micro-interactions of the everyday have been made visible in major sociological works. In their editorial of the special issue on the sociology of everyday life, Neal and Murji (2015) trace the ways in which the minutiae have been attended to throughout sociological history. These include Goffman's dramaturgical model (1959) and his aforementioned concept of stigma (1968), Elias' manners (1978 [1939]), Lefebvre's rhythm analysis (2014 [1985]), Latour's Actor-Network Theory (ANT) (1993), more recent turns to materiality (Miller, 2005), and sensory encounters (Pink, 2012). Neal and Murji (2015: 812) suggest that in studying everyday life, we turn attention to the ordinary and an '*immersion in the seemingly unremarkable and routine relationships and interactions with others, things, contexts and environments*'. This immersion facilitates an insight into dimensions of everyday life, through capturing the meso-level interactions.

Sociological studies that have delved into the intricacies of theorising everyday life have illuminated the challenges of definition, since what is mundane or ordinary to one person, may be very different to another (Scott, 2009: 2). Similarly, Highmore (2002) breaks down the idea of everyday life existing outside of, and separate to, the extraordinary. He argues that scholars must shift how the everyday and the extraordinary are put against one another. Highmore suggests that we must see the world not as significant dramas of events and people ahead of the background of daily life, but that the relationship between '*foreground and background needs to be reversed*' (2002: 27). In this study, this would mean not the extremities or overt disruption of IBS, but rather the everyday encounters that facilitate this overall picture. More recently, Robinson (2008: 116) explored what she called '*mundane extremities*' in her work on masculinities and rock climbing. She argued that the boundaries of everyday life and the extraordinary, the normal and the extreme, are '*inextricably bound together*'. Again, this is useful given that accounts of IBS are telling of daily events, practices, and routines of our body that we all do and experience, but show how IBS shifts this somewhat in its sometimes-chaotic change. Hockey *et al.* (2007b: 4), in their study on heterosexuality, suggest that there are challenges in researching what appears

to be ordinary and mundane, precisely because it is ‘*everywhere and nowhere*’. We are all eating, defecating, and negotiating these experiences in everyday life, yet for those with IBS, their experiences may be extraordinary in comparison, or perhaps not. Ellis (2010) advocated a similar positioning in arguing that death can be simultaneously ordinary and part of family life, as it can be unique and unsettling. What these theorists have in common, in sociology and beyond, is the collective task of demonstrating the importance of taking mundane aspects of life seriously (Back, 2015; Pink, 2012). In reflecting upon the ordinary and the extraordinary, the taken-for-granted and the seemingly unimportant, there is an opportunity to think about the everyday ways symptoms of IBS unfold. The lens of IBS illustrates encounters in everyday life that are potentially universally relatable, achieved precisely because of its framing of the minutiae. Neal and Murji (2015: 812) suggest that studying everyday life means capturing the *contexts*, the *routine* relationships, and the *things*. It is within this conceptualisation of everyday life that I turn to the contributions of time, space, and materials, as important in the conceptualisations of everyday life with IBS. These facets of everyday life conceptually inform experiences of IBS, as we shall see in later empirical chapters.

4.3 RHYTHMS AND RECONSTRUCTIONS: SOCIOLOGIES OF TIME

‘Day after day we engage in the same mundane activities, at the same times and in the same order, and this routine predictability allows us to take the everyday world for granted’ (Scott, 2009: 69)

Our everyday activities and the routines they fall into are at times, like most things in everyday life, taken for granted. Our everyday lives are configured by the routines, practices, and times in which we structure them. Yet, for those with IBS, the ability to take everyday routines for granted may not be the case. We see an appreciation of time in the work of Charmaz (1991) ‘*Good Days, Bad Days*’ and Bates’ (2019) use of rhythms to understand bodily experiences of chronic illness and disability. Matters of time have been touched upon earlier in chapter three, when considering biographical disruption (Bury, 1982) and the reconstructions (Williams, 1984) when illness occurs. However, in line with conceptually positioning the *minutiae* as the focal point to assist

in studying everyday life, I will now explore some of the valuable contributions to how we might see the everyday rhythms of those living with IBS.

Barbara Adam (1995, 1998, 2004) was at the forefront of sociological explorations of time. Adam's work on timescapes explained how time represented one of the ways in which everyday life and its practices are organised. She further identified three main ways in which we experience time in the social world: Firstly, the biological clock of birth, death, reproduction (and I aim to extend this to the temporality of digestion) which Southerton (2006) expands by addressing the issue of the life course; Secondly, clock time, the 'objective', 'measurable' way in which we can monitor ourselves and others in accordance with a socially agreed norm; and thirdly, social time, meaning how we as individuals understand and make use of time whether this is a habit, a routine, or our daily schedules. Adam (2004) demonstrated how we develop strategies to challenge the constraints of time, something that could be extended in the context of the strategies taken when living with IBS. Southerton (2003, 2006) has also contributed to notions of temporality, building on Fine's (1996) five characteristics of time which are periodicity, tempo, synchronisation, duration, and sequences. Southerton (2006) states that different practices also have unique temporal demands dependent on how we negotiate them with other people or the position of an activity within a wider framework of our everyday. These spatial and material facets of everyday practice will be attended to shortly.

Zerubavel (1979; 1981) has been another key theorist who has offered insights into the temporal rhythms of everyday life, stating that understanding routines offers a '*temporal map*' for understanding the performances of practices, such as the ordering of structures. Zerubavel was interested in various aspects of everyday life, but deeply explored concepts of time through his works, '*Patterns of Time in Hospital Life*' (1979) and '*Hidden Rhythms*' (1981) and was particularly interested in the standardisation of time. For Zerubavel (1981) the characteristics of temporal regularity offer certainty, boundaries, and expectations of what should and does happen in our social and cultural world. When thinking about the relevance of this to everyday life with IBS, one might reflect upon the temporal structures of a morning trip to the toilet *after* breakfast but *before* work. There are tacit understandings of *how long* this should take, when this should be done, *where*, and *how often*. Southerton (2003; 2006) and Zerubavel (1979; 1981) have in common the ability to pay attention to the daily rhythms and sequence,

despite their empirical settings being different. In a similar vein, Pickering *et al.*'s (2013) study into recovery from heroin addiction traced the return to 'normal' and 'regular' through participants' occurrences of defecation. Of course, this return to a regular bowel habit is not at all so straight forward for those living with IBS, reiterating the importance of shedding light on the everyday routines of those living with IBS. Adam's (2004) idea of '*biological*' clock time, and later applications of this (see for example, Earle and Letherby, 2007 in their work on reproduction) are useful when thinking about the daily rhythms of IBS. Whilst the conceptualisation of a '*biological*' clock has tended to focus on matters of reproduction or the lifecourse, one might extend this concept to matters of the bowel. The rhythms of when we eat, the time it takes to digest, the time necessary for defecation to occur and the regularity of such an event all come to the fore in the study of IBS.

Scott (2009: 90) states that within our everyday lives, '*time is both constraining and enabling*'. When considering the constraints of time further, Southerton (2003) unpicks the ways in which society '*squeezes*' time and how we can often feel rushed or harried. To relate this more closely to IBS, Inglis and Holmes (2000) document the ways in which toiletry time is constrained through a Marxist, feminist, and civilising lens. For example, Inglis and Holmes (2000) argue that these structures of modernity have imposed increasing levels of guidance and administration and thus enforced temporal regulations of when toiletry practices can occur. However, they also argue that whilst these temporal regulations and increasing constraints occur, the human body and its products still operates on its own clock. The temporal rhythms of our bodies (Adam, 1995), our mealtimes and eating practices (Southerton *et al.*, 2012), and work time (Brannen, 1995) have all received attention in sociology, but toiletry time is perhaps a '*private calendar*' (Sacks, 1987) that we are yet to acknowledge and credit as a worthy area of inquiry. My previous work on toilet mapping identified how precious time can be; how time can be tactfully managed in accordance with everyday practices and routines (White, 2016a, 2016b). For those with IBS, the time they take in the bathroom, the toilet trips in work time, and times of travel when desperate to get to the destination of defecation are areas of concern. There is often the embarrassment of excusing oneself when taking longer than socially expected, using an alternative explanation for delayed toilet time, such as a fictional queue.

Kelly's (1992: 36-7) study on colitis highlighted some of the ways in which individuals living with the condition '*break off conversations, meals, social interaction in order to go to the toilet*'. This is something which can be further applied in the context of IBS. Our activities of washing, eating, and excreting define and punctuate our everyday routine. Twigg (2006: 119) states that '*much of our ontological security derives from this bedrock of bodily comfort, comportment and care*' and like other matters of our daily lives, these are often taken for granted, trivial, and personal, yet fundamental to our sense of self. For those with IBS, everyday routines may be disrupted due to an unpredictable bowel, together with the rhythms and pressures of social clocks. Regular or prolonged trips to the toilet have the potential to create insecurity in the temporal trajectory. This has been acknowledged as particularly the case for women, with oversubscribed cubicles and a queue, leaving those inhabiting toiletry spaces conscious of the time spent and how they use such a space, knowing that someone may well go straight in after them (Blumenthal, 2014: 104). Carter (1987: 87) noted that control of time spent and places to defecate in is one of the most crucial and fundamental features to an individual's autonomy; a human right. Blumenthal (2014: 102-3) states that one rule in toiletry use is to minimise the time and space that you take when visiting the bathroom, particularly in public ones where the goal of minimal time is to avoid embarrassment, transgression, or shame. There is room to think about how time is experienced in different ways, with various others and in various spaces, as well as thinking about the unpredictable and irritated clock of the digestive system. One can contrast the medical discourse of treating constipation by avoiding holding it in with the social regulation of toiletry time and place. Elements of time such as waiting, queueing in public toilets, and how time may uncover the realities of the condition are areas that research into everyday life with IBS can explore. Of course, it is important to think about where these routines happen, which takes us to the conceptual underpinnings of spaces and places in everyday life that are of importance to understanding IBS.

4.4. EVERYDAY PLACES AND SPACES: PRIVATE HOMES AND PUBLIC TOILETS

As my analysis moves through facets of everyday life, the spaces and places in which our lives unfold are pertinent. In his paper on why everyday life matters, Les Back (2015) locates his analysis in the social life of particular places in London and their presentation of Christmas lights. He draws attention to the mundane, and very much situates everyday life in the places in which it unfolds. In seeking to understand the everyday experiences of life with IBS, understanding of space and place, and the boundaries of such, become worthy of acknowledgement when we consider the commonality of the condition and the ways in which it is hidden. IBS, due to the nature of its symptoms, happens ‘behind closed doors’ and often in the privacy of one’s home or the privacy of a singular, public toilet. What this work seeks to do is bring these mundane spaces and places to light. With this in mind, I will then consider the places of importance when we think about the everyday lives of those with IBS – the home, and the bathroom. Whilst there is sociological literature that explores the home as a key place in our everyday lives, I aim to explore the importance of what Twigg (1999) calls, ‘*the ordering of privacy*’ and more specifically, how notions of privacy can be transgressed in domestic space, through the work of Gurney (2000a, 2000b). This is important when understanding the symptoms of IBS, particularly when such symptoms include management of smells, sounds, and (in)visibility. I will consider mobilities, drawing upon my previous work on toilet mapping, but also the meaning (both symbolic and emotional) of spaces such as toilets, that elicit feelings of embarrassment when ‘back stage’ behaviours are presented ‘out front’. This leads to a greater need to explore further the liminality of what we consider public and private, particularly in relation to the tensions of the toilet, when other sensory elements transgress boundaries of ‘personal space’. Toilets have received significantly less attention in sociological studies, and I look to reiterate their importance as a key social space and place worthy of academic scrutiny.

An understanding and appreciation of place and space has become an important feature in sociology. As Urry (2001: 3) argues, ‘*space (and place) should be central to sociology*’. Gieryn (2000) defines and separates the meanings of space and place. He delineates space as an abstract geometry compared to place which captures location, materiality, and meaning. Sociologists have focused on the ways in which spatial structures are ‘*not merely...an area in which social life unfolds, but rather...a medium through which social relations are produced and reproduced*’ (Gregory and Urry,

1985: 3). Similarly, Lefebvre (1991) advocated that space is often a site of struggle. Terrani-Brown's (2013; 2019) work into the sanitary practices across the city of Kampala utilises spatial methodology and draws upon Lefebvre's work (1991a; 1991b). In coining this geographical work as '*shitscapes*', she explores how spatial maps only tell part of the story and reflects upon the assumptions and moralities made of toiletry practices. This appreciation of the spatial understandings of everyday life and of toiletry practices in particular is a useful piece of the puzzle in understanding everyday life with IBS. I wish to transfer these spatial understandings to understanding IBS, in the context of public and private life, if indeed the two can be separated. Another important conceptual tool in understanding the movement through everyday space and the interesting distinction between public and private and the spaces between, comes from Hockey and Robinson's (2011) study of masculinities. They argue that masculine identities transition and shift as they move across space and time, and from public spheres to private places. These blurred spatial-temporal boundaries in everyday life are something that can be carried through to understanding the lives of those with IBS.

NO PLACE LIKE HOME?

As mentioned earlier, one of the key places in which we experience everyday life, and that has received significant attention in sociology, is the home (see for example, Allan and Crow, 1989; Sixsmith, 1990; Gurney and Means, 1993; Massey, 1994). The home has been understood in the sociological and geographical arenas, offering insights into understandings of relationships through everyday practices (Pink, 2004; Smart, 2007). In particular, the home has been conceptualised as a place that offers privacy, security, and identity; home is where you can close the door on the outside world (Twigg, 2006, 1999). Twigg (1999) argues that there is a *spatial ordering* of privacy and intimacy within the space of the home. The areas hidden from strangers are more closely associated with the intimate side of personal life, one of which is the bathroom. Lewis' work (2011) on shutting the bathroom door demonstrated the ways in which intergenerational relations could be understood; namely, children begin to shut (and lock) the bathroom door and manage their own bodies as they become older. In the context of IBS and the management of its symptoms, there can be '*no place like home*' (White, 2016b). Similarly, Sixsmith (1990) argued that to be at home is often to be '*at*

ease'. Lea (2001) demonstrated in her work on understanding defecation that there are complexities in (un)familiar places, such as the finding that people may wait to go home before defecating when out at work or at a friend's house. However, the '*privacy*' of the home is not so clear cut. Heath *et al.* (2017) have unpicked the phenomena of *shared* housing, offering insight into what it means to share domestic space. Gurney's (1998, 2000) work questions the spatial concept of privacy within the home and corporeal vulnerability. This is highlighted in his work on the transgression of the private-public boundaries of the home in the context of coital noise, an '*unasked for intimacy*', where intrusions are '*out of place*' and noises expand to the ears of others (Douglas, 1966). Thus, in reviewing the literature on the home as a key site of everyday life, we see the conceptual value of how those with IBS manage private symptoms in private spheres, but also how we might use the opportunity to build on new questions of sharing domestic space and the transgressions of privacy when IBS symptoms come to the fore.

A SOCIOLOGY OF TOILETS

It is important to sociologically explore bathrooms and toilets when understanding everyday life with IBS. Toilets have historically received little attention in anthropological research (Lea, 2001; van der Geest, 1998, 2002). Studies exploring toilets are similarly scarce in sociology (Inglis, 2000), only recently becoming an area of sociological inquiry (e.g. Molotch and Noren, 2010; Blumenthal, 2014; Pickering, 2012; Pickering and Wiseman, 2019). However, as Molotch (2010: 1) advocates, sociological insight into toilets is a '*route worth taking, precisely because of the shadow under which it normally falls*', similarly fitting in with the lens of everyday life as taken for granted, but incredibly significant. Toilets offers insights into socio-cultural understandings of hygiene, stress, the power at play, and the cultural values when negotiating and regulating toilet activity. The toilet becomes a tool to understand wider society (Molotch, 2010). Similarly, Blumenthal (2014: 71) has stated that public toilets have historically reproduced and continue to reproduce such divisions as well as issues around morality, health, sanitation, and urbanity. Kafer (2016) explores the politics of '*hovering*' in public toilets, questioning the process of disregarding others and the unpicking of concepts such as '*safety*', '*comfort*', '*cleanliness*', and '*sameness*', through the lens of transgender and disability studies. Kafer (2016) provokes us with

questions of how we might reimagine toilets as an everyday site of collective belonging. Slater and Jones (2018) have similarly called for a rethink into the accessibility of toilets, with an intersectional consideration of gender, ethnicity, and disability. These insights unpick the mundanities of toilets, and why they should be worthy of sociological attention. These reflections offer an important platform when living with IBS, posing an insight into how a mundane space and material feature of our everyday life can be scrutinised in terms of access and belonging. This is important in the context of IBS where toilets can increasingly become a space and place within daily routines and disruptions.

Toilets have often been theorised using the sociological lens of dirt. Indeed, we cannot deny the work of Mary Douglas (1966) and the boundaries of dirt, with toilets keeping 'dirty' products in a correct, private, and bounded place. The latest sociological work '*Down the Pan*' (Pickering *et al.*, 2019) has placed the theorisation of dirt in everyday life on centre stage, with toilets being an important part of this (see Wiseman, 2019 work on '*toiletsapes*' in the lives of disabled people). Blumenthal's (2014) exploration into the history of the western toilet acknowledges that the development of a '*private*' toilet and the '*private*' acts within led to the socialisation of '*modesty*' and consequent bodily shame and aversion for our waste. We can see this in the work of Elias' (1978 [1939]) civilising process, whereby excretions became increasingly private and separate from others, made possible by the dedicated space of the private lavatory. Moreover, Cahill *et al.* (1985: 36) stress that it is not just the creation of a dedicated physical space of privacy that a toilet stall offers, but it is also the behaviour attributed to the boundary, a normative protection for prospective audiences. Blumenthal (2014: 102-3) acknowledges that there are rules in the bathroom to *minimise time* and to *uptake as little space* as possible.

However, toilets are not as exclusive as you would think. Penner (2013: 9) stressed that the bathroom is not a discrete site cut off from wider society; it is a place that connects the body to technology and to society. Lea (2001: 91) also argues that the backstage region of the toilet is very much part and parcel of performing the self, particularly in the case of a place of work or at school, where there is the possibility of someone else entering the space. For Lea, public toilets threaten the identity in two ways, as the outside world coming in and the inside personal world coming out (2001: 94). For those

with IBS, finding a toilet to manage their symptoms is an important feature of everyday life. In sociological studies on IBD, Kelly's work (1992: 36) highlighted being '*on the lookout for toilets*' and Ogden's (2010) on children with IBD highlighted the mapping out of locations of public toilets along travel routes. My previous work on toilet mapping (White, 2016) when living with IBS sought to understand toilet use in everyday life, particularly regarding negotiating access to toilet facilities by planning, mapping, or looking for toilets in social spaces and places. In doing this, the work understood toilet mapping in line with broader societal attitudes of bodily boundaries, etiquette and matters of contemporary western society, placing the materialities of toilets and the journeys to them at the heart of understanding life with IBS. This work looks to take this forward, and to take toilets as everyday spaces and the issues of getting to them, seriously. One might also consider Robinson's (2008: 116) concept of the '*mundane extremities*' in the issue of accessing toilets. Toilets are significant materialities as well as places within our social environment, and the issue of getting to them is important for us all. However, the everyday access and physical presence of toilets can become an extremity in the lives of those with IBS.

4.5 FROM TOILETS TO CAN'T WAIT CARDS: THE SOCIAL LIFE OF THINGS

The previous section has drawn attention to the value of the home and the physicality of toilets. With these spatial and material facets of our everyday worlds, it is important to take stock of theoretical insights into materiality, or what Appadurai (1986) called '*The Social Life of Things*'. My interest in things also follows the trend of the '*material turn*' seen within the social sciences (Hicks, 2010). Miller (1987: 5) wrote on the '*humility of things*', stressing that objects in our lives are often important because they enable or constrain, but precisely because we often take them for granted and fail to '*see*' them. This failure to '*see*' objects as immediately important engages in the taken-for-granted nature of our everyday things situated within our everyday worlds. Within this taken-for-granted nature lies the sheer powerfulness of objects and their capacity to affect without often being open to question. Woodward (2015b) has also highlighted how everyday objects can lay '*dormant*' within our domesticities, kept in wardrobes or cupboards when their usage is not immediate. One might suggest this humility and dormancy can be seen in the domesticities of our bathrooms, their material value only

made conscious in times of urgency and when living with IBS. Only when circumstances require the necessity of toilets (i.e. in the face of illness), do their material presence become noticeable and appreciated.

The value of these objects has seeped into public discourse in recent times. For example, there have been cases where shopping outlets have failed to grant access to toilets with the presence of a ‘*Can’t Wait*’ card, resulting in upsetting circumstances for many (The Independent, 2019; The Metro, 2017). I use these as an example of the everyday things that can matter for those living with bladder and bowel conditions. The ‘*Can’t Wait*’ cards illustrate the capacity of objects in recognising legitimate illness, granting access to public spaces, and the reassurances of owning one. The keys, the cards, and the ‘*quiet materialities*’ (Pink *et al.*, 2014:432) for people with IBS are often kept in their pockets and bags and are an important feature of their everyday. This brings to attention Buse and Twigg’s (2014) study on handbags for women with dementia, demonstrating another way in which material artefacts have multiple capacities, not only in biographical ways but also working to construct private space in public spheres and to establish security in doing so. Buse and Twigg (2014) apply Giddens’ (1991) concept of ‘*ontological security*’ to the use of handbags to give weight to the meaning and agency that material items have. Similarly, Miller (2008) explores ‘*The Comfort of Things*’, through a modern street in London, finding that the things that matter are the things people have, that bring comfort in times of sadness. These themes of privacy, comfort, and certainty established through objects are increasingly relevant given the nature in which we manage our bowels as private sides of our lives, that are often negotiated in public encounters.

Studies into health and illness have begun to appreciate the role of material items as part of everyday lives. There has been a recent focus on the ‘*materialities of care*’ told through the lens of food (Ellis, 2018), care homes (Lovatt, 2018), blood pressure monitoring (Weiner and Will, 2018), and dress (Buse and Twigg, 2018) as a few examples. Reed and Ellis (2019) utilise the go-along method in the context of the mortuary, drawing important intersections between materiality and mobility in healthcare settings. These contributions of the things we have and where we go provide a useful framing for how one might think about the things carried on the everyday journeys of those living with IBS. All of these examples pay attention to the mundane

and material ways in which health and/or illness are experienced and leave a useful platform for thinking about the materials that affect everyday negotiations of IBS. In keeping with this, I further Woodward's (2015a) call for a '*material imagining*' into the everyday ways people negotiate their IBS symptoms. This is also something directly implicated in the research process of this project as we shall see later. What I have hoped to show is the value of including things in the contexts of both studying everyday life and their role in health. Building upon the current literature, I take the opportunity to consider the role of material items in the context of everyday lives, not as static but as part of broader processes of our day to day happenings; as part of, and together with, the places we can and can't go, and thinking beyond domesticities. As a final note and in line with the everyday, I take away the value in studying what Pink *et al.*, (2014) call the '*quiet materialities*', giving light to the objects we possess, but which, like the theme of everyday life and the glossed over nature of IBS, are taken-for-granted.

4.6 CONCLUSION

The aim of this chapter has been to lay the conceptual foundations for studying IBS through the lens of everyday life. Choosing this conceptual framework comes as a response to the substantive contributions within the sociology of health and illness, and how IBS has somewhat fallen under their sociological radar. Whilst studies within health and illness have an attentiveness to everyday experiences often in the form of biographical accounts, this thesis pays particular attention to the workings of daily life. This is because IBS falls to everyday life more than the realms of health or clinical settings, because of its category as a medically unexplained set of symptoms. Therefore, it is within the everyday that we access such experiences. However, conceptually approaching IBS through the lens of everyday life, there is an enlivenment of daily experiences and symptoms that are glossed over, discounted and rarely discussed. Through everyday life, these can be listened to, reimagined and, most importantly, taken seriously. Thus, as I explored the contributions that have sought to define and explain the sociology of everyday life and why it is important, I have made a case for taking the mundane seriously.

As part of this task, I considered three dimensions of everyday life that will facilitate this. First, I reviewed sociological explorations of time and the everyday, from macro understandings of clock time (Adam, 2004), right through to the micro interactions of daily routine. I illuminated the possibility that everyday life with IBS might reveal a *'private calendar'* (Sacks, 1987) yet to be explored. This works together with an opportunity to take forward understandings of the *'biological clock'* (Adam, 2004; Earle and Letherby, 2007) to include the bowel as part of the rhythms of everyday life. These are valuable in not only viewing IBS through biographical understandings of time as is often seen within the field of health and illness, but rather the temporalities of the microcosms that make up people's daily encounters. These contributions to understandings of time within everyday life come to be of value as participant accounts will show not disruption, but reorganisations of daily routines and a recognition of the body clock that includes the bowel.

Next, I turned to sociological theorisations of place and space as an important facet of everyday life. I started with Les Back's (2015) exploration of a familiar estate and the story told of its Christmas lights. This paper sought to demonstrate how places are important in the study of everyday life, and thus offer an important opportunity in this study of IBS as I look to situate experiences of symptoms in the spaces and places in which they happen. I reviewed some of the broader theorisations of space and place and then engaged with two particular places worthy of attention for the topic at hand: the home, and the bathroom. Whilst understandings of the home have come to be well established in sociological literature, only more recently has sharing domestic space come to the fore. Together with Twigg's (1999) '*ordering of privacy*' the literature on the home provides a useful opportunity for considering the negotiations of IBS in domestic spaces, and the focal point of the supposedly most private space in the house, the bathroom. This led to my review on the sociological literature to date in the study of bathrooms and toilets, which I argue has been scarce due to the status toilets occupy. I have suggested that toilets are an ordinary place that we all frequent. However, through the study of IBS, we can see how the urgency of symptoms together with problematic access can lead to what Robinson (2008: 116) might call '*mundane extremities*'. As such, this thesis looks to take toilets as an everyday space and place seriously, making this visible through the case study of IBS.

The topics of the home and the toilet, as well as places, are important pieces in the jigsaw of our material worlds. As such, my final turn was to sociological understandings of materiality as a way of theoretically placing the things that may matter in the everyday lives of those with IBS. I reflected upon the '*material turn*' (Hicks, 2010), offering insights into some of the key literatures that take the things we hold as worthy of serious exploration. I also documented the '*material imagining*' (Woodward, 2015a), seen within recent studies in the sociology of health and illness, offering a useful platform to take the things that matter in the negotiations of those with IBS forward. Moreover, I stressed the importance of how this work might take not only objects as part of everyday life, but their intersection with the routines of people's days and the places they can or cannot go. These varying dimensions into everyday life in some ways seem to be vast. However, Jacobsen (2009: 14) summarises the 'complication' of everyday life that includes place and space, temporality, artefacts and experience that this thesis looks to capture.

Ultimately, this chapter offers a conceptual framework for studying IBS through the lens of the sociology of everyday life. This is achieved through giving explicit attention to matters of health and bodies that are hidden or glossed over. In its absence from the realm of health and illness due to its unrecognised and taboo nature, the sociology of everyday life offers a way of understanding IBS. Through exploring the quotidian life with IBS, there is an opportunity to see where symptoms unfold, when, how often, the role of things, and how all of these facets simultaneously work at giving weight to a condition overwhelmingly present, yet missing from academic and public discussion. This thesis fills an empirical gap by studying IBS within the field of sociology. However, it also offers a contribution to the sociology of everyday life through the inclusion of experiences of health and illness and, specifically, a common and taken for granted one. With this conceptual approach in mind, I now lead on to the methodology. This addresses the methods utilised to explore the places people go, the routines of their day, and the people and things that matter.

CHAPTER FIVE

METHODOLOGY

5.1 INTRODUCTION

In this chapter, I provide a critical and reflective engagement of the journey of this research that encounters the everyday experiences of those with IBS. I trace the background to the research, providing an overview of my approach and the steps taken whilst embarking on the data collection process. As with the rest of the thesis, I reflect upon how the spatial, temporal, relational, and material facets of the everyday come to be intertwined with the diaries as a chosen method. In particular, I delve into the diversities of the diaries as a method, and how the multiple ways in which the diaries were completed should be celebrated through their capturing of different forms of knowledge. First, I explore how this diversity in completion allowed for further reflections on diaries as *biographical facilitators*. Second, I reflect on how the diaries captured *daily monitoring*. Third, I unpack how diaries, by their very recording, give rise to the everyday *routines* and *temporal logging* of events. Fourth, I reflect on how the methods allow for the documentation of *private thoughts* and intimate lives. These methodological reflections work in conversation with the rest of this thesis and specifically with the empirical data chapters that shall follow. Following this, I reflect upon the follow up interview that worked as a process of building on the diary entries and how they were situated within both individual lives and the social context in which they are embedded. In line with the social and material relations sought out with this thesis, I reflect upon the material items that came to be notable features of the research process and empirical findings. Next, I map the journey into my analysis and stress how the pen portraits and biographical accounts have been crucial in this process and in the formation of this thesis. Finally, I offer reflections on the ethical considerations that this research has presented, capturing my own emotions and position as I engaged in the process and how the methods themselves engaged with ethical contemplations. By tracing these methodological processes, I look to document how the personal and intimate lives of both my participants and I are intertwined within the methods that are implemented. This chapter works to also reiterate how these methodological tools compliment the sociology of the everyday and the ways in which space, time, relations, and materials can be embraced through these methods.

5.2 RESEARCH APPROACH

This research is an exploratory study of the everyday lives of those living with IBS. The research aligns with an epistemological approach that takes as the focus how individuals make sense, negotiate, and experience their everyday lives in meaningful ways. This approach has been useful in previous studies of other narratives of living with chronic illness (Bury, 1982, 2001; Frank, 1995; Ville, 2005; Kleinman, 1988) and therefore felt to be the most appropriate to understanding everyday life with IBS. A qualitative methods approach was used to explore the everyday experiences of individuals living with IBS, allowing for a rich understanding of the processes involved in individuals' experiences (Mason, 2002). Zimmerman and Weider's (1977) Diary and Diary-Interview method has been utilised in this study. By using diaries and follow up interviews, these methods facilitate an understanding of how IBS is revealed in everyday life. Diaries and subsequent interviews sought to capture the stories of everyday practices, the 'doing' of everyday life when negotiating the symptoms of IBS. The methods also offered space to reflect on the wider social implications, norms, and a sense of self that may come from writing and discussing these experiences. As a reminder, this thesis questions, '*How do people negotiate IBS in their everyday lives?*'. I also engage with the following research questions:

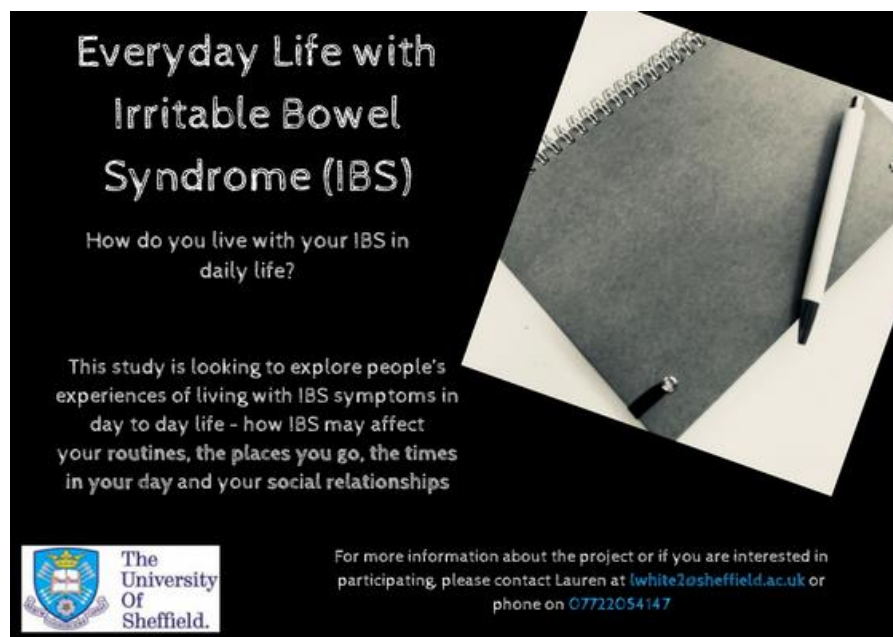
- How are symptoms of IBS experienced in *mundane everyday spaces*? How are these symptoms negotiated as people *move between* these *places* of the *home*, the *workplace* or the *dinner table*?
- What are the *daily routines* and navigations of *time* for those living with IBS? How might these routines be disrupted, (re)organised and (re)imagined?
- What *social* and *material* relations are at play for those with IBS? How might these relations play out in '*public*' and '*private*' life?

5.3 ACCESS AND LIAISON

Information about the study was shared through charities who offer support to those with gastrointestinal conditions including IBS. The charities that were approached included the Bladder and Bowel Community, GUTS UK, and The IBS Network. I have an established relationship with the IBS Network, participating in their advisory board

as well as being involved in previous work with them. I also built connections with Guts UK and the Bladder and Bowel Community charity, with ongoing conversations and updates on the progression of this research. I contacted each of the charities with information about the project (see figure 1 below), which they added to their websites and distributed via their social media. However, I was also conscious of gaining access to those who were not seeking support from charities. Consequently, I advertised through social media such as Facebook and Twitter. Recruitment through these social networks became the most successful way of gaining participants in practice. This is perhaps also telling of the ‘everyday’ and common nature of IBS. For some participants, contact was established via my own social networks, sharing with family and friends who passed on the details of the projects to people of interest.

Figure 1: Image developed for Advertisement of Study



I sought to recruit 20-25 adult participants within the South Yorkshire region. I made an active decision that participants did not need to have a clinical diagnosis of IBS through a medical practitioner. My justification for this was that I wanted to prioritise experiences and knowledge of individuals and their symptoms rather than medicalised categorisation. This is particularly pertinent with IBS, as it is often categorised as a diagnosis of exclusion. Over fifty initial enquiries were sent regarding the advertisements, mostly via email. I initially sent an informal email that outlined who I

was and what the research involved as well as tailoring the email to the individual and their introductory email. An example of this is below:

Figure 2: Example Email to Prospective Participants

Dear [insert name],
Thank you for getting in touch - I really appreciate it.
For my research, I'm looking for people to document their experiences (in a diary) of how they manage their IBS on a daily basis, and what kind of things it affects e.g. places you go, your daily routines, travelling, relationships. I can post out a paper diary to you, or you can type up using MS Word or make audio recordings. After that, I'd like to chat more personally about things that are important to you when it comes to IBS. I'll attach an information sheet that explains the project in more detail, and a consent form. Please note that although it says Yorkshire area, it's fine if you're further afield.
If you want to have a read of the information, let me know if you have any questions, and if you are still interested in participating, we can take it from there.
Best wishes,
Lauren

As with all research studies, not all of those who enquired took part. Some prospective participants indicated that diary writing was not for them or they did not have the time. Alternative provisions and flexibility were also offered for those who did not wish to complete a diary. For instance, participant Sophie expressed that she could not fit diary keeping into her current schedule but accepted a face to face interview to discuss her everyday life with IBS. Like all research, some failed to respond following the initial email. Some began the process and were sent diaries, but contact was then lost upon chasing up. In the end, I had a collection of 25 diaries and follow up interviews. The participants were either self-diagnosed, 'medically' diagnosed through the process of exclusion of other health conditions, or diagnosed within primary care without further investigations. I was also driven from the beginning of the project to try and challenge gendered connotations of IBS for several reasons. Firstly, IBS fits under the category of being a functional disorder, with psychosomatic connotations, and thus undertones of female hysteria (Werner *et al.*, 2004). Second, Bjorkman *et al.* (2013) have also

explored the gendered nature of IBS demonstrating how gender stereotyping by healthcare professionals perpetuates the challenges of IBS symptoms with women being trivialised and men being overlooked. Finally, sociological work has explored the gendered nature of health seeking behaviour whereby women attend the doctors and thus are more likely to receive a diagnosis than men (see for example, Annandale, 2014). With these factors in mind, it was important to try and challenge these gendered associations and capture the diversity of the experiences of those with IBS. Towards the end of the project, I opted for a purposive sampling approach in order to recruit more men, by advertising the study again with the aim of achieving this (see figure 3).

Figure 3: Men and IBS advertisement

I am looking for men who have Irritable Bowel Syndrome (IBS) aged 18 or over, who live within the South Yorkshire area and would be interested in participating in my research. I am interested in hearing how your IBS may affect your routines, places you go, times of the day and your social relationships.

I would like to invite you to complete a two-week daily account of how your IBS affects you. I would then like to speak to you about how you found completing this and discuss any aspects of your life with IBS that you wish to share.

This research is part of my PhD into the social experiences of IBS. This project has been ethically approved by the University of Sheffield and has the Reference Number: 016164.

If you are interested in participating or would like to find out more about this study, please contact Lauren on lwhite2@sheffield.ac.uk or phone on 07722054147

In total, sixteen women and nine men took part in the study. These participants were aged twenty to seventy-five years old. The participants were a variety of socio-economic backgrounds. Participants were predominantly White British. Due to the self-selective nature of this work and with it being a preliminary study, diversity of a range of ethnic backgrounds have not been captured. However, this provides an important and necessary direction for future research, with a stronger focus on intersectionality. The pen portraits of each participant (seen in chapter 2) work to form an identity of each of the participants based on what they chose to disclose. The occupational status and nature of work is intertwined with many of the stories, forming part of the day to

day negotiations of IBS as later chapters will show. Data collection commenced in November 2017 and came to an end in June 2018.

5.4 DIARIES: CAPTURING LIFE ‘AS IT IS LIVED’

To engage with the overarching question of ‘*How do people negotiate their IBS in their everyday lives?*’, methods were chosen with a view to capturing how symptoms were navigated in spatial, temporal and socio-material ways. Diaries allow for exploring the questions of individual daily activities, levels of interactions with others, temporal sequences of events, and ‘*a window onto the minutiae of everyday events*’ (Scott, 2009: 187; Elliot, 1997). In this way, diaries lend themselves to empirically exploring the research questions and the ways in which IBS is experienced through space, time, and in social and material ways. On a similar note, Bartlett and Milligan (2015: 14) describe how diaries ‘create a record’ of participants ‘*everyday actions and worlds*’. In terms of the temporal engagement, which was a key focus for me, diaries, as Bolger *et al.* (2003) argue, are a process of ‘*capturing life as it is lived*’. This is something I wish to capture in my thesis.

Participants were invited to complete a diary for a two-week period. This is advocated by Jacelon and Imperio (2005: 994) as the optimal period for completing a diary, as after this time participants can ‘*run out of things to write*’. However, the time spent keeping diaries varied amongst participants in this study. Some participants wrote for under two weeks, some over and some stopping and starting their accounts dependent upon what was happening in their life at that time. Participants were given the option of written diary entries or the opportunity to complete an audiotape. Equipment was provided to all participants to maintain their diaries including a notebook, pen, or audio recording device, dependent on their preferences and abilities (Jacelon and Imperio, 2005). Diaries were posted to participants alongside a pre-paid envelope for them to return after the two-week period. Fourteen paper diaries were written, nine diaries were electronically recorded, and one was audio recorded. One participant chose to participate only in a face-to-face interview. The decisions of method for diary keeping were often articulated and reflected upon by the participants. For example, those who opted for an electronic diary liked to keep notes on their phone as and when things occurred or simply disliked their own handwriting. Alternatively, Tony who was the only person to audio-record their daily diary did so because he has dyslexia and thus

felt it suited him best. In Tony's audio diary, the direction of the account towards me as a researcher became more apparent. This is something Jacelon and Imperio's (2005: 995) explain, as each recording was punctuated with remarks such as '*that's all for now, will update tomorrow*'.

Brief written instructions (see appendix) were offered to the participants regarding the ways in which they could complete their diary, with suggestions of descriptions of activities, references to time, where things take place, and the material things important to them. It was highlighted that participants should not discount events or activities that they felt were too '*mundane*'. When Zimmerman and Weider (1977: 487) used diaries, they recognised that no participants recorded the mundanity of going to the toilet: participants with '*extraordinary bladder and bowel capabilities, since no instance of the elemental act of elimination was reported*' in their use of diaries. This is of particular significance when reflecting upon understandings of life with IBS, a condition characterised by problematic defecation together with a focus on the everyday toiletry habits. Moreover, due to the nature of the symptoms, IBS is a condition often hidden from public view. It is a topic that often does not make for public discussion, and thus the personal and private nature of diary keeping provided a way to articulate a side of life that often fails to be spoken.

During the research process, I created a table of participants and the 'stage' they were at in the research process. This included their names, the initial email sent with the information sheet and consent form, when and how the consent form was obtained, and the date the diary was sent, alongside a reminder of when a two-week window was coming to a close, as a way to know when to re-establish contact with the participant, if they had not remained in contact whilst also completing the diary. This also involved the negotiation of the format of the diaries and the organisation of the delivery to fit with the later interview. This was often a stressful process and something I will reflect upon later in this chapter. Below is the email sent at approximately the end of the two weeks, which worked to remind participants of the timeframe, whilst not aiming to limit or pressure participants with their engagement or participation.

Figure 4: Catch up email for diaries

Dear [insert name],
I hope you are well. I'm just getting in touch to see how you've got on with completing the diary and if you've had any challenges with it. Hopefully, you're near the end and then if it's okay with you, we can see about arranging a time to discuss how you found it and to talk a little bit more personally about life with IBS.
Thank you again for taking part and dedicating your time to this study - it really is appreciated. Please let me know if you have any queries.
Best wishes, Lauren

Despite the carefully thought out guidance that offered prompts into everyday life mentioned earlier and made visible through the diary guidance, diaries were diverse in their completion. All participants completed their diaries in very different ways. In terms of the key differences, I would argue that they can be categorised in four ways: the biographical, the monitoring, the temporal, and the private, intimate reflections.

5.4.1 DIARY AS BIOGRAPHY

One of the highlights of diaries as documents in social research is, as Plummer (1983) explains, they are 'documents of life'. Without pressing for this in the diary guidance, participants often started by telling me a story of their life; who they were, what they did, and their childhood stories. Furthermore, their accounts of IBS included how their life was disrupted with the onset of IBS or 'biographically disrupted' (Bury, 1982), the reconstruction of their narrative (Williams, 1984), or the familiarity of IBS as a 'normal illness' (Faircloth *et al.*, 2004; Pound *et al.* 1998) that has been part of their life from their earliest memories. The biographical accounts connected the individuals to the histories and the relationship between the two (Mills, 1959). The historical and biographical accounts that were made present at the start of diaries and now in the pen portraits set up and then facilitated the daily accounts of participants' current worlds. For example, Julie began her diary with a biographical description, which has been retained in the pen portrait at the start of this thesis. Following her biographical account, Julie went on to document the daily monitoring of her IBS. Upon asking Julie about her diary in the follow-up interview, I stated that it was nice she started off by telling me

about herself, to which Julie replied that she ‘*wouldn’t know how to start it otherwise*’. This has stuck with me in terms of the analysis of the accounts, and indeed the layout of this thesis. The history and biography of the participants cannot be separated from the daily interactions and practices of negotiating IBS on a more micro and everyday level. I have sought to retain these historical and biographical accounts of IBS throughout the thesis and specifically at the start with the introduction of the pen portraits.

5.4.2 DIARY AS MONITORING

As previously mentioned, Julie went on to do a smaller scale monitoring of her food and symptoms after her introductory biographical account. Previous research has acknowledged the value of diaries for tracking daily health activities (see for example Jacelon and Imperio, 2005: 994; Verbrugge, 1980, 1985). Macdonald *et al.* (2018) have also drawn attention to the value of diaries for gaining an understanding of the mundane practices associated with food. Despite diary guidance being open and free with suggestions of areas for discussion and reflection, several food diaries were sent. My initial feelings of frustration and worry that I had misled the research eventually turned into a reflective engagement with the subject matter itself. Specifically, diaries are encouraged in healthcare as a process of finding patterns with symptoms, paving the way for a broader understanding into the experiences of illness and its consequent management. This was also highlighted by several participants, where they stated that participating in the research and completing a diary would be a beneficial process for them to engage in. However, participants expressed frustrations in logging, and annoyances in not finding routines and patterns as part and parcel of living with IBS. These were made *precisely visible* and tangible by the documentation in the diary.

Figure 5: Examples from 'Food Diaries' and 'Symptom Diaries' (Brenda's Diaries)

FOOD I CAN'T EAT.

- * Tinned baked beans
- * CAULIFLOWER
- * GREEN BEANS
- * PEAS
- * SPROUTS
- * RHUBARB

_____ CAN EAT SMALL AMOUNT
 _____ MANGE TOUT

BREAD (YEAST?)

BEER "

WATER CRESS

ICE BERG - OTHER LETTUCE _____ I'M OK WITH SALAD LEAVES

STRAWBERRIES _____ I MAY HAVE 1 or 2 ONLY

PLUMS _____ (OKish WHEN COOKED

GRANVY _____ VERY LITTLE OR NONE

Day	Notes	Normal	FAST BROWNS	LARGER LUMPS	VERY SOFT	WIND	BLOWN-UP TUMMY	TOMMY CRAMPS - PAIN	NEED MEDS TO GO OUT
9 th	Don't GO AT ALL								
10 th									
11 th									
12 th									
13 th									
14 th									
15 th									
16 th									
17 th									
18 th			LATE X MID AM	EARLY		X	X		
19 th					X	X	X		X ONE TRILET
20 th							X		
21 st				X			X		
22 nd			X EARLY			X	X		
23 rd									
24 th				X			X		
25 th		X	X						
26 th		X					X		

Figure 5 above shows an extract from Brenda’s diary in which she wrote a list of things she cannot eat, alongside a month’s worth of daily tracking of her symptoms. Whilst this was not in alignment with the diary guidance, it nevertheless provided a useful reference point for us in discussing particular days and the type of symptoms she experienced. The way in which Brenda articulated foods and the patterns of her bowels each day in her diary keeping reiterates the medical model of how IBS is expected to be studied and monitored. Sharon offered a similar account of monitoring her IBS and, interestingly, said that she already kept a diary in daily life. What was striking was how Sharon distinguished between her usual, reflective diary that she kept for herself, and the one she sent me which was somewhat medicalised and focused entirely on the symptoms and treatments of her IBS:

“I have a diary like, ‘I went to work, this or this...’ so I just incorporate it [IBS] in that so I keep diaries obviously for health reasons and things. Also, if I’m going to the GP, I like to give timelines, not that it really matters but I like timelines, so that’s why I keep diaries.” (Sharon’s Interview)

This draws attention to the *'timelines'* Sharon traces in making sense of her IBS symptoms, and thus highlights the diary as an important timekeeping tool and temporal lens.

5.4.3 DIARY AS TEMPORAL: A RECORD FOR TIME KEEPING

As Plummer (1983: 17-18) notes, *'each diary entry...is sedimented into a particular moment in time: they do not emerge 'all at once' as reflections of the past, but day to day strive to record an ever-changing present'*. Studies in health research have implemented diaries as a way to examine individual experiences of illnesses or treatments over periods of time (see for example, Killien and Brown, 1987; Rosner *et al.*, 1992; Stoller, 1995). Building upon the reflections of diaries as important for record keeping, temporality was threaded through the diary accounts. As with food and monitoring, this is discussed in later chapters in which I discuss the routines and time in participants' accounts. Diary data includes the dated and timed records, the descriptions of times of day, the time that is taken for particular activities, capturing body clock to societal clock (see for example, Adam, 2004). Another classification of time that was captured in the diaries were periods of normality, the banal, and the experience of no symptoms. The diaries captured the *'non-existent'*, the boring, and the uneventful as part and parcel of everyday life. Susie Scott (2018) talks about the sociology of nothing. By theorising *'nothing'*, there is an understanding and an appreciation of precisely the opposite. This is shown by the presence of symptoms against days which have no symptoms to report, or nothing featuring in that day. Below is an example from Shaun's interview where he described this:

"There were some days...most days I was well into it, I was doing a lot of activities, so I could write about what activities I was doing and what I needed to do, so contingency plans, that kind of thing. When it was just ordinary, a couple of days, ordinary days together, it was difficult to just put down, because I thought, well I said that yesterday. Like I say, if I'd have been a busier person in terms of going out in that particular fortnight, it would have been a bit easier. I quite enjoyed doing it, it was nice to put stuff down actually, to think and to contemplate." – (Shaun's Interview)

This documentation of time within the diaries that capture both the usual and expected, and the disruptions, speaks to the broader aims of this thesis, which capture the thread of the familiar and the strange situated within the daily negotiations of living with IBS.

The value of capturing the ebbs and flows of everyday life, and the negotiations of time and their locations are built upon and appreciated in the upcoming chapter on temporalities.

5.4.4 DIARY AS REFLECTIONS ON PUBLIC AND PRIVATE LIFE

Finally, and one of the most important reflections of diaries as a research method, was how the diaries allowed access to the world often happening behind closed doors. The diaries captured the private nature of IBS and the personal and intimate ways in which it comes to be experienced. For example, there were reflections on the sequence of events or anticipation of them, the embodied feelings, the practices within the home, the reflections on personal relationships, and the hidden thoughts that other methods may not necessarily uncover. Previous studies have utilised diaries for sensitive topics and more private and personal sides of life, such as sexual practices and sleep (see for example, Okami, 2002; Hislop *et al.*, 2005). As Gibson (1995: 72) notes ‘*diaries seem to be the most useful in intimate situations*’. This is demonstrated through a snippet from Carly’s diary which documents her private thoughts and public exterior.

“Day 4: I had to cancel on my friend. I left it late because I kept thinking I might just be able to do it, but eventually I succumbed, feeling awful when I constructed the Facebook message telling her. I even toyed with the idea of making something up I felt sounded more credible but decided to tell the truth in the end. That I had diarrhoea and was exhausted...Instead, I spent the day in the house. I put the Christmas tree up with the help of my partner and felt incredibly tired. I seem to be losing a lot of mucus at the moment, I googled this and apparently, it’s a standard IBS symptom. I feel very blah.” (Carly’s diary)

A similar private moment is documented here:

“Day 12: As it was my mum in laws birthday we went out for a meal. This is when the anxiety really kicked in. As soon as we got to the restaurant, I needed to go. I went immediately and returned to the table, trying to carry on with the conversation. It dawned on me then, that it if I were to need to ‘go again’ it would look a bit odd. I then felt a bit trapped. I went hot and felt on the verge of a panic attack. This then made me feel upset; all the while from the outside I plastered a smile on my face pretending I was fine. I’m reflecting on this now thinking, why didn’t I just say I didn’t feel well? I think this is another case of me not wanting to project an identity of being the poorly one. Eventually, the anxiety subsided as we finished and returned home. Since I’ve been home, I’ve been to the loo again. Feel exhausted and fed up. Had a Panadol and

peppermint tea, and decided I'm going to bed early as tomorrow has quite a busy schedule.” (Carly's diary)

Building upon these examples of private thoughts and intimate practices, these snippets of private lives are interwoven throughout the upcoming chapters, and in particular in the chapter on intimacies and familiarity.

5.5 THE INTERVIEWS: A PROCESS OF EXPANSION

Interviews were conducted once the diaries were complete and allowed for ‘*a process of expansion*’ that worked to highlight areas of the diarist’s ‘worldview’ (Zimmerman and Weider, 1977: 491). Upon completion of the diaries, I requested that participants send their diary entries to me to ensure that I could read or hear the accounts to pinpoint areas for further discussion and clarification following my own interpretation. As Zimmerman and Weider (1977: 489) highlight, ‘*the diary interview converts the diary - a source of data in its own right - into a question generating and hence, data generating device*’. However, this was trickier than anticipated. There was often a delay in sending the diaries back, and several of the participants actually brought the diary to the interview, kept it closed and handed it to me to keep and read afterwards. In this case, an open, narrative approach to interviewing was crucial.

Participants were invited for an interview to discuss the process of completing a diary and to discuss elements of the diary that were of interest or significance. The discussion within the interviews of the entries within participants’ diaries sought to act as a prompt to discuss the sequences of their activities more broadly, as well as digging deeper into the social meanings and wider significance (Elliot, 1997; Zimmerman and Weider, 1977: 485). Upon receiving each diary, I engaged in a process of analysis and preparation for the interview, by reading or listening to the diaries, and then transcribing them into my own document from the participants’ handwriting as a way of immersing myself in their individual accounts. I also used open interview questions such as ‘*tell me about you*’, ‘*tell me about how your IBS started*’ and ‘*how did you find completing the diary?*’. Specific diary related questions were also implemented such as ‘*in your diary you mentioned...*’ a technique also highlighted by Jacelon and Imperio (2005: 995). On the opposite side of this, participants made similar reference points. For

example, Terry in his interview would say ‘*it’s all in there*’ whilst pointing to his paper diary. By the latter stages of the data collection experience, I became so familiar with the process of interviewing, that the interview schedule became minimal or redundant in terms of its involvement. This reflection suggests both my increasing confidence as a researcher, together with my dedication to keeping the interview as informal, personal, and conversational as possible. This happened so much so that often I came away from having such conversations worried I’d forgotten what I was initially ‘*looking for*’, particularly in the case of Brenda and Molly who I visited and bonded with.

The interviews were held in a place suited to the participant, whilst ensuring both my safety as a researcher and that of the participants. The location in which the interview took place featured as part of the narrative that came from the interview itself and added to the understanding how IBS and its symptoms are discussed in particular places (Hockey, 2002). For example, during his interview, Terry used reference points from around his home as he pointed to family bathrooms. In another interview, Deborah chose a particular table in the café in a department store she is familiar with and knows where their toilets are, together with a table suitable to discussing sensitive material in a public setting. However, due to many of my participants contacting me through charities and through social media, many were not in proximity for a face-to-face interview. For this reason, many interviews took place via phone (see figure below). Holt (2010) considers the value of telephone interviews when participants are geographically dispersed and builds on the value of speaking on the phone when doing sensitive research (Sturges and Hanrahan, 2004). The geographical dispersal and the sensitive nature of IBS were both relevant in the research at hand. Interviews lasted between forty minutes to three hours, with the average interview being just over an hour. The times of interviews were often negotiated dependent on the timeframes of participants, such as balancing conversations in lunch breaks, free times in work schedules, or when they might have an hour to themselves. I left this open and negotiated whatever suited participants best.

Figure 6: Table of Data Collection Formats and Locations

Name of participant	Diary format	Nature of Interview
---------------------	--------------	---------------------

Kelly	Paper (written)	In Person (office location during lunch break)
Shaun	Paper (written)	In Person (nearby café to his home)
Stacy	Paper (written)	In Person (a café library)
Julie	Electronic (typed)	In Person (a nearby café)
Martin	Paper (written)	Via Phone (phone call at work)
Amy	Paper (written)	Via Phone (phone call from her home)
Carly	Electronic (typed)	In Person (a meeting room)
Deborah	Paper (written)	In Person (department store café)
Katie	Paper (written)	Via Phone (phone call from home)
Dean	Paper (written)	Via Phone (phone call from home)
Rosie	Electronic (typed)	Via Phone (phone call from home)
Gina	Paper (written)	In Person (local café)
Sharon	Electronic (typed)	Via Phone (phone call from home)
Ellie	Electronic (typed)	Via Phone (phone call from home)
Caroline	Paper (written)	Via Phone (phone call from work – lunch break?)
Molly	Paper (written)	In Person (in Molly’s home living room)
Carl	Electronic (typed)	Via Phone (phone call from home)
Terry	Paper (written)	In Person (in Terry’s home kitchen)
Joyce	Paper (written)	In Person (phone call from home)
Brenda	Paper/typed up table	In Person (in Brenda’s home dining room)
Sophie	Did not complete	In Person (coffee shop)
Lucas	Electronic (typed)	In Person (coffee shop)
Tony	Audio recorded	Via Phone (phone call from the car)
Keith	Electronic (typed)	Via Phone (phone call from work)
James	Electronic (typed)	Via Phone (phone call from home)

The interviews were recorded digitally and transcribed following completion. In using the diaries as a prompt in the interview, they also worked to allow the participant to be

both the ‘*observer*’ and the ‘*informant*’ of documenting their everyday routines and encounters and in explaining them (Zimmerman and Weider, 1977: 483-4). The interviews also enabled a shared understanding to emerge from the informants’ accounts. It prompted me to ask further questions regarding things left out or not explored in the diary, and to move beyond the everyday events to create wider understandings (Zimmerman and Weider, 1977). The interviews worked to expand and situate wider understandings about how their routines, schedules, places, things, and other people have a role to play in making sense and negotiating their IBS.

One of the challenges of the two-part process of this research was the difficulty of being in the thick of it. At times I was simultaneously distributing diaries, reading accounts, organising, and meeting participants. Each diary entry, especially those with a biographical grounding, made me increasingly conscious of *remembering* what was written in the interview setting. I made efforts to not draw constant and deliberate attention to the diary itself (unless participants did so themselves), working hard to sustain a natural and friendly conversation. This juggling act of being in the field operated as a reminder of the importance of balancing emotions, the pursuit to be personal and sensitive to each individual participant, whilst also simultaneously navigating the pace and pressures of multi-method qualitative research. On a similar level of ‘*emotional work*’ (see for example, McQueeney and Lavelle, 2017; Dickson-Swift *et al.*, 2009), there were times where my emotions became apparent. Often opening diaries at my desk became a moment where I had a heavy heart and I began to wonder what our conversations would be like. This was the case in reading Joyce’s diary in particular, and I was struck by the difference in nature when it came to our conversation. I learnt that written thoughts and spoken words had very different tones. Similarly, I remember having an interview with Katie one evening, returning to the sofa at home and worrying about how she was after the conversation we had had. This reminded me of Smart’s (2014: 147) provocation that we ‘*live among the fragments of lives which people [our] own imaginary*’. After each interview, I sent an email a day or so later to thank them again for their time and sharing, but also to ‘check in’ after sometimes what was quite an emotive process.

5.5.1 'YOU NEED A BIG HANDBAG WHEN YOU 'VE GOT IBS' REFLECTIONS ON MATERIALITIES IN THE INTERVIEW SETTING

Of course, the face-to-face interviews were designed to facilitate and build upon the often-material aspect of the diary itself – the diary as a tangible, physical object that worked to elicit further conversations and reference points. However, other materialities came to light in the interview process, leading to and engaging this research with the '*material turn*' (Latour, 1993; Miller, 1987). This builds upon the work of Hockey (2002) who explores the embodied and material dimensions that the interview process offers. This includes entering people's homes and having an awareness of the material surroundings and sensory experience. Many of the interviews involved a significant amount of interaction with participants' home and their pets. In the interview with Terry, dog walking and the routine nature of it appeared to act as a prompt for discussion on how his day was scheduled in line with his IBS. Terry's walk with his dog (the time of day the walks happened, how many walks, where the walks are, how far) spoke to his broader negotiations of routine with IBS. During the interview with Brenda, we sat at the dining table as she pointed to the downstairs and upstairs toilet. She went off to the kitchen cupboard and brought back her medications as she explained them. She also opened a cookbook as we discussed cooking with her husband. The opening of Brenda's cookbook allowed for conversations not only of the recipes used and who cooks what, but it also captured the broader insights into her experiences of living with IBS and how they are situated within family life and intimate relationships.

I also want to touch upon what Woodward (2015a: 363) calls the '*vibrancy*' of materials, situated within a development of '*live methods*' (Back and Puwar, 2012). Another aspect of materialities that came out through the face-to-face interviews was the contents of people's bags. These were frequently discussed, as often those living with IBS carry spare tissues, medication, radar keys, and '*Can't Wait*' cards as part of navigating their symptoms when going out. Buse and Twigg (2014) have sociologically explored handbags through a material lens in their work on women with dementia, demonstrating how the contents of bags are often significant for those who carry them. Often without being prompted, several participants opened their bags and showed me the contents. For example, Sophie opened her handbag and explained the contents of her toiletry bag that contained medications, tissues, and wipes that she often turned to

when having IBS symptoms. Similarly, Deborah opened her bag to reveal a small leather purse, detailed with an embroidered flower, that she unpacked and, object by object, explained the medications inside; from paracetamol, Rennie's, and Ibuprofen, to more specific medications such as Loperamide, Buscopan, and her important Rescue Remedy. Pink *et al.* (2014) discuss the importance of these mundane but 'quiet' materialities to include things such as wipes, soaps, and hand gel, and this is applicable to the paracetamol and the tissues in many of the participants' bags. Prior to the interview with Deborah, which was based in a town centre, Deborah explained how she had visited Boots to 'stock up'. In a similar vein, I often found myself getting my own purse out in interviews, to show the 'Can't Wait' cards. Making sense of this encounter, I reflected upon how objects are not passive but have agency and affective capacities (See for example, Gell, 1998). The presentation of the 'Can't Wait' card affected and shifted conversations when I brought one to attention. I kept one inside my purse and retrieved this for participants who were not familiar with them, and this often became a topic of conversation. For example:

*“Lauren: Have you seen the 'Can't Wait' cards? I'll show you one I've got one in my purse [gets purse out]
Brenda: No. Gosh, I'm glad you've come! Let me write this down.”* (Brenda's interview)

Image: My Own Purse and a 'Can't Wait' Card



Several participants, Brenda and Molly in particular, were encouraged to hear of the scheme. I wore several hats in this scenario. First and foremost, as a researcher interested in the topic at hand and what would then become an interesting methodological tool. Second, I somewhat promoted these cards as someone who supports the charities who provide them. Finally, I presented them as an important dissemination of knowledge in my 'toilet activism' whereby these cards have potential to spread awareness and make lives easier for those living with the conditions that they come to represent. Upon retrieving the 'Can't Wait' card, Molly asked if she could keep the card that I presented to her. In that moment, I gave her the one that I owned. I reflected back on this and felt was an '*ethically important moment*' (Guillemin and Gillam, 2004). The revealing of the 'Can't Wait' cards in conversation brought to attention their importance. The conversations and presentations of the 'Can't Wait' cards came to feel like important encounters in the interview process. Moreover, the interactions with pets and their homes, and the intimacy of revealing objects also spoke to the broader negotiations of IBS. Later in this chapter, I will also deal with my own negotiations with the materialities of the diaries, as kept in my locked cabinet, lying dormant (Woodward, 2015b) as the research moves on.

5.6 JOURNEYS THROUGH ANALYSIS

I call this section a journey through analysis, as analytic processes are not temporally distinct, nor are they ever really finished, even in the final write up of this thesis. As Hammersley and Atkinson (2007: 159) state, analysis is an *'iterative process'*. However, in order to contain and put a lid on this process, I will explain the journey up to this point. As I mentioned at the start of this thesis, my exploration into IBS began in my undergraduate dissertation (White, 2016a) and continued in my master's dissertation (White, 2016b) The findings from these two projects progressed my knowledge and sociological curiosity into the ways in which IBS comes to be socially experienced. The findings gathered from these research projects, together with the literature and my sociological curiosities, informed the research questions for this thesis. I have sought to keep these questions with me throughout the analytical journey of this thesis to date. From the participants' perspective, a degree of analysis was done somewhat on their part in the reading of the diary guidance and the interpretation and response to these prompts.

Upon receiving the completed diaries one by one, reading, digesting, and transcribing handwritten accounts to a digital word document was the first level of analysis. Mason (2002) talks of the importance of taking the time to simply *read* the data or listen in the case of Tony's audio diary. For me, this was the crucial part of becoming immersed in participants narratives before considering the themes or *'what's next'*. Elsewhere in this chapter, I have also alluded to the emotive nature of reading the diaries, and this forms part of the analytical process. As the research was a two-part process in terms of data collection, diaries were used as a platform to generate prompts and reference points for the follow-up interview (Zimmerman and Weider, 1977). For example, there were unique but everyday situations that struck me, such as taking the dog for a walk or visiting the hairdresser's. These became topics I wanted to discuss when we finally met or chatted over the phone and are now notable features of the upcoming chapters. As I went beyond the diary, I aspired to have the interview as open as possible to retain everyday, personal narratives. As a result, I opted for open questions that kept stories and biographies in mind. Similarly, I asked participants *'what's most important to you?'* as another analytical tool but also as a way to strive for authenticity and retain the importance of issues that come directly from participants, not my own agenda. I made efforts to analyse *with* the participants as they articulated and made sense of their diaries in the interview process. This was done in an attempt to, as Fine (2002: 218) states,

'give voice' to the participants' accounts, but I also kept in mind my own theoretical and personal worldview. However, this was a process of negotiation, dependent upon *when* the diary was given and how much of an 'open book' the diary was in a literal and metaphorical sense.

Analysis also sought to keep in mind the nature of the research questions and the focus on the minutiae of everyday practice. Following data collection, the analysis took a broadly thematic approach, although narrative analysis ideas were utilised in the understanding and interpretation of the everyday accounts. It was important to ensure that the context of diary entries maintained their chronological flow and that the individual accounts remained intact (Riessman, 2008). Thematic analysis entails '*identifying, analysing and reporting patterns (themes) within the data*' (Braun and Clarke, 2006: 79). Using accounts from the diary entries, follow up interviews, and supporting fieldnotes, analysis worked with the research questions. Specifically, I looked at how the diary entries and in-depth discussions worked alongside each other. I looked to highlight how participants may write or speak about time, places, materials or social relations in reference to their IBS. Accounts derived from the diaries, interviews, and field notes were utilised to identify themes, which later became chapters in this thesis. As Braun and Clarke (2006) demonstrate, thematic analysis is a method that works to reflect both 'reality' and an unravelling of what may be under the surface. Furthermore, it also works to look at the accounts of everyday life with IBS, but also the taken for granted, everyday aspects that work to show meanings of the social world.

One of the crucial moments in the analytical process was my frequent return to, or the stickiness of the biographical '*data*'. I felt a tug towards to the biographical accounts when engaging in my first theme of food. This required me to return to the stories and ensure the biographies of each person were clearly articulated before there were any talk of later themes. Smart (2014: 147), in her piece '*Fragments: Living with Other People's Lives as Analytic Practice*', suggests that '*the trick is to value the person while addressing the social*'. My starting foundations with the pen portraits in the thesis seek to value this. I could not write any thematic chapters without talking about the people who took part first. Upon this realisation, the writing of these, or integration of the already written biographies presented from the participants, gave way to making sense of, and speaking to, the substantial areas of everyday lives and the justifications in

relation to the people involved, highlighted in later chapters. Here, it is hoped that this process is what Les Back (2007: 176) terms, '*the art of listening to the world, where we take the people we listen to as seriously as we take ourselves, [which] is perhaps the most important quality that sociology can offer today*'. I hope the analysis and the writing up of this thesis are very much included in this conceptualisation.

Beyond the biographies, there was the necessary practice of thinking of thematic elements that brought all the participants together, and that form the following chapters. As each participant had both a diary and an interview transcript, it became troublesome to keep all of this together. I was initially reluctant to use the software NVivo for fear of losing the narrative (Riessman, 1993; Ritchie *et al.*, 2003: 229) and the crucial linkage between the two distinct sets of data, linked by the individual around whom it centred. However, due to the sheer amount of data, NVivo became an important device for data management, keeping together all the accounts to begin a broader analysis of themes and locate common ground. Coding in NVivo allowed me to find what was coming out as most important between participants and to whom. For example, the striking dominance of food as socially important came about from the analysis and thus formed the first empirical chapter. Furthermore, the structure of each chapter and their ordering also speaks to the analytical process. Namely, the ordering works to navigate everyday life and move from intimate everyday practices or 'private troubles' to public and social issues (Mills, 1959). As explained earlier, the placing of the pen portraits at the start of my thesis reflects their early formation as part of the analytical process as well as part of capturing the shift from medicalised struggles to everyday negotiations. I have frequently tried to imagine my work as threads, thinking about the weaving of food with a crossing stitch of accessibility and inclusion, something that I return to in mobilities and toilet access. I have also frequently considered how a participant would feel if they read the analytical processes and the chapters of which they form part. Previous research has acknowledged the challenges of presenting research findings to participants (Hoskins and Stoltz, 2005). Whilst my research has not been participatory *per se*, this is something I have reflected upon and would like to pursue further in future research.

5.7 ETHICAL CONSIDERATIONS

Ethical considerations are paramount for any research process, particularly research on health conditions that are taboo and often ‘embarrassing’ for individuals, such as bowel habits. The project obtained ethical approval through the University of Sheffield and worked to adhere to such guidelines. Participants were provided with an information sheet detailing the aims, process, and outcome of the research, with potential ethical issues highlighted, including guidance for concerns or complaints regarding the research. Participants were asked to sign a consent form. The consent form confirmed an understanding of their participation and how their data may be used in future publications (see appendix). All those who participated also had an opportunity to ask any questions before taking part, and throughout the research process. Participants were made aware that they were free to withdraw at any point. All participants were given a pseudonym in order to respect their privacy. The data has been kept confidential and stored securely in a password-protected file for electronic information, and a lockable cupboard for any physical copies of data such as written diary entries. Interviews were conducted in a safe and appropriate space for participants to discuss their diary entries and life experiences, usually decided by them. It was equally important that I considered my own safety when I entered participants’ homes, and steps were taken to ensure this was the case. At the end of each process of diary keeping and follow up interview, I sent a thank you email alongside a high street voucher of small monetary value (£10) as a token of my gratitude. Whilst some of the participants declined this, others were surprised and thanked me for this as I sent it off in the post. This was done not as a means for recruitment, but as a token of gratitude for their participation.

I strove to keep participants fully informed of the progression of the project, communicating that I would share the conclusions of the research as a matter of course. The National Charity for IBS, GUTS UK, and Bladder and Bowel Community were on hand to provide support, advice, and guidance for participants. For all participants, a contact card for the IBS charity was provided. Due to the sensitive nature of IBS symptoms, the research was conducted delicately according to its subject matter. I worked hard to ensure that participants were comfortable and confident throughout. I kept in mind the ethical issues inherent in discussing sensitive topics, whilst also being aware of negotiating the associated stigma and ways in which this could be navigated. I also worked closely with my supervisors and personal networks to maintain my own physical and emotional wellbeing. At times, regular conversations about the embodied

experience of illness from participants drew attention to my own body in both physical and emotional ways.

5.8 ABOUT ME

It is also worth noting that the research also has an auto/biographical grounding (Stanley, 1993), as the research has some origins in my own personal experiences of living with digestive illness. I assert that my own experiences lend themselves to the research process, connecting my personal position to that of others (Goodson, 2013; Oakley, 1979). All my life I have experienced digestive illness. Around the age of 7, I was hospitalised for unexplained abdominal pain and ‘tummy ache’ was an everyday feature of my childhood. Then, aged 15 I began with further gastrointestinal symptoms which led to countless investigations, finding ulcers in my small bowel, and consequent surgery aged 17 to restructure my bowel following a serious obstruction. At the time, doctors suspected that I had Crohn's Disease. However, since this surgery, further tests have been inconclusive and/or ‘normal’. As such, my symptoms remain in a liminal space in terms of diagnosis. The fact that this has been a huge part of my life has inevitably pushed my research interest and made me *‘in tune’* with the experiences of digestive illness when speaking to participants in my research. I do not wish to make my own experiences a focus of the research but to acknowledge that my experience and relations to participants are inextricably bound together and this is something I continue(d) to reflect upon. I chose not to disclose this immediately in the interviews, revealing aspects of myself as and when it felt appropriate to the open nature of the conversation, or if participants brought it to attention first. In some cases, such as the interview with Julie, she repeatedly bounced questions back to me. I was also conscious of what it might mean to participants to reveal that I had ulceration and surgery (as ‘legitimate’ and ‘real’) in comparison to IBS symptoms, which often lack the weight of legitimacy. In a similar vein, I could acknowledge the feelings and frustrations of inconclusiveness and dismissal of symptoms associated with IBS as something I had also experienced. This was particularly the case in my interview with Carly, who lives with both IBD and IBS. Here in these spaces, I am reminded of avoiding the binary of insider or outsider but like Dwyer and Buckle (2009: 62) look to *‘embrace and explore the complexity and richness of the space between’*. Located within the space of commonality, there was an appreciation from participants of speaking to someone who has some form of understanding.

However, my ‘illness identity’ was only one of the ‘selves’ I presented in my research. I was also aware of my gender, age, ethnicity, social class, and background. I was aware of my position as a researcher, and particularly that of a sociologist, *not* a medical professional. Participants picked up my familiarity and knowledge on the subject of IBS academically, my personal experience, but also my knowledge gained through my charity work. Negotiating these was often challenging. I often felt guilty for ‘only’ being a sociologist as many asked me about latest treatments for IBS or biomedical research. Moreover, in some interviews local to me, I became aware of the prominence of my regional accent as well as the knowledge and familiarity that came from living in an area that related to the research participants; such as knowledge of areas, buildings, and toilet locations.

One factor to reflect upon in my recruitment process and research more generally is my presence on the internet through my ongoing work discussing IBS. I have an online presence through various social media platforms and have a profile on the IBS Network website in my role as an advisory board member. Prior to my data collection, I was involved in a short video with BBC Radio 5 Live which explained my personal knowledge and academic research into ‘toilet mapping’ (White, 2016b). This video has received 1.8 million views. In a similar vein, I won an ESRC writing competition with an essay titled ‘*Living and Looking for Lavatories*’ (White, 2017), which explained the sociological importance of toilets and indeed related to my research on IBS, and has been shared via the Guardian over a thousand times. One participant found me via this route. During the interview with Julie, she stated that prior to the interview she and her husband ‘googled’ me to find out about my research and who I was. One of the ethical matters that relates to the public facing nature of this research is how this public engagement goes beyond the data collection and the participants that have featured in this thesis. At the point of writing, I am no longer recruiting and thus engaged in the processes of offering out information and obtaining consent, to put it crudely. However, due to the reach of my discussions of IBS beyond this thesis (see White, 2017), I frequently receive emails from individuals who have come to know me from my piece written in The Guardian (White, 2017) and wish to share their experiences of living with IBS. These communications are often fraught, and I find myself in frequent negotiations of ethical practice, signposting to charities to provide support for those looking to share their experiences of IBS.

5.9 DIARIES AS RELEASE AND REALISATION

“There were some days where it was just flowing you know? I was thinking, ‘I’m nearly doing two pages here!’ I had a lot of thoughts you see. It’s surprising actually... I always think it’s a shame that people don’t write. It’s free thought flow at the time.” (Extract from Shaun’s Interview)

Zimmerman and Weider (1977: 484) explain that solicited diaries work by allowing the participant to be both an observer and an informant, offering a ‘*view from within*’. A key facet of diary usage is the ‘release’ that they can offer. Words on a page can mean more than the sum of their parts. Moreover, it has been said that diaries can ‘give voice’ (Meth, 2004; Thomas, 2007) to social groups who may have been marginalised through difficult or traumatic experiences. Indeed, in many of the accounts, there were challenging life events that became known in speaking about IBS. Likewise, the difficulties in the diagnostic processes of IBS and its symptoms alluded to feelings of marginalisation and traumatic experiences. Some of the participants knew of the therapeutic value of keeping a diary, whether this be a way to understand their everyday experiences of IBS, or as a way to self-monitor symptoms as a path to management. Shaun wrote eloquently about the value of keeping a diary:

“So, it’s the last day of the diary today, I realised earlier. It’s been handy jotting things down. Never kept a diary before so it might come over as being a bit rubbish, but I actually found it handy with expressing my feelings during this period. My feelings are the same everyday with it really. Some days the pain is worse than others, but you just have to get on with it.” (Extract from Shaun’s Diary)

Whilst Shaun found the process of diary keeping ‘handy’ as a way to express his feelings, this was not the case for all of the participants. Stacy explained in her interview that she was very wary of diary keeping and logging symptoms, for fear of becoming too immersed or obsessed in the tracking of this. On a different level, Kelly explained that she somewhat surprised herself, as her thoughts and feelings of living with IBS were made visible on the page:

“Lauren: So, with the diary was there anything that you found was particularly difficult or?”

Kelly: Yeah, I don't think I really realised until I saw it all written down over a two-week period, just how much it does affect my social life. Just because you get so used to modifying as you go along, you don't sort of realise that actually, this is quite significant. It is having an effect on where I go and what I do. I don't really realise how many of those situations there are in my life. So, to see them all written down, it was a little bit upsetting in a way.” (Kelly's interview)

Carly echoed similar feelings and recognition to Kelly:

“I'm increasingly aware of how negative I sound in this diary. I don't view myself as a moaning sick person but I'm starting to think 'Goodness, I do come across as a bit of one!' I guess until it's written down, you don't realise the number of bad days you have.” (Carly's Diary)

Bartlett and Milligan (2015) stress that diaries can draw attention to negative experiences that participants have had by the process of recalling past events or drawing attention to daily practices and thoughts. Upon Kelly expressing the weight of discovery with her diary, I asked if this was a useful process for her to engage in. After the initial negative realisation, Kelly spoke of the value of the things she does to negotiate her IBS. Kelly's uneasiness stayed with me, however, and I have pondered the process and negotiations of participants' emotions. I hope my practices following data collection and in dissemination, both in this thesis and in future writing, reflect experiences and emotions in a way that does not risk constructions of narratives that are upsetting. In capturing the recognition of participants realising emotions through diary keeping, I now turn to my own emotive experiences of looking after and storing the diaries in their material format.

5.10 MY DEAR DIARIES: THE MATERIALITY OF 'KEEPING DIARIES AS A RESEARCHER

“It's year three of my PhD. I'm surrounded by piles of books, journal articles, teaching materials and the beginnings of my analysis. I say to myself that I'll tidy up and clear out at some point - clear desk, clear mind and all that. I head to my locker in the corner of the room which, upon opening, bulges out a similar amount of stuff. I sit there and inside are a stack of research diaries. I pause. The accounts from the participant written diaries are transcribed now, it's taken on a new form. I have 'the data' to put it crudely. So why do I stop, take a moment and return to the greeting card sent with Katie's diary, look at the signature in Molly's, the attached letter from Deborah? I carefully place them back in my locker. It appears that I simply cannot part with them.” (fieldnotes)

I finish this chapter with this methodological reflection, as I feel that this moment reflects broader questions of *'leaving the field'* and moving forward with research. As well as the contents inside the diaries, I feel they have symbolic and material value. They have signatures, greeting cards enclosed, supporting letters and were battered from the postal journey. They are now very much part of my everyday life and I have reflected on this process. I offered all participants who wrote a physical diary the opportunity to keep their diary, reminding them that I had transcribed their accounts. Some kept their diaries and others were happy to see the back of it, which is equally as important. Smart (2014: 131) talks about how research encounters are quickly forgotten by most people, but how researchers often do not forget, with *'meetings, the boxes of transcripts and notes that document them'* staying with her in some form or other. Similarly, Les Back (2010) talks of his emotional attachment to his tape recorder as telling of sociological craft. In engaging with this 'material turn' (Latour, 1983; Miller, 1987) that Sophie Woodward (2015a; 2019) calls for in relation to qualitative research methods, I have also considered how the paper diaries' 'social life' throughout the project spoke to broader issues within social research. These include the agency and embodiment of the diaries, the relationality through diaries between researcher and participant, and how these physical diaries are handled with care (White, 2019). In finishing with my field notes on my attachment to the 'research data', this brief reflection works as a reminder as I open up the chapters that give life to the inner workings of what was inside, and those who are behind them.

5.11 CONCLUSION

This chapter has documented the methodological processes that have created this thesis. Firstly, I have explored the foundations of this research, the motivations for my approach, and the practical negotiations including access, recruitment, and liaison. I then unpacked the value of diaries, and the ways in which participants were guided in what to include. Further to this, I have unpicked the nuances of diaries and the diversities they brought with them. These have included the biographical stories, the diaries that monitored symptoms and food, that captured the temporalities of everyday life and the private and intimate lives that people live. I have worked to argue how these

multiple dimensions have further engaged with the everyday ways in which IBS is experienced and lived in day to day life. Building on this, I have reflected upon the interview as a '*process of expansion*' (Zimmerman and Weider, 1977: 491), and discussed how interviews also included ethnographic and material encounters. Next, I documented the journeys into analysis to include the narrative foundations through to the thematic processes and how these entanglements form the structure of this thesis. Finally, I have reflected on ethical issues, relating to the overarching processes, myself and my participants, and what diaries can provoke. I finished with a note on my ethical and emotional departure point as I sit with the diaries at the end of the research. Attention will now turn to the focus of this thesis – the everyday lives of people with IBS.

CHAPTER SIX

FOOD AS A SOCIAL LENS: CARING FOR THE LEGITIMATE CONSEQUENCES

6.1 INTRODUCTION

“Lauren: Did you go to the doctors and did they do any tests when you first started having symptoms?”

Molly: Yes. I've had a colonoscopy...coeliac...they tested for that, no not coeliac, just IBS. It's just put up with it sort of thing.

Lauren: Do they do regular check-ups as well?

Molly: No, sorry but no [laughs]. They never mention it at all at my doctors. They never mention IBS. They give you a diet sheet and that's it, that's your lot.”
(Molly's interview)

An envelope on my desk meant another diary had been returned. Upon opening, I often felt frustration at receiving what appeared to be more of a food diary than the narrative account I had hoped to elicit. This led me to question the guidance I had provided respondents with. However, I then began to consider that perhaps the daily documentation of food was the story they thought was to be told in terms of IBS. For those with IBS, a turn to food and what is being eaten is often the direction pushed by medical professionals as a way of alleviating symptoms, as we have seen in the account above from Molly. Food is something that is monitored, modified, eliminated when one is ‘*allergic*’ or ‘*intolerant*’, and something that individuals have to be responsible for. As Warde (2016: 93) suggests, ‘*food has often been, and is becoming again a primary tool of medical intervention to maintain and improve health*’. IBS is by no means an exception to this, especially given its digestive nature. As Molly explained, a diagnosis of IBS often comes with a basic diet sheet and a recommendation to review eating practices. First-line medical advice is dietary observation and often change, an identification of food intolerances, and for patients to reflect on any ‘*stress*’ or ‘*lifestyle*’ factors that may be considered as contributing to their symptoms. Whilst for many,

these changes can improve symptoms, it is important to consider the everyday narratives that often come alongside. Accounts of those living with IBS are often imbued with feelings of *'blaming oneself'* if deviating from a restricted diet that constitutes *'healthy'* foods against a *'bad diet'*. If symptoms present, there can be notions of them being *'self-inflicted'* and a result of *'indulgence'* for taking part in social events.

For others who wrote more in-depth accounts, food was often integral to their everyday lives. Participants told stories from childhood or past times that worked as a reminder of the joys that foods could bring and of the losses of no longer being able to eat it. Memories of the onset of IBS were also told through a story of particular meals or foods (Fox and Alldred, 2018). What became clear in these food diaries and conversations was how food offered a social lens for understanding the everyday experiences of IBS. Food works as an anchor to elicit the stories through which everyday life can be explored. As Warde (2016: 31) highlights, in doing this it brings the sociality of food to the forefront of our minds. Whilst not all people with IBS exclude foods, adopt particular diets, or attribute their symptoms to food, many of the participants reflected on the social side as part of their daily life. Changing diets and negotiating them often works within the context of intimate lives and personal relationships, both at home and in public life. These encounters *with* food and *who* we eat with, are also situated within particular *times* and *places* that further make up these negotiations. There is a story to be told of the intimate experiences to the public encounters with food that show processes of inclusion, exclusion, and how people resist advice. Negotiating these builds on Will and Weiner's (2014) acknowledgement that individuals invoke multiple repertoires in relation to eating, linked to being healthy, but also socialising and enjoying food.

Food also reveals social accounts of the processes of accommodation and inclusion made by others. In contrast to this, I will also argue that food offers insights into both the anticipated and enacted practices of exclusion in everyday social life. Negotiating these two former points of participation and exclusion, there are also sites of resistance. Namely, individuals resist dietary monitoring or exclusion of food precisely because of the social importance of inclusion and broader sociality. The participant accounts presented in this chapter demonstrate how the social practices of eating can be

problematized when faced with IBS. Here I draw upon Murcott's (1993) contribution that highlights the *consequence* of eating, that is, elimination³¹. By understanding IBS as characterized by its symptoms, the social practices of eating draw attention to the importance of the *consequences* of food and how these are spatially, temporally, and relationally situated. Importantly, this consequence is also intertwined with a face of illegitimacy as IBS is a contested condition featuring food intolerances and not allergies (Nettleton *et al.*, 2010). This chapter seeks to offer an original contribution to debates on diet and eating practices within the field of sociology of health and illness. In this chapter, I work at binding the sociological work of food intolerances together with the consequential nature of eating to include excretion. In doing this, I will illuminate how those with IBS navigate social experiences of food with the undertone not only of a questionable and contested diet, but one that also involves the potential consequences and portrayal of IBS symptoms.

6.2 ACCOMMODATION(S) AND ACKNOWLEDGING CONSEQUENCE

For many with IBS who had dietary requirements, steps were often taken (or at least attempted) to account for their intolerance to particular foods and the symptoms they could bring. From checking ingredients in restaurants or food packets to friends having an understanding when booking meals out, gestures and thoughts about diets were present. Here, eating is not only social but founded upon the love and care of family, friends, and the kind acts of others (Ellis, 2018; DeVault, 1991; Lupton, 1996; Warin *et al.*, 2008). Some accounts also acknowledge how relationships and family practices play out through food 'choices' and preparation. This includes participants conforming to the family dinner, and loved ones asking questions or passing ownership over to the individual with IBS in terms of what's '*on the table*'.

One account that demonstrated the small acts within family life is Brenda's. When I arrived at Brenda's, she presented to me a diary that consisted of a list of things she could not eat, along with a daily graph of her symptoms. Despite this heavy monitoring of her symptoms, our conversation took on a different form. Brenda and I chatted about

³¹ Murcott (1993) discusses the processes of elimination in the context of food through her study on infant feeding.

how life was for her and Ken, her husband. Brenda talked about how she lived quite an independent life from her husband and that they had separate hobbies. Brenda explained that when Ken retired, she was still working and so he took on the responsibilities of cleaning and cooking in the home. Ken has continued these roles after Brenda retired, which goes against the more traditional model of the woman as the cook (DeVault, 1991). When speaking with Brenda about her diet at home and what happens when Ken cooks, the small act that she recounted felt significant:

“Lauren: So, when Ken does the cooking, does he know the things you can’t have and change things?”

Brenda: I try not to say too much, ‘don’t do this’ because it’s stopping him. If it’s something I can’t have, I can’t have sprouts or beans; he cooks them. We always have something with them anyway, it’s rare we have just two veg, it’s usually three or four.

Lauren: So, would he plate them up for you or would he just have them, and you have the other?”

Brenda: Yeah. The other stuff. Like last night when we had three, he said, he knocked on the door and I went in and he said, ‘Just tell me how much green you want on there’ [laughs] you know because he knows I struggle the next day.”(Brenda’s interview)

Whilst Brenda acknowledges that Ken does still cook the vegetables she cannot eat, there is a selection to choose from. What I feel is important here is the recollection of the plating up at teatime, the calling from the kitchen to the living room and Ken’s questioning of greens for Brenda. Ken knows the *consequences* of particular vegetables for Brenda on *the next day* (Murcott, 1993). The dishing up of food is an acknowledgement not only of necessity and preference for managing Brenda’s IBS, but an act of love and care from her husband (Ellis, 2018; DeVault, 1991; Lupton, 1996; Warin *et al.*, 2008). In Brenda and Ken’s interaction, there is a focus on what Ken ‘does’ rather than what is said and felt (Graham, 1983). This relates to the broader literature on the role of families in illness and dietary change (Ellis, 2018; Webster and Gabe, 2015). It presents the ways in which, despite ‘*not having*’ or having an ‘*alternative*’, the everyday practices of love and care within family life and personal relationships still work within this. The account shows how Brenda doesn’t want to stop Ken in what he does and doesn’t eat, further demonstrating the reciprocal nature of care, accommodations, and acts of love.

A similar but perhaps more explicit account of these accommodations and alternative food products is the account that Ellie offered. Ellie described having a sensitivity to 'dairy' and 'cereal'. For Ellie, this became noticeable when she was at university and 'eating a lot of pizza'. In Ellie's diary, she documented the conversations that she had regarding food whilst staying at her boyfriend's house. She explained that he would ring her from the supermarket. Her diary read:

"I'm staying at my boyfriend's tonight – he rang me from Aldi asking if I can eat curry – he checks the ingredients and they all have cream in it. It's a school night, so I don't want to risk it." (Ellie's diary)

Whilst Ellie cannot eat the jar of curry that her boyfriend suggested, the attention here is the phone call to acknowledge that her symptoms and intolerance to dairy present and accounted for. What Ellie's diary also draws to attention is the intersection between *when* it is appropriate to 'risk' foods of which she is intolerant. Ellie's account sheds light on the ways in which social eating and the working week are not compatible. For Ellie, her eating choices with her partner flag up the potential for symptoms at work *the next day*. Ellie later explained the changing practices around what is eaten by the time it gets to the weekend. We discussed this further regarding her relationship with her boyfriend:

"He has adapted to things really well although he will say "when you [Ellie] aren't here", he will eat all the things I can't have. What we are going to do when we move in together is kind of have a couple of days where we eat different things like mega spicy or creamy, so he doesn't feel left out." (Ellie's interview)

In the accommodations made by Ellie's partner, there is an acknowledgement of what happens 'beyond' their intimate relationship. Ellie speaks of the anticipations of accommodations on both parts when they move in together. Eating *together* and *separately* becomes a regular feature in their day-to-day lives. This captures her boyfriend's enjoyment of creamy and spicy foods, and Ellie's avoidance of them. Ellie also spoke of the accommodations made for her sensitivity to milk by her family members. She explained:

"When I go home at Christmas, my mum will make a cheesecake with all the lactose-free stuff. She will buy the milk and cheese in even if I'm only there for one night and I might not actually want any. My brothers and Dad say, 'we don't like stuff with your milk in, it tastes funny'. They do eat it, but they tend to make jokes about it. They're actually fine." (Ellie's interview)

Within Ellie's 'funny milk' is the negotiation and inclusion of alternative diets within the family even if the other family members may tease at the taste of it. This shows the intimate actions of acknowledging dietary changes in family life and intimate relationships. Like Ellie, Gina explained her partner's involvement as she tried the low-fodmap diet. She explained:

“Lauren: Do you talk to your partner much about it at all?”

Gina: Yes, particularly when I was doing the low-fodmap diet, endlessly but I think now that it's more she doesn't always remember there are things because I don't know if whether its fructose or gluten necessarily, so she bought some gluten-free pasta and it was green and it made me pee which would be the fructose element, so I was thinking to myself, shall I say anything but by this point she had already put it into the pan so thought we are going to try this but it was awful and it turned into mush and it tasted horrible she tried one piece and she said 'we are not eating that'. OK problem solved” (Gina's interview)

Despite the unsuccessful outcome of the green gluten-free pasta, the attempt to include this as a shared meal speaks to the accommodations of changing diets as an act of love and care. The accounts from Brenda, Ellie, and Gina all capture the reciprocal nature of care. For Brenda, it's not wanting to stop Ken. For Ellie, it's not wanting her boyfriend to miss out. For Gina, it's not wanting to discourage the attempts of her partners gluten free pasta. These efforts are part of the negotiations and of the accommodations. This echoes previous literature where this care is shown by feeding others and sharing (Devault, 1991; Lupton, 1996; Warin *et al.*, 2008). It similarly builds on the ideas of nutritional altruism whereby shopping and choosing food for others fall under care for another's health (Crawford *et al.*, 2010). Returning to Brenda and moving from the intimacies of home life to more 'public life', she told a story of her encounter with a fellow player at the bowling club she attends.

“I've tried cutting out bread more than once, and I do feel better but then I go back on to it, but this time I've cut it out and it's been a long time. My stomach went down a bit and then I was bowling, and this lady was making a cup of tea for herself and she'd been taking tea bags in a little box. I said, 'what are you doing?' she said, 'oh, it's me decaf tea' I said, 'really?' she said, 'do you have a blown-up tummy?' I said, 'yeah' she said, 'I haven't anymore. Brenda, go and try it!' [laughs]. So now we have two lots of tea, and that works. Simple! I have very little coffee; I'm wondering whether to try the decaf. We've got decaf to filter, and I've been ok with that. So, I might get a jar but Ken's [husband] enjoying the filter as well now so [laughs].” (Brenda's interview)

Morgan's (2009) acknowledgement of the social importance of *acquaintances* is pertinent here as it reminds of the importance of mundane, passing encounters. It illuminates Brenda's encounter of making a cup of tea with another and why it should be important. In declaring their bloatedness and move to decaf tea, there is an opening up of the alternative ways of approaching dietary changes and the communal ways in which this is done beyond those who are immediately intimate and close to us in our social networks. Like Brenda's encounter in public life with her fellow bowls player, Molly acknowledged encounters on holidays where her friend made accommodations for her diet and the symptoms of IBS. Molly explained that she often went away with her best friend Katherine and told me about the holiday they had planned for the year ahead. Part of this plan was how to accommodate Molly's IBS, told through *when* and *what* she can eat during the holiday. She explained:

“Molly: We're going on holiday this year to Spain, and she [Katherine] knows what I'm like, toilet wise, and she'll say 'right, we'll go out such-and-such a day and then you can have your breakfast on this, this and this day' so we work it out that we're in the hotel and we can sit in the hotel and have a breakfast two or three days a week and rest of time we go out and I don't have anything to eat but I always get something from hotel so I can have it for me dinner when I get back [laughs].

Lauren: Yeah. Do you go half-board?

Molly: Yeah, usually half board. I always make sure I've got something for when I get back. That's what we do. If we go out this day and that day, and then at least you can have breakfast on the other days. Coming back obviously I don't have anything to eat and going I don't have anything to eat.” (Molly's interview)

Molly explains her friend Katherine's intimate knowledge of her IBS and how it affects her on her day-to-day basis as she says, '*she knows what I'm like, toilet wise*'. The pair co-ordinate eating breakfast from the hotel on days when they are resting, and thus not out and about with potentially limited access to a toilet. Importantly too, Molly's negotiation of *what* to eat, *when*, *where*, and *on what days* draws attention to food and its consequences, working to situate this in time and place.

To finish on a more practical note in terms of 'accommodation', Julie explained that in more recent years, going out and eating at restaurants has changed for the better. She explained that now it is common for her to visit a restaurant and ask for a gluten-free

menu, or to point to a section of a menu that is deemed appropriate for a gluten-free diet. She explained a recent encounter:

“Some of the restaurants are very good, I have to say. They are a lot better than they used to be. If you go in and say, have you got a gluten-free menu? They give you a gluten-free menu or just tell you that you can have that bit. Others give you reams and reams of pages, so you've got to look through to find out whether or not it has gluten in it. The restaurant I went to last night was a French restaurant, not a chain or anything, I said to him, ‘What have you got that’s gluten-free?’ He gave me a menu and said, ‘anything that has got two or three after each item, it put numbers from one to nine, anything that has 2 or a 3 you need to avoid’ It wasn’t shouted about, it was the menu, if was a 2 or 3 you couldn’t have it, but other numbers you were alright. Presumably, they use that to give to people that have allergies to all sorts. I think that’s nice, but it’s something a long time coming, isn’t it?” (Julie’s interview)

Julie’s account documents the accommodation of diets and what she describes as ‘a long time coming’. However, what Julie’s account also illuminates is the binary of what she can have and what she can’t, made visible by the menus at the restaurant. Importantly too, IBS adds nuance to these classifications in that foods can ‘*sometimes*’ be eaten or *in moderation*. This also moves beyond understandings of food intolerances or allergies such as lactose and gluten. Accounts such as the lactose-free milk, partners’ eating practices, and the allocations of breakfast time on holiday work to demonstrate the broader issues of accessibility. It also demonstrates the exclusions that can accompany food, in both emotive and material ways. These accounts draw important attention to the processes of inclusion. In particular, the accounts are telling of broader everyday lives, intimate relationships, and the reciprocal nature of care when IBS is a factor, and there is an acknowledgement of the *consequences* of food. However, these kind and accommodating acts are not always the experience of those with IBS.

6.3 EXCLUSION(S) OF FOODS

For many, food and the following of particular diets meant that taking part in social activities presented challenges. Often at the root of this is the inability to speak about symptoms, or the fact that taking part in a social event involving food can cause the onset of symptoms themselves. Woven within the participants accounts of the foods they exclude from their diet are the tacit feelings of social exclusion that they experience as a result. These events include birthday parties, Christmas meals, and work meetings. Here, the practical talk of exclusionary diets implies what one cannot do or

take part in. There are also examples where food is excluded completely. As with Molly, there are some social activities where she does not eat. This is the case where eating food happens in a 'public' environment that may not have an accessible toilet nearby, or where the knowledge of one is *uncertain*. Here, avoiding food is easier than the discomfort and anxiety of needing the toilet and being unable to access one. Finally, it is also important to stress that the practices of excluding food with IBS are often not associated with allergies, but intolerances. This raises concerns of legitimacy in social circles. Stacy captures this with her suggestion that *'people are intolerant to intolerance'*. This builds on Nettleton *et al.*'s (2010) work on food intolerances and their relationship with medically unexplained symptoms, as is often the case with IBS. Nettleton *et al.*, (2010) posits that food intolerances present a *'moral threat'* compared to food allergies. The mediation of food intolerances on the social stage weighs a great deal heavier, especially when you add the difficult declarations of defecation into the mix.

Building upon these ideas of exclusionary diets and how they affect the ability to participate in social events, it is also important to consider the social relationships that the participants work to mediate within this. Kelly explained how she has stopped going to particular family events, because of her *'awkward'* diet that people do not understand. Kelly's diary read:

"I call in on my parents on Sunday. I haven't eaten at their house for years. My mum can't cope with my diet - it seems to upset her and make her worried, so I just don't try it. I have sidestepped invitations to eat dinner at friends' houses for years and now rarely get such an invitation if I do it makes me stressed. I do try to be truthful and just say I have an awkward diet but obviously people don't really understand. Extended family is really difficult. I can't really go and see relatives for the day; it's just too difficult. We have been invited to stay with my Aunt and Uncle, but I just think that's too difficult. There is the food at their house but then when they want to show you around and take you to places it's also really hard. If it's just me and my partner, we know what we need to do and if it comes to it, I can just buy a few bits from a supermarket and sit on a bench somewhere - I remember when I did that one lunchtime. But when your relatives are trying to show you all their favourite places and recommend things to you how do you say, 'thanks but I'd rather sit on a bench by myself with a tub of hummus and some crackers'. You want to explain it, but you just can't."
(Kelly's diary)

Kelly explains that her mum, *'can't cope with her diet'*. Because of this, Kelly has decided not to upset her mum and eat with her parents or extended family. Ellis (2018)

explores the tensions within families in what she terms *'food fights'*, when illness and food disrupt family practices and thus the performances of care *through* food. Kelly's declaration of her *'awkward'* diet that *'people don't really understand'* shows that, with IBS, it is often not a case of one particular food group being excluded. Instead, it is a range of foods like onions, tomatoes, bread, and milk. For those with IBS, there is not always an easily defined tick box that their intolerances can fit into, as we see in current categorisations of *'vegetarian'*, *'vegan'* or *'gluten-free'*. One cannot translate these negotiations into a *'simple'* request for a *'special'* diet, such as at a work conference dinner or an extended family meal. As Nettleton *et al.* (2010: 302) argue, *'food intolerance implies an altogether less clear-cut and therefore questionable identity than does the allergic "binary"'* and thus avoidance of foods are implicated in these *categorical and moral uncertainties'*. Specifically, those with IBS lack the security in declaring their dietary needs and so the social structures do not meet the complexity of the condition. The complex and unpredictable symptoms further question the legitimacy of food exclusions at hand. One might have an adverse reaction to a particular food one day, and not the other. In addition, the fact of declaring dietary needs also means that there may be a disclosure of IBS. Kelly articulated this earlier by saying, *'you want to explain it, but you just can't'*. This inarticulation reflects both the complexities of an individual IBS diet but also the challenging negotiations of having to declare oneself as having IBS, which has the symptoms of diarrhoea, constipation, and wind underpinning it. Kelly wants to tell people, but this is difficult. As a result, she has found strategies whereby she can sit and eat her carefully chosen foods with her partner on a bench. Similarly, Caroline discussed the awkwardness and complexity in her diet and how this leads to feelings of exclusion:

"You feel a bit excluded. Everyone else is sitting there having a lovely meal. I have also been excluded from work dos. There was a Christmas thing I just look at the menu and the vegetarian stuff I can't have because everything has onion or garlic in it then there's all the veg like broccoli or cauliflower. It's so frustrating." – (Caroline's interview)

Kelly also reflected on the opportunities for inclusion and sociality that Christmas offered, but how her IBS compromised this:

"Kelly: In other cultures as well, inviting them for food can be such, it's what you do to bond, to welcome people. You think, it's not that I don't want to eat your food; it's just that I can't."

Lauren: How is Christmas for you?

Kelly: I stay at home. So, me and my partner have Christmas dinner at home, just the two of us. I mean we are lucky really in that family do live close by, so we don't have to travel to see family. That would make it more difficult if we did. I just stay at home for all of the meals. I literally don't eat in other people's houses or go out for meals. I just kind of stay at home. I don't know what I'd do if I needed to see family that lived elsewhere; it's really difficult.” (Kelly's interview)

Throughout all of Kelly's diary and in our conversations, she described the barriers and the exclusions that her changing diet presented. From the trips away to the seaside staying at their friends' holiday home to the Christmas dinners with family, Kelly reflected on how food was not without limits and worries. In negotiating all of this, Kelly explained her love for dancing classes. For Kelly, her dancing classes with her husband represented an activity that was social, communal, and fun. More importantly, dancing as a social activity did not involve food. Dancing removed the pressures and woes of eating with others when her diet felt difficult to articulate.

As mentioned earlier, the exclusion of food can be taken in a very literal sense. Many of the participants explained their days of eating nothing when going out, travelling, or participating in social activities. If food is eaten, there is an expected *consequence* (Murcott, 1993). Thus, the consumption of food and the participation in events sit beside the hidden nature of the symptoms and the pertinent issue of being able to access a safe and accessible toilet. Several of the participants noted that in some social situations, it was easier to avoid eating completely than it was to navigate symptoms. As part of her voluntary work, Molly goes on regular day trips to the seaside. For Molly, these trips are troublesome, and she often avoids eating all day to minimise potential toilet trips whilst travelling. Her diary read:

“I will not have anything to eat all day due to the fear of not finding a toilet quick enough. I do have water to drink and a sweet to suck.” (Molly's diary)

In our interview, she explained further:

“I go on a lot of trips, we take people on trips, so I don't have anything to eat and I won't have anything to eat all day, because I know that if I have anything to eat, I'll need a toilet. So, I just don't bother. I'll have a sweet, I'll suck a sweet and have a sip of water. I'll go and sit in a restaurant, they can all have fish and chips, it dunt bother me because I know that I'll be safe so that's what I do. It

might be eight o'clock at night when I get home, but I still don't have anything to eat until I get home. But, I'm not hungry, it's weird because you know that you can't have anything, I think you must programme your mind that you can't have anything, so you know, I don't get hungry...I once got told off, I went to London and me and my friend had to do this speech of how we started as volunteers so we'd done this speech between us and I had something at night when we went to this hotel and following morning I wunt have anything and there was a paramedic that went with us as well and they were all having sandwiches and he said 'aren't you having anything?' I said, 'no, I don't have anything' he said, 'if I was you, I would eating something' I said, 'no I can't because you know, I have IBS and it worries me' and he said, 'well, I'll be taking you to hospital with low blood pressure because you've not eaten anything, it's not good for you' I said 'no, but I do it regularly so I'm used to it' he said, 'no it's no good for you' and he were going on and on at me. I said, 'Yeah but you don't suffer with IBS obviously, so you don't know the predicament'" (Molly's interview)

The tensions between Molly and the paramedic show the tussles of eating, care, and how people look to feed others (Ellis, 2018; Lavis *et al.*, 2015). Molly makes the decision that, whilst travelling and being responsible for others in her volunteering role, it is easier for her to avoid eating. Her trips to the seaside involve sitting with others whilst they eat their fish and chips. She declines, sucking a sweet and sticking to water. This way, Molly explained she feels that will be 'safe' until she gets home and can then eat. Molly also describes '*programming*' her mind to know she cannot eat. This says something about the embodied effect of being concerned about the consequences of eating (Murcott, 1993) in public spaces. In addition, Molly draws attention to how others perceive this abstinence from food, which relates to the moral and normative conduct of *when*, *what*, and *how much* someone should eat. This jars with her lived experience and anxieties of IBS.

Tony also often avoided food and eating out. He described going out for dinner with his partner as an important practice for their relationship. However, Tony explained that this often meant that his wife was left feeling conscious if he did not eat anything and she was the only one '*sat with a plate*'. Tony described how he often orders something to save face. Goffman (1955) discussed '*facework*', explaining how one might work to save their face and ensure the other person in the given interaction does not have a negative opinion of them, and to sustain the social situation at hand. For Tony, the continuation of eating out with his partner despite his dietary restrictions demonstrates the attempts not to draw attention to the challenges that his IBS diet brings as well as sustaining the relational performance of *eating together*. I asked Tony about the daily

routines of eating with his partner at home. He explained that they had different meals, but he still cooks for her.

“Lauren: Do you eat with your wife, and does she have similar meals to you?”

Tony: No, she has different meals. When we moved in together, we both had a go at cooking, I was better, and we've built on that. So, I still cook her meals. With her job as she does events, she has random times, some nights she doesn't come home at all, so we tend to do a big batch of cooking and have freezer meals, if she's in I'll cook her something fresh. We stopped eating the same stuff about a year ago.

Lauren: Do you still eat together? I guess it depends on the time.

Tony: Yeah, if we're both in together we do but I suppose not because I cook hers first, so she'll eat while she's talking and I'm still cooking.” (Tony's interview)

The account above demonstrates that despite their dietary differences and routines, Tony still works at making food with his partner *social*. Tony also described moments of eating out with colleagues as he has to go out for meals as part of his job. He said:

“When I go out, that's probably when I have to do meals and stuff with customers, you can't really sit there with nothing in front of you, so sometimes I'll order it and move it about the plate” (Tony's interview)

Tony's diary offered a scenario of eating out with colleagues and the consequences of this. Tony and his colleagues went away for the weekend to see a football match, with a meal and drinks afterwards. Below is an extract from Tony's audio diary:

“It's the evening now and I'm regretting my actions for Saturday. Saturday night I went out to a Turkish Restaurant, had a yoghurt based dish...I did have my medication, it was a bit of a pain but I ended up drinking red wine, full of fructose, high in fructose which didn't help so I did end up going back, we we're supposed to be going out for the night, most of them didn't get in until the early hours, I was back in the hotel for half past ten with symptoms, I had to use the bar toilet with bad diarrhoea so it's my own fault. I had a good week, let loose a little bit and paid the price...I'll be honest, I did enjoy the football, did enjoy the meal so sometimes it's a weigh up. A lot of pain, but a good memory. A nice time with friends. But yeah, it's my own fault.” (Tony's audio diary)

The following diary entry continued with the same narrative:

“Still paying the price for Saturday, it's my own fault, yesterday I thought it was mainly worth it because I did enjoy it but an afternoon of fun for two days of

pain, maybe three. I always say I learn my lesson and not do it but sometimes it's hard, you want to socialise like you used to, when I was without it, when I didn't have the illness. Sometimes you get that snippet, you kind of think you're cured when you're not. You know better, because of the work you've done - getting rid of stress, eating the right things, and then you just let it go - I suppose that's just human nature.” (Tony's diary)

Tony practices a low-fodmap diet by excluding lots of food in his diet as one way to manage his IBS. However, the application of the low-fodmap diet cannot always happen in practice in restaurants and in the company of others. This can be seen in the work scenario for Tony. Despite Tony's rigorous practice of his low-fodmap diet and his work commitments to socialise with colleagues, Tony describes the regret and frustration at himself for eating and drinking with colleagues and the symptoms that followed. These lead him into the bar toilets and to return to his hotel room at ten thirty pm with others carrying on with the evening. In Tony's exclusion of food, and negotiations to include and participate in the social involvements of work life, this leaves feelings of frustration not of the structures of the environment or of the condition, but of himself. Tony refers to his '*human nature*' response to wanting to take part in events, and undoing the regimented and tight work of monitoring his IBS. In doing this, Tony situates the experience as an individual responsibility rather than a structural one. This builds on notions of '*control and release*' that Crawford (1984) suggested, showing the negotiations between being disciplined over one's health and one's body, but also having the ability to 'let go' with enjoyment being as equally significant (Backett, 1992). For Tony, the notion of '*letting it go*' is deviating from the strict low-fodmap diet to the inclusion of the social. This again draws attention to food as '*consequence*' (Murcott, 1993) as we see Tony back to the hotel bar toilets with diarrhoea.

This section has sought to unpick the exclusion of food as a complex endeavour that is often difficult to articulate, and that those with IBS feel others rarely understand. Because of this, there is the exclusion from social events, especially where food forms an important part of such socialising, such as Christmas dinners, birthday parties, meals out with friends, or being cooked for. These events often bring these challenging conversations to the fore where there is a declaration of not only the complex and contested food intolerances, but an admittance of having IBS and its implicit or explicit *consequences*. Second, several of the accounts have demonstrated the literal exclusion

of food, whereby food is avoided completely, and nothing is eaten if social participation is necessary or desirable. Importantly, as demonstrated in Molly's account, this avoidance of food is *spatial*, *temporal*, and *embodied*. Molly's eating is dependent on where she eats, what time this is in line with the time food takes to have an effect, and how this meets with the necessity of a nearby and accessible toilet. These factors thus change the body in place and time, whereby inaccessible environments lead to an avoidance of food in order to prevent the consequences of IBS symptoms. These literal exclusions are at odds with normative pressures to eat as part of biological necessity and to be part of social convention. Likewise, in the account that Tony presents, there is evidence of exclusion in a very literal sense where he has a very limited diet or chooses not to eat. However, it also shows the trickiness of negotiating this in line with the requirements of social life, leading to processes of negotiation and a frustration when he cannot stick to his diet. This difficulty in social eating and of taking part in some instances says something not only of the social, but of the disconnect concerning the legitimacy of IBS and its understanding from others. In Tony's social event and his dealings with the deviations from his strict diet, lie important facets of experiencing food. These deviations work to demonstrate the social weight of participation, the desire to enjoy, and perhaps most importantly, the need to pass as normal and to be included.

6.4 'I'LL TAKE THE HEARTACHE': MOMENTS OF RESISTANCE

In describing accounts of resistance, it is important to stress the multiple layers of IBS and different '*severities*'. This is not to say that one person is worse than another, as it is subjective and experiential, nor is it to place IBS symptoms in a hierarchical way. For some, resistance with food and their diet is not an option. Here, we are reminded of the struggle this brings in the face of IBS and questionable food intolerances. For those with food intolerances in comparison to food allergies, their status remains increasingly ambiguous and thus leads to a questionable identity (Nettleton *et al.*, 2010). However, within this careful complexity, diversity and ambiguity are also moments where people can afford to resist. Often this is dependent upon their symptom severity, where they are, and who they are with. Those with IBS can also arrive at a place where tracing their symptoms in line with food finds no answers. When no immediate food intolerances are noticeable, individuals can resist monitoring food in order to prevent social exclusion. Thus, resistance and choosing food becomes a desirable option. For many

with IBS, there is an understanding that particular foods can sometimes affect them, and sometimes not. Because of this instability, social participation can override potential consequence.

Here I want to display examples of resistance to the pressures of monitoring and excluding foods. I want to illuminate how people disrupt dietary compliance for the small pleasures in life – Keith’s Friday night fish and chips and Tony’s key lime pie. This relates to the multiple repertoires of eating that Will and Weiner (2014) illuminate, alongside the balancing act of ‘*control and release*’ (Backett, 1992; Crawford, 1984). In the tensions between participating and feelings and/or practices of exclusion, many of those with IBS seek to resist dietary monitoring. Some refuse to allow an IBS diet to place such a heavy emphasis on their social life. There is a recognition that limiting, or heavily monitoring food may also consume the social. There is often a process of negotiating and arriving at a place of balance and acceptance. When participating in eating practices, pleasure and enjoyment become important to everyday experience. As seen in Brenda’s earlier account of dishing up the greens with her husband Ken, she explains how she holds back on voicing what she can and can’t have, as she doesn’t want to ‘*stop him*’. In Ellie’s partner eating differently without her, we see the tensions and ongoing negotiations of what is at stake in relationships and how the differences in needs and desires are negotiated through relationships in a shared space and time. In a remarkably different way, Molly resists the pressures of others who expect her to conform by eating, but who do not have the felt experience of the anxiety of urgently needing to find a toilet in public life. Resistance and exclusion work in multiple ways, dependent upon the social circumstances and the people and place in which they occur.

In the accounts, there are practices of compromise, of muddling through multiple ways of being amongst food. These repertoires of health show how pleasure, sociality, and practices for health are simultaneously weighed up and negotiated (Will and Weiner, 2014). Keith was one participant who negotiated these multiple ways of being with food. He explained how his family, like many others, had ‘*Friday night fish and chips*’ (Murcott, 2013). Keith excludes gluten from his diet and therefore cannot eat fish batter. When visiting his parents on a Friday, his mother expressed concern over his ability to eat the battered fish. Keith explained he would go ahead and ‘*take the heartache*’.

“*Lauren: Since going gluten-free, have your symptoms improved then?*”

Keith: Yeah. I mean, as I say; I do find now that I can, every now and again I'll push the limits do you know what I mean? I'll think 'oh I'll have that; I'll have that bread' like when we we're in Spain and sometimes I can get away with things. I mean I love fish and chips for instance [laughs] so battered cod I absolutely love it, so on a Friday every now and again we'll be like 'oh alright yeah' and you think 'oh I'll just take the inconvenience after' and sometimes it won't affect me that much, I don't know why and then other times it will be really bad...I'll be honest with you, I don't kind of shy away from it or get embarrassed from it or anything like that, so all of my family know and my mum and dad will, whenever I go to my mums, they love having fish and chips on a Friday night, so if I'm over there I'll be like 'yeah, yeah I'll have fish and chips with you' and my mum will be like 'you can't eat battered fish' and I'll be like 'yeah I'll just, don't worry about it, I'll take the heartache, I'll take whatever comes' but yeah, my mum is obviously really good with that sort of thing.” (Keith's interview)

In *'pushing his limits'*, Keith participates in family life and the Friday night fish and chips. Despite knowing the *'inconvenience after'*, Keith recognises the negotiation with his mum in her care towards his IBS, alongside his desire to participate and enjoy family life. This again echoes Murcott's (1993) idea of the *'consequence'* of food, but nevertheless a resistance to it. Stacy also reiterated that despite her IBS symptoms and their troublesome nature, she was wary of letting this consume her or take over. She resists monitoring food and chooses instead to keep a regular routine. Stacy explained that in negotiating food, she took the discomfort in the bargaining of eating her mum's lamb stew and dumplings:

“I know that I'm likely to get pains after a big Sunday roast but there's absolutely no way I'm cutting that out or altering what I have and how much. Instead, I factor in a good hour or two after dinner where I plan to just relax and watch TV, just in case I do get some discomfort. That's exactly what happened tonight, but I don't mind because there's no way I would forego my mum's lamb stew and dumplings!” (Stacy's diary)

As well as her love for family Sunday roasts, Stacy explained how she and her partner frequented Beer Festivals at the weekend. This does not suit her IBS, but it is important for her relationship that she enjoys and is not willing to give up. As Lupton (1994: 682) argued, memories of food or rituals of mealtimes in families and relationships and sensibilities can be more powerful than a rational criterion of food choice. Here this *'choice'* is a decision for participation and relationships, despite knowing of the *'consequence'* that may come from doing so. On a similar note, there is a striving for normality despite IBS symptoms. This is also performed through resistance to dietary monitoring, restriction, or elimination. Prout *et al.* (1999) suggested how *'normality'* is

significant in responses to illness that situate themselves within the family, to include both being the same as others, or the same as pre-illness or pre-diagnosis. Here, it is sought through the choosing of the family meal or the social event, for enjoyment and participation. Brenda explained a similar experience:

“I probably eat more cake when I go out. I like afternoon tea. I feel horrendous when I’ve finished, but I loved it. Last time I went with my sister, I didn’t know what to get her for her birthday in January, and we finished up going to the garden centre. I thought, ‘I really shouldn’t eat all my portion’ but I did. You do don’t ya? I loved it. I suffered half the night. Did it matter? No. No because we’d had a nice time. So, it cost me a bomb, it doesn’t matter [laughs].”
(Brenda’s interview)

Sometimes there is a balancing act between moderating food and the resistance or leniency when the social becomes pertinent. For example, Amy talked about the balancing act of knowing foods that bothered her, but knowing how important social participation was on this day:

“My sister has broken up with her boyfriend today so comes to our house after work. My husband suggests we all order in pizza and watch a film to take her mind off it. I am wary because the last time I had a takeaway pizza, I woke up in the middle of the night with excruciating stomach pains, which got so bad that I passed out. I then spent most of the night on the toilet and had to have the day off work. However, I do really love pizza and didn’t want to miss out, so I decide to compromise by having a couple of slices and not overeating.” (Amy’s diary)

Amy partakes in the takeaway pizza with her sister, but limits this and ‘compromises’ in looking to manage her IBS. Amy later documented in her diary she was ill in the night like the previous time she had pizza. However, what this reiterates is that despite Amy knowing the potential ‘consequence’ of eating pizza, the importance of the social and her sister's situation overran the potential of symptoms. Similarly, James tried implementing the low-fodmap diet whilst away at university, but this was disrupted when he returned home. He explained:

“James: I was trying the low-fodmap diet, the reason I decided to put an end to it is because I got home and my nan had made some scones for me and my mum was going to do spaghetti Bolognese for tea, I just thought, do you know what, I can’t be bothered with this. My family know I’m not fussy when it comes to food, in terms of taste and things like that, they’ll cook whatever. Sometimes I’ll be cooking at home.”

Lauren: I suppose you can never turn down a nice scone, can you?

James: No, she puts chocolate chips in them as well.” (James’ interview)

For James, returning home means a revival of the home comforts of food, allowing for the attempts at dietary changes to be pushed to the side. James also stresses his family do not see him as a fussy eater. This reiterates the importance of tinkering with diets in the company of others (Green *et al.*, 2003). We can see family meals as a site of conflict or tensions (Wilk, 2010). But there is also the argument that mealtimes are a continuing cultural ideal of eating together as a moment of unity (James *et al.*, 2009; Stapleton and Keenan, 2009). Within this is also an identity of James being known to his family as ‘*not fussy*’. Being ‘*not fussy*’ is also a normative aspect of eating, with there being differing tolerances for individualism in eating, and the weight of commensality that comes with sharing food (Fischler, 1998). Thus, sustaining a low-fodmap diet is changing face in the context of the family. This builds upon the substantive body of sociological literature that demonstrates how everyday relationships with food shape both individual and collective social identities (Caplan, 1997; Fischler, 1998; Nettleton and Uprichard, 2011). This social weight can be seen in particular with negotiating families and tensions with food (Ellis, 2018). In a similar way, Tony connects to this identity work in his resistance as he reflects on his favourite dessert from the past, Key Lime Pie:

“Sometimes I’ll order food and move it about the plate or sometimes if I fancy something, my weakness is key lime pie which is full of sugar, dairy, only makes me ill but there’s one hotel that I stay in and I know every time it’s going to make me ill but I’ll tend to eat it fast because I know it’s going to make me ill so by time I’m back up in my hotel room I’m really ill, but I just can’t resist it. It’s a strange story, you have that one dessert when you’re at primary school which I could never find as an adult and I always thought it was a cheesecake. My friend made us key lime pie, and that was what I was looking for. I’ve never liked cheesecake, but I’d always been looking for that flavour. It always reminded me, if you put a piece in front of me now, I’d eat it, I can’t say no.” (Tony’s interview)

In Tony’s nostalgic search for the flavour of Key lime pie, we can see the identity and memory work found in food (Fox and Alldred, 2018). We can also see how this works in the practices of resistance. Tony recognises that in resisting his diet and enjoying the key lime pie, he does this in a way that acknowledges the *consequences* of doing so (Murcott, 1993). He anticipates symptoms of IBS, and so ‘*eats it fast*’ ready to be back

in his hotel room. The conflict between the enjoyment of food and the repercussions that this can have on one's health is an ongoing negotiation. This enjoyment is often accompanied by the historical and biographical yearning that food can embody. Tony's account also links to the discourses of health that discipline pleasure with food and how this can bring consequent anxiety and guilt (Coveney, 2000). He knows the pleasure of the key lime pie will bring the *consequence* of his IBS.

Situated within the decision of whether one should eat particular foods or not, is the underlying thought of whether there will be a '*consequence*' for doing so. Namely, this '*consequence*' being the onset of symptoms. To trouble this further, IBS occupies a contested status, and food is a factor located within this. This begs the question of whether or not food will cause symptoms. This can also be exacerbated by the complexity of IBS, and its causal relationship with food as an uncertain, unpredictable, and often an unreliable trigger. The ambiguous nature of whether food is a factor in the onset of symptoms or not often informs people's decisions in their day-to-day life. For example, Stacy recalled a day in her diary of a future social event involving going out for a curry:

"Friday 24th November, 20:30: On Tuesday I have a role play exam, which is the type of stressful situation that can provoke my symptoms. I've been invited out for a curry the night before and I don't know what to do. Part of me thinks that as the curry is unlikely to have a huge impact given that I never have anything too spicy, I should go. Not least because if I stay in, I'm more likely to get myself a bit worked up about the exam and get stress-induced symptoms. It'd be particularly awful if I got the awful stomach pain, especially if I've deliberately forgone a curry the night before. Tough decisions..." (Stacy's diary)

Fast forward to Monday's diary entry:

"Monday 27th November, 21:30: My mum suggested that maybe I should skip the curry, but I really didn't want to stay in on my own. Plus, given that stress appears to be a key cause, I really wanted to go out and be distracted. Weirdly enough, a good portion of curry and beer, my IBS is now behaving the best it has all day!" (Stacy's diary)

Stacy weighs up whether she should avoid the social event because of the potential consequence of the food being a trigger. In choosing to partake in the social event, she later realises that she did not in fact have any symptoms when it came around to it. Stacy then deconstructs the complexity of the causes of IBS when food does not disrupt,

and thus allows for a degree of leniency in dietary life. In this lies the complexity of IBS with food and the multiple experiences of intolerances, but also how these meet the social world when choosing to take part takes precedence. Exploring the practices and sites of resistance with food and IBS uncovers and builds upon notions of '*control and release*' as demonstrated by previous literature (Backett, 1992; Crawford, 1984). There are negotiations in seeking to control IBS symptoms, but also in how this is disrupted in the face of social participation and enjoyment. Importantly, and threaded throughout this chapter, this resistance is also met with an understanding of the potential or actual *consequences* of eating (Murcott, 1993). The interplay of the consequences of food, together with the contested nature of intolerances (and the connotations of such for legitimacy), can be viewed through two conceptual ideas that offer meaning and certainty to the social experiences of food.

6.5 CONCLUSION

For individuals living with IBS that located eating practices in their diaries and conversations, these practices reiterated the everyday importance of social participation, belonging, and exclusion. The accounts, in both their narrative and food diary formats, have shown the feelings or practices of how an IBS diet can accommodate, exclude, and resist. Returning to the research questions, food is present within the home, the workplace, and the dinner table. Food forms part of the rhythms of the everyday, providing an insight into what we eat and when, and the later consequences for doing so. Food also provides an important example of how relationships and care are performed in both 'public' and 'private' life.

First, the accounts have demonstrated how the complexities of diet can be accommodated within the context of intimate and familial relationships. This shows how this can often be telling of the practices of love and care. Within the attempts of inclusion, there is a knowledge of the *consequences* of diet in everyday relationships. Ken's understanding of Brenda's struggle with vegetables *the next day*, through to Molly's friend negotiating holiday breakfasts, demonstrates the accommodations made and the care for others in knowing the consequential nature of eating. Food connects individuals to social groups, binds families together and establishes social norms. The accounts have documented how illness and changing diets play out in family life and relationships. This may be the tensions at the dinner table, the acts of love in food

preparation, or the negotiations between pleasure, health, and social participation. Second, with the accounts, I have sought to demonstrate how exclusions can play out in daily life. Specifically, people with IBS can retreat from social events that involve food due to the difficulties in articulating diets and the potential to reveal symptoms. I have attended to the times where food is completely excluded and avoided, as a way to be able to participate in social activities. Food is removed from the equation to prevent the consequence of IBS symptoms. Third, I have documented the moments of resistance in striving for social participation. Between the lines of inclusion from family members and the exclusions of food, lies the muddy ground of wanting to be part of something. Similarly, there is a continuation of balancing the moderation of diet alongside the pleasures that food can bring. Finally, what has also been made present in the moments of resistance for those with IBS, are the occasions when people wish to resist the medical discourse of dietary monitoring and/or elimination. This monitoring and/or elimination of food often results in social exclusion, and so there is an opting for pleasure and enjoyment, with an acceptance of what may follow.

This chapter contributes to the existing literature on the negotiations of food that reflect food as social, and part of relationships and family life, particularly when related to health and illness (see for example, Ellis, 2018; Webster and Gabe, 2015). Second, this chapter builds on literature that acknowledges the repertoires of eating in relation to health and enjoyment (Will and Weiner, 2015; Crawford *et al.*, 2010; Backett, 1992; Crawford, 1984). This chapter contributes to the specific sociological work on food intolerances (Nettleton *et al.*, 2010), further acknowledging the ambiguous nature of excluding foods when intolerant, but not allergic. Specifically, I look to make this explicit through the connotation's 'intolerance' carries in how food is experienced and the 'moral threat' it can pose to social situations. I have suggested that this 'moral threat' is twofold with IBS. First, there is a lack of recognition and legitimacy associated with the complexity of an IBS diet. Second, is how this illegitimacy sits alongside the potential stigma faced when declaring, anticipating, or experiencing the symptoms of IBS. There is a search for recognising food intolerances as legitimate, but an awkwardness in articulating this precisely due to the taboo nature of the consequences. This is situated within the morality of intolerances, but also in the process of avoiding the discussion of bowel habits in everyday scenarios.

In this chapter, food has provided a gateway into the intricacies of social life. It has acted as an elicitation tool for broader meanings of belonging, legitimacy, and exclusion. Acknowledging food as a social and relational tool is not new in sociological studies. However, what is pertinent in the accounts of negotiating IBS is *what is at stake* when engaging in the social, particularly when this jars with eating practices. I have drawn upon Murcott's (1993) conceptualisation of food and its *consequence* of elimination as an important undertone for those negotiating food and IBS. The feelings associated with food and the practices of inclusion or exclusion meet with an acknowledgement of what may come *afterwards*. Importantly too, this awareness of the consequences of eating sits within the context of where, when, and with whom food is consumed. To finish, I am reminded of Stacy's resistance to monitoring and eliminating food groups, but how she instead ensures mealtimes are appropriately timed, thus establishing a routine to negotiate her IBS. Like food, time works as a negotiation of IBS. This leads to the next chapter on temporalities and (re)organising time, to which I will now turn my attention.

CHAPTER SEVEN

‘LIKE CLOCKWORK’: REORGANISING DAILY ROUTINE(S)

7.1 INTRODUCTION

“Until I was about 26 or 27, I was as normal as anybody. One bowel movement a day, first thing in a morning, that was it. Then, it was two events. I’m not quite sure what caused it. I started running marathons, and that’s when I had my first problem after doing a long training run and having a very long bowel movement and that kind of continued BUT at the same time, I was getting divorced. So, stress, running, I don’t know what triggered it. That’s when it started, really. It got progressively worse, I’ve never experienced the pain that I know other people experience with it, but loose bowel movements, unpredictability have always been an issue. In terms of how it affects my life, it’s like the routine thing, really.” (Terry’s interview)

In the quote above, Terry describes a life of ‘*normal*’, regular bowel functioning, a ‘*once a day, first thing in the morning*’ scenario familiar to many. What Terry then articulates is a change in circumstances, with his marathon running and getting a divorce. Alongside this change is the disruption of an altered bowel, and a consequent shift in routine.

Terry’s account reflects what Bury (1982) identifies as biographical disruption—the life events and illness that shift an individual and their sense of self. Bury (1982: 169) suggests that the onset of chronic illness causes disruption to the structures of the everyday, and the accompanying knowledges that go alongside. Another participant, Julie, described that her IBS began a few years ago, following a bout of gastric flu at Christmas time. Since retirement, Julie has changed her routine and organised her day in line with her IBS. For others, IBS and a ‘*disrupted*’ bowel have always been part of their biography. This presence echoes previous research that encapsulates illness and disability as part of individuals’ identities from a young age (Lowton *et al.*, 2017; Monaghan and Gabe, 2015; Williams, 2000). For example, Ellie reflected that her

symptoms were always there, but only came to be diagnosed with IBS as she left for university. Many of the participants described the onset in their teenage years or when starting at university. However, what this chapter pays attention to is not the *'disruption' per se* that involves a life pre and/or post-illness or diagnosis, especially as IBS is a contested and sometimes shifting diagnosis, but it offers an exploration of the *routines* of the everyday. This is what Shaun described as a *'managing routine'*, that includes the adaptation and normalisation of symptoms. Perhaps here it is useful to consider Bury's (1991) concept of 'strategies' for negotiating IBS with a focus on what people do with their time. These strategies or (re)negotiations of time involve the weekly planning, early mornings, timed activities, and the taking of Imodium for the day ahead. The keeping of a daily diary drew attention to the temporal rhythms, evolving questions about routines, allocations of time, and the temporal ordering of everyday life.

The aim of this chapter is to explore the (re)negotiations of time when living with IBS, through developing an attentiveness to the temporal nature of the bowel. First, I will document the importance of weekly routines and the periodicity of symptoms (Southerton, 2006). The participant accounts will show the how symptoms of IBS come to be experienced within a week, offering both regularity, disruption, and what Amy terms, *'like clockwork'*. Second, I will utilise mornings as a significant fragment of time within everyday routines. Mornings offer pertinent insights into the importance of (re)ordering time when the rhythms of our bodies, and specifically our bowels, meet with or jar against the pressures of 'social' time. Here, there is an emphasis on pacing and giving way to slowing down (Kafer, 2013; Charmaz, 1991). Third, I will turn to the timing of tasks when living with IBS; from the trips out with friends, eating foods, to walking the dog. In examining these activities, I hope to demonstrate how such allocations of time are thought about in line with the places people go, who they go with, and how the built, material environment can all play a part. For example, when in the day can one walk a dog? Where can one go? How long for? How might the route reflect the availability of toilet access along the way?

More broadly, through these rhythms and (re)organisations of time, this chapter considers issues of flexibility in light of uncertainty, and accommodation in light of symptoms. Bates (2019: 81) suggests *'with our lives running on abstract time, from the*

hours of sleep and waking, to mealtimes, work and private life, we force our bodies to fit a rhythm that is not our own'. She concludes that when living with illness, it becomes necessary that bodies need to run on their '*own time*'. Existing literature on the sociology of sleep also offers a useful platform for exploring how a basic bodily need can be understood not only as a biological process, but one that intersects with *how, where, when, and with whom* we sleep, connecting individuals to the structures in which we live (Coveney, 2013; Williams, 2011; Meadows, 2005). Throughout, there is also the pertinent issue of the biological clock of the *bowel*. Specifically, the processes of eating, taking medication and the time it takes for things to '*work their way through*' and being prepared spatially, temporally, and materially for when this happens. The accounts presented in this chapter will therefore build upon the sociological understandings of time, specifically paying attention to the '*body clock*' and '*embodied time*' (Earle and Letherby, 2007; Adam, 1998; 2004). I look to extend this to the temporal rhythms of the digestive system by drawing upon everyday understandings of bowels being cited as '*like clockwork*'. Moreover, it offers a further contribution to theorisations of '*toiletory time*' (Inglis and Holmes, 2000), considering the broader structures that implicate such a taken-for-granted part of our daily lives. Through the everyday lives of those with IBS, we see how everyday rhythms of bowels meet with the social organisations of time, and the navigations necessary in both times of regularity and disruption.

7.2 WEEKLY ROUTINES AND THE PERIODICITY OF SYMPTOMS

Whilst some participants wrote a biographical account at the start of the diary, these were often followed with dated and timed logs of daily life. One day was not in isolation to the others within a week, and participants reflected this in their daily accounts. Many anticipated future events whilst they told the stories of everyday practice. The reflective daily accounts involved looking back, thinking about the present day, and anticipating the future. This could have been an upcoming holiday or social event that forced participants to consider and mentally plan, anticipate symptoms, or work to prevent a '*what if?*' scenario of symptoms. Zerubavel (1981) outlined that the characteristics of temporal regularity offer certainty, boundaries, and expectations of what should and does happen in our social world. Imaging a paper diary that is 'a week to view', seeing Monday to Sunday and moving on to the next week as you turn the

page metaphorically captures the weekly routines and the periodicity (Southerton, 2006). This, in line with symptoms, is what participants look to make sense of. Lefebvre (2014: 29) articulates in his work on rhythmanalysis as a means to study everyday life, that the body serves us as a metronome by keeping to time and establishing rhythms. With IBS, the symptoms draw attention to the (dys)appearing body (Leder, 1990). For Leder (1990) individuals without illness or symptoms have less of a connection to their bodies: their body is not present. In times of illness, the body reappears and thus the functionality of the body is brought to attention. IBS illuminates the functions of the bowel, bringing awareness to the body. These symptoms situate and map onto weeks at a time as those with IBS question their last toilet trip, or when they last had food or drink that may cause symptoms a day or two later.

Of note were the rhythms of people's individual weeks and the times at which IBS was most likely to affect them. As Lefebvre and Régulier (1985: 85) suggest, when questioning everyday rhythms, there must be a return to the parcels of time and the activities that fragment it. For example, Shaun noted that Tuesdays were a significant day for him. His diary explained:

“Went out for a few drinks which I’ll probably pay for tomorrow... I think I’ll be suffering tomorrow as my tummy appears to have a two-day cycle after consuming any alcohol... I’m always the same on Tuesday because of my lifestyle choices on Sunday. I guess I’m too stubborn to change but I will have to one of these days...Boy, do I suffer from IBS pain on a Tuesday, especially Tuesday evening. It all stems from the weekend and any alcohol I’ve had. It’s 8:30 pm now and my stomach is in bits.” (Shaun’s Diary)

Shaun and I discussed Tuesdays ‘two-day cycle’ and what most likely affects him with his IBS. He stated:

“I can tell when or what I’ve done or had on a certain day, I kind of know when that is going to come through if you know what I mean. As I put in there [diary], Tuesday is usually one of my worst days. That’s really self-inflicted really because I do like to meet my friends on a Sunday evening, and I have more to drink than I should. I know it’s a trigger; it’s definitely a trigger. But it seems to take two days before I see any signs of it. Like yesterday, Monday I wasn’t too bad, I had bloating, but it’s Tuesday that is the worst day because everything has worked its way through.” (Shaun’s Interview)

Here, Shaun shows not only the routine of his Sunday night social drinks at the pub with his friends, but an acknowledgement of *how* and *when* his body will receive and respond to this. Within Shaun’s bowel routine, there is a *sequence* and *periodicity*

(Southerton, 2006). Having an embodied awareness of his IBS, Shaun acknowledges the time it takes for everything to ‘*work its way through*’ and the ‘*two-day cycle*’ he has familiarised himself with. Shaun makes temporal calculations with his body, a body clock (Adam, 1998; 2004). However, this biological clock is the workings of his digestive system, from the point of eating and/or drinking on a Sunday, to the flare up and excretions on Tuesday. There is an overtness in the attention paid to the temporal calculations and the periodicity of the bowel in relation to Shaun’s week. Amy also frequently mentioned in her diary that her weekly routine of IBS symptoms were ‘*like clockwork*’. For Amy, her shifting symptoms from diarrhoea to constipation and vice versa are repetitive and disruptive. These also tie into the rhythms of her working week and the activities within. She explained:

“Thursday: Like clockwork and like every Thursday, today I am constipated. I have had diarrhoea pretty much every day this week but now that it is my day to weigh in, I am unable to go. I guess it must be linked to nerves or anticipation or something, but it literally happens every week.

Saturday: Like clockwork, after drinking wine the night before and combined with an early start (another of my triggers) I get straight up and go to the toilet before heading off to do an early morning stint on reception at my dad’s GP surgery” (Amy’s diary)

Like Shaun, Amy notices a similar experience every Thursday. On Thursdays, she feels constipated and maps this with her frustration as the day when she goes for a weigh in at her weight loss club. Williams and Annandale (2018) unpack the ‘*weight of expectation*’ at weight loss clubs and how the broader pressures of weight loss become reflexively embodied. Amy feels her constipation on Thursdays when she wishes to be lighter. By Saturday, Amy is urgent to go to the toilet. Here the routine is not from Thursday’s constipation to Saturday’s return to ‘normal’, but to looseness and urgency.

“Lauren: You talked about in your diary about Friday evenings and food then can throw things as well.

Amy: Yeah, definitely. It’s always nice because I feel that I can finally relax and I’m just at home so I can have food and I’m always surprised when I don’t have to go to the toilet in the evenings but as you see in my diary, 9 times out of 10, it’ll catch up with me in the morning.

Lauren: So, do you usually have quite a strict routine in the week or?

Amy: Yeah, I do tend to get up at the same time each day, so I don't know if my body is used to that, then obviously when I get up on Saturdays slightly earlier, it kind of shocks it a bit I suppose. Obviously in terms of eating, in the week I'll be eating at very regimented times just because of when my lunch break happens to be at work, time I eat breakfast and I guess at the weekend I tend to not be so regimented and I do think that I probably eat takeaway I suppose and things like that at weekends, because I feel comfortable, I know it will probably upset my stomach if it's going to, but again I'm at home. My routine especially my stomach does definitely go out of the window at weekends, probably started by that early start and then it kind of carries on from there.” (Amy's interview)

Arriving at Saturday means she feels the freedom of eating and drinking more casually (Murcott, 2000), with Friday night signifying the working week ending. Murcott (2000) highlights the role of ‘treats’ at the weekend with food practices, which is useful in thinking about the decline in structure Amy has when she reaches Friday night. Previous theorisations of food have acknowledged the ways in which weekend often signifies letting loose and enjoying the social. However, Amy highlights that in her body and of her week, ‘*nine times out of ten*’ it will catch up with her in the morning. Amy's comfort of being at home at the weekend and the changing routines relate to Lea (1999; 2001), who suggests that in understanding the control of bowel functioning, this relates not only to the ability to contain, but works at ensuring that the act is done within a socially prescribed time and place. During the week, Amy has a regular and established routine including regular mornings and regimented lunch breaks. This changes at the weekend, and thus changes her body and her IBS. Amy also maps this alongside her routines with food, and the changes in eating by the weekend where she often enjoys a takeaway as any ‘*side effects*’ of that food are more manageable in the comfort of her own home. Fast forward to Saturday mornings where Amy helps at her dad's work, and there is a disruption in her bodily rhythm. As Amy was one of the few participants that documented her experiences of constipation, she also noted the frustrations and ‘*wait*’ of not being able to ‘*go*’. She explained:

“Eventually you know, it is going to have to come out and I don't know when that's going to be, and if it's a normal kind of toilet movement or whether it's going to be diarrhoea so that's the kind of worry and panic that starts to come in around the 8 to 9-day mark.” (Amy's diary)

Amy's shifting states in her bowels lead to an unpredictability and uncertainty of how her IBS will manifest, as she waits for her bowels to react. Here, it is important to acknowledge the non-existent, the waiting, or the regularity that exists throughout

people's weeks, in and amongst the more 'disruptive' symptoms such as diarrhoea that may also occur. Similarly, when people have no symptoms, there is a recognition of and contentment about the lack of symptoms. Somewhere between having symptoms and not, Stacy discussed her IBS as having a stage whereby she conceptualised it as '*being present*'. Shilling (1993) discusses '*absent presence*' in which the body is there, but not brought into immediate attention. For Stacy, she acknowledges that sometimes during the week, she experiences moments where her IBS is '*present*' but not fully active nor is it absent. In the disruption of symptoms and their changing nature throughout the week, there was a recognition that symptoms can also be absent. Within the accounts of IBS, there is weekly cycle and periodicity to both the regularities of the clock of the bowel, and to the experiences and onset (whether anticipated or unexpected disruption) of symptoms themselves. For example, there was a deliberate recognition of the '*regular*', the '*normal*', and the relief that this brings:

"My bowels have actually been quite regular over the past few days, which makes a change (it is normally not going for days, or I can't stop going!) I feel quite happy and normal for once!" (Katie's diary)

Rosie again echoed the absent symptoms in her diary:

"Thursday 11th January: Again, another day at work with no issues. No meetings today either, so that was good. A pretty boring, uneventful day. Not that I am complaining after the past couple of days." (Rosie's Diary)

The diaries and the completion of them with a temporal lens in mind offered recognition of looking back and forth into the regular and the disrupted, the present and the absent. In Rosie's '*boring, uneventful day*' of '*no issues*' there is a comparison to the '*past couple of days*', that were quite the opposite. Following the dates above from Rosie's diary, she is interrupted by symptoms on Sunday as she ate a piece of cake and found herself at the toilet shortly after. Up to the 18th of January when her diary was completed, Rosie takes '*precautionary*' Imodium. She reflected on the ebbs and flows of her IBS as it settled back down again:

"Thursday 18th January: My IBS seems to be settling down now, perhaps it's getting back into my normal routine that helps. I like to eat healthily, so I have pretty much fruit and vegetables for lunch and a piece of toast for breakfast. I know not to pick anything that might give me any issues, so I am not surprised to have an ordinary day." (Rosie's diary)

Rosie's diary draws attention to the ebbs and flows of the days and weeks that pass by. It demonstrates what it means to have an 'ordinary day' compared to past days that may have been disruptive. This section has sought to draw attention to how there is an established routine and periodicity of symptoms, as with Shaun's Tuesday symptoms and Amy's Thursday constipation. Implicit within these accounts are how these weekly routines and changing bowel habits are also situated within broader social structures of the working week, the trip to the weight loss club, and the arrival of a weekend. Accounts have sought to show an attentiveness to the digestive symptom and its symptoms, given the knowledge or expectation of when symptoms will appear within the week or a given period. I will now turn my attention to a specific moment of time within a week—the morning. By focusing in on a specific period within our everyday lives, I demonstrate how morning routines offer broader insights into not only the 'biological' requirements of the body and bowels, but its crucial intersection with structural pressures. These structural constraints lead to individual (re)organisations of time in an attempt to accommodate an irritable bowel.

7.3 EARLY MORNINGS AND THE ELEVEN O'CLOCK RULE

“On days off, when I'm at work, say I work a standard five-day week, I'll be governed as to when and where I can go. If I get two days off, I probably won't go to the toilet in them two days, because I know I can go where and when I want, and I don't think about it. When I know I've got to be somewhere at a certain time, then I'll usually pay for it. I usually pay for it on a Monday morning... come Monday morning I know I'm going to be governed by times and travelling... I'll get up 45 minutes because I catch the bus to work, I leave her with the car, and there have been some mornings that I have missed the bus because I have needed to go more than once. I'll go downstairs, I'll have a coffee, I'll have a smoke or a vape, and I'll then factor in getting all me gear together and gonna toilet before I have to go for the bus. The stop is only just down the road, but there have been some mornings where I've been, I've got me coat on, and bus is three minutes away and then it's a five-minute bus journey, and that's what worries me, like 'will I make it until I get to work?' and there have been times where I've been just about to go out of door, and I've got that gut wrench, and I've thought, 'no I'm gonna have to go again' just as I've got out of door and the bus has gone.” (Carl's interview)

Here we have an insight into Carl's Monday morning routine, where he gets ready to head to work, coat on and one foot out of the door, only to be disrupted by IBS and another trip to the toilet. For people with IBS, mornings are an important capsule of time that offer an insight into the negotiation of bowel movements. Mornings are often

a ‘*time squeeze*’ (Southerton, 2003). They involve getting ready in a limited time frame, often being ready to leave for work or the activities of the day. Southerton (2003: 5) stresses that in a society where individuals feel it is necessary to generate personal schedules, aligning these temporally with others become problematic and can leave feelings of anxiety. Like Carl, Martin told me how his IBS was ‘*more of a morning thing*’:

“It’s more of a morning thing for me, I would say. I guess it’s almost habitual, like your body almost kind of gets yourself in that frame of mind. Those are the times of day where it’s an issue. Normally on a typical day by mid-morning towards lunchtime then it’s less of an issue whereas obviously kind of between 8 and I guess half 10/11, that’s kind of when it’s at its worst. If I know that I’ve got something the next morning where I’m not going to be in a position, or a place that I’m not familiar with, you kind of take that protective measure, taking some tablets the night before or whatever but you definitely have to kind of work around it and try to accommodate and be aware of what might come up the next day. Some mornings, you’ll be fine, and you might not have to go until the back end of those two hours and some mornings it’s kind of almost when you wake up you know, you know you’re going to need to go before you jump in the shower. It does tend to almost be mini phases as well like, you know, a bad week to 10 days and then there might be another time where you have a couple of weeks where it’s not so bad. It’s kind of really hard at that point to put your finger on why but you know if you’re 2 or 3 days in a row, you might just know that you might have a few days where it’s not going to be great. Generally, I try to get in a routine that gives me time if I need it.” (Martin’s interview)

Martin describes the morning as a key time. He allocates a time slot between eight and half-past ten where he feels his IBS is most likely to be at its worst. As with planning the week, Martin describes the anticipation of mornings and what will accompany that day. The unpredictability of Martin’s symptoms in the mornings meets with the disruptions and rhythms of working life.

Sophie works as a makeup artist. Her work has required her to be mobile at times, such as when travelling to venues to do makeup at weddings. This has often meant early starts alongside lengthy travel times, which made her anxious. She explained:

“If I was starting a wedding at ten, I’d be fine because my body is in normal functioning mode. I’d have got up, had my coffee and I’d have gone to the loo, had some breakfast and I’d have been fine. It used to be when I’d be getting up at four or five o’clock to go and do a wedding, everything is out of sync.” (Sophie’s interview)

Sophie's work demanded her to disrupt her rhythm and routine of beginning the working day. This meant that these days caused her to feel *'out of sync'* and thus created further unpredictability. Thus, reiterating the importance and centrality of synchronisation in relation to work and personal time (Southerton, 2006). Because of the early mornings and travel time for her job, Sophie now declines such events and works from her own salon, local to her. Kelly's account echoed this disruption of early morning routines because of work, explaining early morning starts at work *'throw [her] routine out'*. For Kelly, this means she has to use the work toilet which she dislikes due to fear of seeing others in there. Sharon too explained that her mornings were important, but for different reasons. This included the pressures of maintaining a lifestyle that allowed mornings to be slower.

"I always remember this doctor telling me to get up with plenty of time, sit and eat my breakfast slowly and relax but I don't. I just get up, wolf down my breakfast and I'm out the door. Some mornings I don't even have my breakfast because I've not got time so I'm probably my own worst enemy in the mornings because I know I should take my time and relax and not have any like, I usually have the radio on, not even have that on, just silence and just... I know what I should do but I don't really." (Sharon's interview)

Sharon recognises the unpredictability of mornings, and how her doctor advised her to take time to slow down in an attempt to manage her IBS. However, Sharon felt this jarred with the stresses of everyday life. Taking enough time in the morning was a juggling act of getting enough sleep, eating breakfast slowly, and allowing for enough time to get to work. Taking time for IBS is difficult with the structural struggles of everyday life. Here too, Sharon describes herself as *'her own worst enemy'* for not changing her morning routine, placing blame on herself rather than the structures of working life. In comparison, Caroline described the opposite where she takes things slowly in the morning:

"I suppose I've never had a kind of routine where you have breakfast and go to the loo before going to work. I do things quite slowly in the morning, so I have to get up quite early because I do often go quite dizzy, So I allow myself extra time to wake up quite naturally before I jump up out of bed." (Caroline's interview)

Caroline explained that she has never had a routine of breakfast and going to the loo before heading off for work. However, the importance of pacing and slowing down is highlighted here. Charmaz (1991: 161) talks to the intricate trade-offs of *'juggling and*

spacing’, recognising that often maintaining a job calls this into question. Caroline recounted missing work a lot in her diary, taking days ‘*off sick*’ to ‘*recharge her batteries*’ or working from home to cut out the stress of commuting to work without a toilet when her IBS was bad. Caroline revealed feeling bad that she has ‘*the highest amount of sick time off*’ and how she felt frustrated at her efforts to control this.

In accounting for these pressures of ‘*squeezed*’ time (Southerton, 2003), getting up *earlier* became a prominent feature of extending time in the morning, before leaving the home to go to work or to social events planned for the day ahead. For many of us, rising in the morning and having breakfast is often when bowel movements occur. This makes mornings significant and important. When exploring IBS, Molly identified a similar routine to Deborah, allocating extra time for her morning routine:

“If I know that we’re going out and we’re going out early, I will get up a couple of hours earlier, purposely so I’ve been to toilet before I go anywhere. If I get up, say I’m going to pick my friend up at quarter past nine to go swimming I’ll get up earlier, so I know that I’ve been to the toilet before you know. You feel safer because you’ve already been, and that’s it. Sometimes you think you’ve been and then you go again before you go out. But I think if you’ve been before you go out, then you do feel that bit safer.” (Molly’s interview)

Molly and I talked about having ‘*already been*’ and what that means for the rest of the day. There is a security of ‘*going*’ (to the toilet) in the morning *and* in your own home, working as an assurance measure for starting the day and being out the door. Twigg (2006: 119) alludes to this by stating that ‘*Washing, dressing, drinking, eating, excreting mark out and punctuate the day, giving it rhythm and structure; much of our sense of ontological security derives from this bedrock of bodily comfort, comportment and care. It creates routine and regularity at a directly physical level, underpinning our sense of security and ease*’. As Twigg’s (2006) account shows, there is a lot to be said for the certainty gained from our regular routines in getting ready, and toiletry practices form an important part of this certainty with our bodies in the social world. Ellie described a similar feeling of the assurance of a morning trip to the toilet and what it meant for her if this did not happen.

“So, if I don’t go in the morning and particularly if I have a dodgy feeling the night before I think ‘ok the likelihood is, I might have to go at work’. No one actually likes to go at work. It’s not the end of the world but its worst if I have a bit of a sensitive stomach because I know there are lots of people using those toilets.” (Ellie’s interview)

Again, for Ellie, it is not only the morning routine and the certainty this offers, but the preference for the home toilet, compared to the toilets at work. Nettleton *et al.* (2011) highlight the ways in which body techniques of sleep mean there are social norms that specify *when* and *where* it is appropriate to fall asleep. This is something that can be extended to excretion in public and private spheres (Lea, 1999; 2001). In highlighting the preference for these routines in the morning and at home, participants also acknowledged how they *extended* morning routines to account for their IBS. A striking example was from Joyce, who coined her morning with the ‘*eleven o’clock rule*’:

“Had an interesting thought today as I used to have the ‘eleven o’clock rule’. Because everything has changed so much now, it does not apply. My family used to know that no matter how bad I was in the morning, especially early morning that I would be much better and able to face the day by eleven. Not easy when I had a dance performance during the day with a very early start.” (Joyce’s diary)

Joyce and I discussed what the 11 o'clock rule meant for her:

“The thing I found difficult and still find difficult I can get the same violent pains, which I wake up with every morning, I wake up every morning with pain and then I don't know whether it's going to just wear off or it's going to land me in trouble. That's where your first uncertainty comes. I think it's that uncertainty that is the really hard bit. As I said in my diary, my family has the 11 o'clock rule. If I was really bad in the morning, my daughter would ring me up and say, 'Well mum are you coming to us or not? or are you coming on the later train?' and I could pretty well guess as to which way it would be.” (Joyce's interview).

Joyce's personal time in line with her morning IBS symptoms now meets with the recognition from her family. Charmaz (1991: 172) highlights that *'temporal incongruence results when intimates do not share similar ways of thinking about and structuring time'*. However, Joyce's family meet with this restructuring of her morning, finding an alternative practice for her to participate in the day. Julie also identified eleven o'clock as a time for her IBS to have settled down. Likewise, Martin earlier described his symptoms as being in the eight to half ten zone and thus ending by eleven. Prior to retiring, Julie had to wake at five thirty am to get ready for work, building in *'extra time'* to account for the flare of IBS. Since retiring, she now schedules any appointments for eleven o'clock onwards. Julie also describes how the removal of the ticking clock of the time pressures from work has changed her body and thus her IBS. Freund and Maguire (1999: 89-90) suggest that having control over one's time is a form of power. Shifting to retirement passes the allocation and regulation of time from the place and structures of work into, in this case, Julie's own hands. Again, this reminds us of the importance of how a societal clock intersects with the needs of the body and how this can directly affect it. For Terry, who I introduced at the beginning of this chapter, a routine is crucial in managing his IBS and he thus follows a strict routine. He explained:

“Monday 26th February: Morning routine is the same. Part of managing the condition is sticking to a fairly strict routine. This has become easier since I retired. When I was at work, it was far more difficult to manage. I often had to chair lengthy meetings and was often anxious about the possibility of having to leave the meeting to go to the toilet. When you are chairing the meeting, this is potentially very embarrassing. The anxiety about this obviously exacerbated the problem. For many years now, I have never scheduled any appointments or activity around tea time because I usually require a bowel movement at that time. My partner obviously understands this and fits in with this routine. However, over the years it has restricted work and social activities.” (Terry's diary)

For Terry and Julie, retirement has allowed them to (re)negotiate their routines. This brings to light broader questions on the temporal boundaries and structures that govern working lives. In thinking about living with IBS and how retirement has steadied the routine, it is important to think about how time slows down or is made to be flexible. Charmaz's (1991: 162-3) seminal work *'Good Days, Bad Days'* reiterates the importance of juggling and pacing, and the nature of being able to reorganise and control one's schedule. The concept of *'Crip Time'*, borrowed from disability studies, similarly feels relevant in the acknowledgement that society should allow rhythms and routines to be slower, and for the pace to change. As Kafer (2013: 27) argues, *'Crip time is flex time not just expanded but exploded; It requires reimagining our notions of what can and should happen in time or recognising how expectations of 'how long things take' are based on particular minds and bodies...'*. Kafer (2013: 27) argues that rather than requesting disabled bodies meet the demands of a societal clock, *'Crip time'* changes the clock to meet the diversity of multiple bodies and minds. Together with this point of the inclusivity of *'Crip Time'*, the prominent yet taken-for-granted nature of IBS is also significant. The fact that IBS is so common gives further necessity to the importance of societal clocks meeting the demands of diverse biological clocks. This further suggests a resonance and an inclusivity of the spectrum of 'healthy' bowels as well as those with conditions such as IBS. Turning to the last section on the temporal allocation of tasks, I will examine how everyday activities are temporally organised. This includes the (re)negotiations of everyday activities to include the *time* they take, *when* they take place within the structure of a day, and the important intersection of where these happen.

7.4 ALLOCATING TIME

"Today I meet my friend at lunchtime. I prefer to meet people at twelve rather than one p. m. The reason for that is that if I have any IBS attacks, they are almost always in the afternoons, not the mornings. It's most likely in an afternoon, then perhaps mornings or evening. I mean it sometimes happens that I do go to the toilet with a few bowel movements in the mornings, but my pain and bad diarrhoea are normally only later in the day. If I meet people at twelve, then eat lunch back at my desk, I'm less likely to have an attack when I'm with them. I don't buy food in cafes, only drinks, unless I know the cafe has one of the very few things I can eat in cafes." (Kelly diary)

In the quote above, we see how Kelly chooses when to take her lunch break in line with her IBS. This is based on when or where she feels it may happen, and the places that

she feels most comfortable for this to be the case. I have previously highlighted the importance of the macro-organization of the days and weeks in relation to each other and the symbolic importance of the morning routine. To refine this further, it is important to consider the temporal calculations of particular moments of time. This could be the timing of tasks, including everyday activities such as walking the dog, or certain tasks of the body that include taking medication at given times, or scheduling food and digestion. By attending to daily activities and the (re)organisations of time, a story is told of how these tasks are not in isolation, but fitted within broader routines, places they happen, and the material fabric of everyday life that allow symptoms of IBS to be. As Lefebvre and Régulier (1985: 83) stated, *'there is not time to do everything but every 'doing' has its time'*. From the planning of weeks to the structures and importance of mornings, routines and tasks are important in the negotiation of IBS. Here, I reflect on the time it takes to do tasks as well as the allocation of time given to tasks in line with the broader routines of the everyday, based on the diaries and in the discussions. Chapter five draws attention to the importance of the sociality of food and the broader negotiations of this, but it is important to also take a moment to consider the temporal calculation and allocation of food within time as part and parcel of the rhythms, routine, or disruptions of the everyday. For example, Keith talked about his gluten intolerance and how sometimes he mistakenly eats gluten and waits for the effects.

“Lauren: If you eat like gluten do you have something in your mind in terms of however many hours it will be until it affects you?”

Keith: Yeah, I would normally bank on about two hours, from eating something. That's when I start to get that feeling. It would be about two hours. So, I sort of think, 'well, if I know I'm not going to be near a toilet' like yesterday, I'll make sure that if I've got to eat it, I'll eat it relatively late in the day.” (Keith's interview)

Keith describes how he would *'bank on'* two hours of eating to *'feeling it'*. Importantly, this also relates to the places in which he goes because of this. Abrahamsson (2014: 288) argues that *'food produces rhythms, patterns, and temporalities, punctuating everyday life through practices of cooking, eating and digestion'*. Here, the emphasis shifts from eating to digestion, or as we have seen in chapter five, food as consequence (Murcott, 1993). Specifically, in considering the *'consequence'* of food and thinking about excretion, this requires being attuned to the time taken for food to leave the body,

often as a symptom of IBS. Deborah described her careful eating and the temporal calculations for *the next day*, given the plans she had ahead of her. For example:

“I watched what I ate today. Had a slice of toasted cheese for lunch and then for tea I had cold ham with two croquettes, a tomato and some birthday cake. I didn’t want to overload my tummy as I am going to the pantomime tomorrow (the matinee).” (Deborah’s diary)

Deborah also made temporal notes of the times she took medication. She explained:

“Well, I got up at six twenty am and had tea and toast just after six thirty am. I felt fine, but by seven forty-five am I went for two separate motions. At eight am to be on the safe side I decided to take an Imodium, just in case I started having repeated motions (for some reason I always seem to forget how many times when I feel a bit stressed). Another Imodium, Buscopan and passion flower tablet, I was ready to go out about nine twenty-five am.” (Deborah’s diary)

Deborah’s account tells a story not only of the careful monitoring of what she eats, when, and how much, but how food is avoided at times when travel time is an issue. This is seen in the previous chapter on the *consequences* of food (Murcott, 1993), but here I wish to illuminate the temporal dimensions whereby an awareness of this fits within a temporal trajectory. Moreover, Amy describes the journeys home that can be stressful as she needs the toilet. In line with this, Amy documented in her diary that she tries not to go to a restaurant ‘*any further than twenty-five minutes away*’. She also described having to ‘*pick [her] time to go to the toilet*’ when she works at the doctor’s surgery. However, she is constrained due to the public facing nature of being on a reception desk. Similarly, Ellie’s work highlighted the temporal allocation of toiletry time:

“I used to work on a TV show like a shopping TV channel but live TV. I was a floor manager and couldn’t leave. But obviously with my problems some days I would just have to so I would say over the Headset Could someone please come into the studio. Then I would have to say to someone please ‘Can you cover me for 5 minutes while I go to the toilet?’ but then you are impacting upon their work when they have other things to do. Yes, so I’ve had 2 jobs where I can’t easily leave to go to the toilet. If I know I’m going to have a bad day I may tell my boss at the beginning of the day, hey I may need you to come and cover for me cause if I run in at some point and they will say it’s fine.” (Ellie’s interview)

Again, Ellie’s account reiterates the importance of having control over one’s work environment, the structuring of working time and the time allowed to leave for a toilet

break. As with flexibility in the morning routine and the pace of such, being able to take time out is made visible.

One daily errand that drew particular attention to the allocation of time to do an activity and the time of the day in which this happens was dog walking. As mentioned earlier, Terry's daily routine had changed since retiring, and he now takes things more slowly. For Terry, he finds routine and predictability are the best way to manage his IBS. Walking his dog Bertie is part and parcel of his everyday routine, and Terry's and Bertie's routines now work together. Terry and I talked about how their days together unfolded. I asked Terry about the routines of walking with Bertie:

“Lauren: With taking Bertie [the dog] for a walk, do you factor in the time of the walk?”

Terry: Yes. I factor in what time I get up and what time I need to go to the toilet before I take him out. I make sure I go twice before I take him out in the morning. I wouldn't dream of not doing that. I wouldn't be able to. So yeah. That's an issue. I always take him out and get back by about half-past four just in case. Teatime bowel movements has kind of eased since I've stopped working but I used to always have a bowel movement around tea time when I got home from work, always, but that's, I'm never quite sure if I'm going to or not so I wouldn't be out with him after half-past four, do you know what I mean?”

Lauren: Yeah. I suppose it's a routine, isn't it?”

Terry: It's just there, I suppose for anybody else, that would be an issue. It's automatic; it's just what I do and part of my life. It's become that over the years because it's been going on for so long, really.” (Terry's interview)

Dog walking draws attention not only to the time and places in which it happens. In caring for the toiletry needs of one's pet, there is often a recognition that one's own needs cannot be accounted for in this social context. Walking the dog often requires visiting a green area such as a park or a woodland where toilets are often not present. If walking the dog alone, there is the responsibility of leading and holding on to the dog which means one cannot leave to visit the loo if needed. Similar to Terry's routine dog walking, Rosie drew attention to this as important in her life and how this everyday practice demanded a rethink of negotiating her IBS symptoms:

“Tuesday 9th January: I walked the dogs today as I don't like sitting down doing nothing for one day, let alone two. I don't take any precautions; I just need to time it right so that I don't have to suddenly rush off home. However, I did pick

the normal circular walk around my immediate area rather than something a little further afield, it would be just my luck that I get too confident and start to panic about something going wrong whilst I am away from any toilets etc and panicking does not do my IBS any good whatsoever!” (Rosie’s diary)

Rosie’s account is not simply a dog walk that features as part of everyday routines, but a walk that she ‘needs to time right’ to prevent a limited walk in case of the onset of IBS. Furthermore, the practice of dog walking requires a specific place, route, and time. Rosie and I discussed this in our conversation:

“If I’m feeling not that great, I think I mentioned it on the first or second day, sometimes I might not go out at all. Other times I will just go for a short walk. It depends on how I’m feeling, or I don’t tend to go directly after eating and that sort of thing. Because I have Basset hounds, they are so stubborn it’s unreal, so if I was in a panic and I was like, ‘oh no I’ve got to go home’ then it’s really awkward to get them to run with me [laughs] they like to sniff everything so trying to take them for a walk is a long process, so rushing off isn’t really an option. I’ve sort of just timed the walk round stuff that I, like eating or if I’m not feeling very well, I might not go out at all.” (Rosie’s interview)

Tony also highlighted dog walking and how this daily practice brought to attention the disruption of IBS symptoms.

“Last post for Monday 30th of April, it’s half past 8, bad symptoms all afternoon, I’ve had stomach cramps, diarrhoea, did try to go for a walk with the dog and my wife but had to turn back because the stomach cramps and the urge to go to the toilet was too great.” (Tony’s audio diary)

We discussed dog walking in Tony’s interview:

“We take him [the dog], there are some nice woods near our place, so we take him into the woods in the summer, in the winter we tend to go around the estate or into the park about a mile away. Normally I’m fine but a couple of weeks ago, we were halfway around our normal walk and I said to her, ‘we need to head back because I’m starting to get pre-symptoms’ so I’ve had that before but because I tend to stick to the diet, you do sometimes have random attacks for no reason, you tend to get the light symptoms so you do know when you need to get back, it’s only when you eat something that you shouldn’t that you get the instant attack.” (Tony’s interview)

The accounts of dog walking draw attention to the *timing* of the walk and its *duration*. This builds upon two of Fine’s (1996) dimensions of time – the time allocated within a specific time frame and how long for. Southerton (2006: 436) suggests that Fine’s (1996) dimensions of time and Adam’s (2000) ‘*timescape*’ framework offer an explicit

recognition of time's complex formation. Specifically, time is not only a metric, but its multiple dimensions tell us about the rhythms of everyday life. From the temporal calculations of food and taking medication to the routines of dog walking, attention has been drawn to the everyday practices that feature within our day that IBS shifts and reworks. These activities demonstrate how the body meets the social world and the environment, but importantly, the role of time in deciding when and how long and in what space something can happen. Again, the timing of tasks involves the demands of humans and non-humans, public and private spaces, and how these are intertwined and renegotiated to accommodate the symptoms of IBS.

7.5 CONCLUSION

This chapter has engaged the (re)organisations of time and everyday routines when living with IBS. As Scott (2009: 69) argues, we engage in mundane activities on a daily basis, taking for granted the routine predictability. IBS challenges and reworks this certainty. In line with this thesis, this chapter has worked at giving light to the ways in which IBS shifts these routines, but also engages with temporal rhythms that represent everyday life in both regularity and disruption. For those with IBS, the mundane activities such as the early morning rises and walking the dog are anticipated, (re)structured and (re)imagined in line with an unpredictable bowel. In starting with the broader biographical changes to the shift in the smaller everyday practices, this chapter has shown how ticking clocks and temporal organisation are important in the daily experiences of IBS.

This chapter has addressed these everyday practices in three ways. First, I have illuminated the regularities and the disruptions of weekly routines, told through days of significance such as Shaun's Tuesdays and Amy's Thursdays. This explored not only the periodicity of symptoms within a week, but the broader temporal rhythms of the body and the bowel. As Adam (1992: 157) states '*we also are clocks*' and the rhythms of our bodies need to be acknowledged alongside the ticking clock of the socially constructed environment. Participant accounts have demonstrated how the bowel is imagined as '*like clockwork*', alluding to the regularity, disruption, and repetition that IBS brings for participants. As such, I extend theorisations of biological time (Earle and Letherby, 2007; Adam, 2004) to be inclusive of the bowel.

Second, this chapter has focused in on morning routines in an attempt to show the (re)organisations of time within daily life. I have emphasised the negotiations of time being ‘squeezed’ (Southerton, 2003; 2005) and how the social pressures of time demand a reworking of routine or an extension of time in order to accommodate the symptoms of IBS. I illuminated this through Joyce’s ‘11 o’clock rule’, which demonstrated how morning readiness and the time necessary to attend to the bowel is reimagined, paced, and accommodated. This builds up understandings within chronic illness, such as Charmaz’s (1991: 164) suggestion of juggling and pacing that allows social participation in light of illness and Kafer’s (2013) ‘Crip Time’ which suggests an appreciation of the diversities of bodies and the time we should allow for them. This also offers a broader contribution by stressing the importance of how the taken-for-granted and private morning routine fits with the public and structural working schedule. Namely, the pressures of getting to work on time and the stresses of everyday life are inextricably bound up with the ‘biological’ necessities and rhythms of our bowel, and structures should recognise this. Moreover, this chapter on routines, like food, demonstrates how flexibility and accommodation within everyday routines is necessary in light of unpredictability.

Third, this chapter has explored how daily activities are temporally located and (re)organised. In particular, I offered fragments of examples where eating is temporally located, medication is taken anticipating future activities, and calculations are made of the body. In working to demonstrate how daily activities are prescribed by the pressures of IBS, I offer accounts of dog walking. This daily encounter has worked at illuminating how tasks are governed, by who, where, what, how long, and with whom. This draws attention to the organisation of daily tasks and how these are met with the demands of others. This extends sociological theorisations of time, drawing upon the distinctions of periodicity, sequence, duration, and pace (Southerton, 2006; Fine, 1996). It does so in a way that recognises the regularities and disruptions of IBS, offering a narrative not only of the mundanities of routine, but by also offering careful attention to the discrete ways symptoms can (re)organise time.

What this chapter also achieves, is an appreciation of an everyday clock that has in the large, been glossed over due to its situatedness in our private lives. That clock is the one of the bowel. We have seen sociological contributions into temporal practices of

sleep (see for example, Coveney, 2013; Nettleton *et al.*, 2011; Williams, 2011; Meadows, 2005) and eating (Abrahamsson, 2014), but '*toiletory time*' (Inglis and Holmes, 2000) demands further attention. Taking IBS as a focal point, there is access to a feature of everyday life that would otherwise be behind closed doors, and without any attention. It is only through the times of disruption and the (dys)appearance (Leder, 1990) of the *bowel*, that we can see how the societal structures of routine rub up against the temporal structures of the clock of the bowel. It is within this that we can see the (re)organisations of time and the ordering of everyday life. In locating this 'private' side of our routines and organisation of daily life, I now turn attention to '*ordering of privacy*' (Twigg, 1999) that happens whilst living with IBS. Just as mornings were of importance here, the routines of our bowels before leaving for the door, so are the private and intimate ways in which we negotiate this.

CHAPTER EIGHT

FROM THE HOME TO THE (HAND)BAG: NEGOTIATING INTIMACY AND PRIVACY

8.1 INTRODUCTION

“I mean there have many of times I’ve got Cath [sister-in-law] out of the shower. My brothers gone in shower, then I’ve gone in shower and they’ve only got one toilet. I’ve gone in shower, come in and sort of had some breakfast. Cath’s had her breakfast then she’ll go in shower and she’ll always say ‘Anyone want to go before?’ you know, me brother is same as me, ‘no we’re alright, we’re fine’ and then she’s gone in shower and like, ten minutes after you think ‘oh, I’ve got to go’ so I’m banging on door ‘are you gonna be long? I’m coming’ [laughs]. There have been so many times where she’s got shampoo on her head and got out quick.” (Molly’s interview)

In the account above, we see the intimate geographies of sharing one of the most private spaces within the home – the bathroom. Molly’s account details the disruptions to routines in family life and everyday practices when living with the unpredictable symptoms of IBS, told through the sharing of domestic space. Together with her brother and sister-in-law, Molly presents the intimacies of everyday life, showing the close associations, privileged knowledge, and trust with intimate others (Jamieson, 1999). This is told through family life, the home, and specifically, the bathroom. I start with this account from Molly to take us to this private side of life and the multiple ways in which space and privacy are negotiated. Molly presents an open and honest account of the intimate side of family life and the sharing of bathrooms. However, throughout this chapter, I will explore the nuances of intimacy and privacy, demonstrating the ways in which this is negotiated. I speak to this through moving from the home, to the (hand)bag and then to public life.

As I have argued earlier in my methodology chapter, diaries were important for offering an opportunity to reveal ‘private’ moments that are otherwise inaccessible, particularly when they are in the home and in the most private spheres. The diary guidance asked

participants the extent to which they spoke about their IBS, including with partners, family members, friends, work colleagues, and even ‘strangers’. Similarly, the diaries questioned the items of importance including toilet roll, spare change, and medication. These items work by tying in the private negotiation of managing symptoms. Questions of the home were attended to as an important feature of daily life. In considering this, this chapter seeks to explore some of the more *intimate* and *private* aspects of negotiating IBS, told through the moments that may be ‘*behind closed doors*’ (Lewis, 2011). This chapter explores the intimacies of everyday life, demonstrated through the accounts of negotiating IBS and how privacy is obtained. I will consider the ‘*ordering of privacy*’ (Twigg, 1999) in daily life. I start with the intimate geographies located within the home, moving this privacy to the handbag and then out to the public encounters.

Firstly, I will explore privacy within the domestic sphere. This includes the negotiated geographies with intimate others and one's own homes, but also visiting or sharing homes. Secondly, I will capture some of the ways in which security and privacy is obtained through the intimate things that are carried when going and about. Drawing upon Buse and Twigg's (2014) work on women living with dementia that examines the role of their handbags as an anchor for ‘*ontological security*’ (Giddens, 1991), I will establish connections with those negotiating IBS as the items carried offer comfort and security. Through the participant accounts of private spaces and personal things, this chapter teases out the intersections between materiality, mobility, and the ‘*ordering of privacy*’ (Twigg, 1999). These accounts work at demonstrating the spatial and material ways in which certainty is established in the presence of unpredictable and hidden symptoms. Furthermore, I will highlight how these intimate belongings become a central feature for those living with IBS – the spare tissues, the medication, and the radar key kept safely in one's presence. Thirdly, I will attend to the ways in which privacy is established, sought out, or *transgressed* (Gurney, 2000a). In particular, I will draw upon an example cited by many participants – the hairdresser's. Accounts at the hairdresser's work at providing an insight into the movement into public yet intimate spaces in the proximities of privacy that become apparent to those who live with IBS.

This chapter draws upon multiple bodies of literature. Primarily, the chapter engages with the ‘*ordering of privacy*’ (Twigg, 1999) as it moves from the private geographies

of the family home, through to the private belongings people carry and the public yet intimate encounters that bring privacy to the fore. Similarly, this chapter builds upon Buse and Twigg's (2014) work on handbags by demonstrating the privacy and 'ontological security' that they offer (Giddens, 1991). Here, I offer a unique contribution by extending Buse and Twigg's (2014) work to those with IBS, as well as incorporating the unique objects that feature in the everyday lives of the participants. However, I also include the suit jackets, car boots, and the laptop cases highlighted by Tony and others. The chapter contributes to understandings of intimacy (Jamieson, 1998, 1999) and intimacies in family bathrooms (Lewis, 2011; Gabb, 2008). Similarly, it offers further contributions into the sociology of the home (see for example, Mallett, 2004; Robinson *et al.*, 2004; Gurney, 2000a, 2000b; Madigan and Munro, 1999; Allan and Crow, 1989) and the sharing of living spaces (Heath *et al.*, 2017). Broadly, the chapter offers an understanding of living with IBS, calling into question the daily practices of privacy within the home and beyond. Finally, it offers an insight into the geographical and material ways in which intimacy and privacy is obtained.

8.2 GEOGRAPHIES OF HOME AND SHARING

“Within 15/20 minutes of finishing lunch at home I urgently need the loo - it's always diarrhoea, and the smell is embarrassing. Luckily, I work from home, so I am able to clean myself up after the event - soap, water, towel, but it leaves me so drained after it happens. Generally, I need a spell of lying or sitting down. I guess my stomach is in shock from this pooing trauma! I had to open the windows this lunchtime after I'd been. Mum commented it was cold, I said it's to clear the stench. It's still embarrassing, even with your family.” (Shaun's Diary)

In Shaun's account above, he describes a moment in the day when his IBS affects him. However, in the allusion to his mum commenting that the open window left her feeling cold, there is an acknowledgement of who is living at home and the sharing of space. In many of the diaries and in some later interviews, participants gave accounts of the private and intimate nature of IBS. This is something which is typically hidden from public life and everyday discussion, and which happens 'behind closed doors'. Lewis' (2011) work into locking the family bathroom door and the negotiation of bodily boundaries as children move into adolescence demonstrates the importance of solitary time. Like Twigg (1999), Lewis (2011) describes the bathroom as one of the few rooms

in the house where the door is closed and often locked. As Rosie described, encounters in talking about IBS with family are often *through* the toilet door. She recalled how her mum ‘*whispers through the toilet door, “are you ok?”*’ before returning downstairs.

First, in considering the intimate nature of IBS symptoms and the practices of everyday life, being at home is increasingly important. As Heath *et al.*, (2017: 21) suggest, ‘home’ is a place where seclusion is to be expected and is tied up with domestic privacy. For many, there was no place like home when negotiating their IBS, due to the comfort and privacy of their own bathroom, or the ability to sleep, rest, and relax. Many participants were relieved or glad to be ‘at home’ should symptoms arise. Caroline explained:

“Being at home is always calming to my system... I always have a sense of relief when I get home after work as it means I have got through the day and I am in my safe place and I can relax. I do not need to worry about it when I am at home.” (Caroline’s diary)

Caroline describes being at home as a ‘*safe place*’ that is stripped of worry and is secure. For her, being at home is like she is ‘*in [her] little cocoon*’. Like Caroline, Amy’s diary stated she also relaxed more at home, due to there being two toilets and nothing to worry about ‘*like there is in public*’. This safety and security correspond with Giddens (1999: 92) concept of ontological security, which he refers to as:

‘The confidence that most human beings have in their continuity of self-identity and in the constancy of their social and material environments. Basic to the feeling of ontological security is a sense of the reliability of persons and things.’

This comfort and ease that the home brings to those with IBS speaks to the privacy that a home can hold. These accounts echo King’s (2004) theoretical contributions on privacy within the home, whereby the home constructs a boundary between the public and private spheres. These divisions spatially separate individuals, provoking further questions about who we have to or feel able to share intimate details with. Second, in the idealisation of home as a place for privacy, the dynamics of family life are often played out through the accounts of living with IBS. This relates to Twigg’s (1999) work on the ordering of privacy, with a specific focus often being on the bathroom as one of

the most private spaces within the home. However, the privacy within this space is also relational between family members. Accounts of sharing and the geographies of the home and of domestic space are acknowledged in the literature (see, for example, Mallett, 2004; Robinson *et al.*, 2004; Gurney, 2000a, 2000b; Madigan and Munro, 1999; Allan and Crow, 1989). These geographies within the home are made present throughout the accounts of those with IBS. King's (2004) exploration of privacy in terms of the home and the domestic sphere implies a state of being *undisturbed*, with private space being personal, restricted from knowledge of others, and secluded. Participants echoed this allocation of space and uninterruptedness in the following accounts:

“Lauren: So, does he know if you are having a bad morning?”

Brenda: He just ignores me; we just ignore one another. Yes. If I have to go in the loo, he knows. We've two toilets, it doesn't matter.

Lauren: Do you have a toilet each or?

Brenda: No, no, it's just whoever's in one. If I'm downstairs in this one, and doors closed, I'll shout, 'I'm in' and he'll go 'alright, I'll go upstairs'. We don't argue about it. [laughs].” (Brenda's interview)

Brenda and her husband have an intimate encounter whereby they acknowledge one another but limit such interaction. They are co-present and in each other's company, but consciously inattentive (Goffman, 1956). Rosie also acknowledged the divisions of toilets within her household. Rosie described how she and her partner have two bathrooms which include a main bathroom and an en-suite. For them, sharing is unnecessary. Like others in this study, Katie discussed the desire for privacy within her home and chooses the toilet *'furthest away'* from her partner. Katie also highlights the practical challenges of finding a home, particularly the comfort found in *owning* a house with multiple toilets. This offers further insight into the potential juggles and what it means to share domestic space.

“I'm quite lucky at the moment because we've got two toilets and there's only two of us living here so it's perfect really. So, I never really have to worry at home. I'm quite comfortable in front of my partner and I know if I need the toilet, I'll just go in the one that's furthest away. We have been looking to buy our first house last year and one of the things that I really wanted was two toilets so I

think, I've come to realise that I don't think we'll be able to afford a house with two toilets in our budget so that could be a challenge, if we do ever move house, but when it's just the two of us, it's fine because I feel really comfortable in front of him but it's if we have people staying over, then I get worried about 'What if they're in the toilet and I need the toilet?'”(Katie’s interview)

Despite Katie saying she felt comfortable with her partner, she still explained that she chose the toilet furthest away to grant herself privacy. Beyond intimate partners, there is an ordering of privacy between people in the home. Julie echoed Katie’s concerns regarding the sharing of space when they had visitors. She explained that if someone stays with them, they have an upstairs and a downstairs toilet. Julie explained that she tells her visitors that if they hear her up in the night and going down the stairs, it is to visit the toilet. She stated,

“I won't go into the toilet upstairs when they are upstairs. I will go downstairs to the downstairs toilet. So basically, you allocate yourself a toilet and they steer clear of it [laugh].” (Julie’s Interview)

Twigg (1999: 384) unpicks these notions of privacy within the home and the boundaries of exclusion. She suggests that *‘friends and relations who come to the house do so on a privileged basis as guests. Restricting access to people and to certain times allows you to conceal the ways in which your life falls short of the domestic ideal’*. Friends or acquaintances staying over in your domestic space disrupts this limited access, working to remind participants of the potential of IBS and its disruptions. On the other side of this, many participants highlighted the challenges of visiting or staying over at someone else’s house, even with relatively immediate family. Deborah and I spoke about this:

“Lauren: How is it staying over at people's houses?”

Deborah: It was very good this time. I was a bit worried especially when they've only got one toilet you know. I was fine though but of course on Christmas eve I started with the tablets didn't I. We stayed for two nights. I find it difficult when people come to our house to stay because we've only got one toilet. I used to be terrible. I hated it when anybody went to the toilet, I didn't want anyone else to be in the toilet in case I needed to go. That happens still a lot in the morning now, often my husband has to get out when he's getting shaved and that, he has to come out of the toilet because I can't wait. That still happens. That's what bothers me when people come to stay. How can you knock? A few years ago, I was getting panicky about that, I just worry. We've got some friends down south, now they know what I'm like and they've got more than one bathroom, I feel better if there's more. If we go away on holiday, we can't just have one, I feel

better if you know as a family that we've got plenty of bathrooms, that's my stipulation." (Deborah's interview)

The anxiety of visiting others centres on the spatial ordering and the bathroom being a 'semi-private space' in an upstairs zone, with strangers visiting only on 'license' (Twigg, 1999: 392-3). Deborah relates and builds upon this in relation to her own home, where disruptions happen, and the sharing of space is negotiated with her husband. Deborah again draws attention to the balancing act of sharing of a family bathroom, the geographies of home and the disruptions to daily routines. This is made visible through her account of her husband's shaving while she interjects to use the toilet. Deborah's account highlights the importance of multiple toilets when sharing with others. Multiple bathrooms increase the likelihood of establishing privacy and minimising disruption. Similarly, Shaun talked of a time where he went away and used 'Airbnb'³². This meant he stayed in another person's home and attention was drawn to using their toilet and what this meant for others there. He explained:

"I once stayed in an Airbnb a couple of years back when I went to a sports ground, but I was really paranoid about it. It was like living with my mum and dad but somewhere else. I wouldn't do the Airbnb again when they live there, because of the IBS it's embarrassing, you know? It's alright when it's your own family but when it's in a stranger's house. I stayed with this couple. I wasn't worried about it before I went but I was very aware of it whilst I was there. I thought, 'oh my god' because I went out of the bathroom and went back in and thought, 'ooh crikey, how do I get rid of this smell?' It was a shared bathroom with the rest of the house. I think they had a daughter that came back at the weekend so there were more people there at that particular weekend. I stayed from the Thursday to the Sunday so there was quite a house full of people, so I thought I won't do an Airbnb again when it's with a family. Like I say, previously, I would have never given it a second thought." (Shaun's interview)

Unlike some accounts that draw attention to the intimate geographies within one's home, Shaun compares the sharing of intimate domestic space in his account of using Airbnb with another family to the experience of sharing with his own. This reflection drew attention to how his IBS changes the sharing of domestic space in a way he had not considered before. As a result, he opts out from doing an Airbnb. Scholars have

³² Airbnb, Inc., is an American online marketplace and hospitality service. Members can use the service to arrange or offer lodging, primarily homestays, or tourism experiences.

begun to research what companies like Airbnb mean for divisions of space and sharing (Pechurina, 2019) and questions of accessibility (Boxall *et al.*, 2018). The case of Shaun further demonstrates the phenomena of sharing domestic space but draws particular attention of the social importance of the intimate sharing of the most private room in the house – the bathroom.

Another key factor related to the entering of ‘*unfamiliar territory*’ but the homely and intimate spaces of others is the effect that this has on the bowel specifically. There is a direct disruption to the functions of the body in which medication is taken when one cannot guarantee comfort or privacy in a space. For example, Katie talked of a particular time as a child where she went on a foreign exchange trip:

“I had it throughout high school and then I had a particularly bad experience, I used to be obsessed with taking Imodium. I went on an exchange when I was 15, I think. I was so nervous about having to use the toilet at their house, so I just took Imodium for like days and days and then obviously then my system was like, we need to get this out and then the opposite happened. We were on this coach trip with all my classmates, and they had to stop the coach. I think that's why I don't like travelling. I remember that experience.” (Katie’s interview)

Like Katie, many of the participants actively took medication to prevent toilet trips in spaces that were not their own. Sometimes, needing to use someone else’s bathroom was unavoidable. As Tony used to work as a gas engineer, he was frequently mobile and visited customers’ houses to perform repairs. There were often times when he needed to use their toilet. He recalled one time that whilst on a visit; he asked a customer if he could use her toilet.

“Lauren: in your diary you mentioned it is difficult to go into people's homes and stuff. Is that something that was bad? Do you still do that now?”

Tony: Yep. It's not too bad, I find if, when I'm working for myself, you can just nip off, say 'oh I need to pick up some bits' you always get the pre-symptoms, you know when it's coming. So, I'll nip off, if I'm near home I'll go home or if I'm near a supermarket, I'll nip there. I can always remember as a full-time gas engineer negotiating with a woman, I told her I had IBS and she wouldn't let me use her toilet, she had a water leak coming out of the ceiling, I said 'I'm not going to be able to repair your water leak' after negotiations I got given a pair of rubber gloves and some bleach and she watched me clean the toilet after [laughs]. I've had one extreme to the other, when I came back from New York last time, a couple of years, it'd gone straight back to work rather than giving

myself a couple of days off, and medication more often. I said to the guy, "I'm sorry but can I use your toilet? I've got an illness so I may be in there a while" and he was fine about it, he went off to make a cup of tea and watched some tv. About an hour later, I resurfaced." (Tony's interview)

Tony's account of visiting the customer's houses offers both a harrowing account of being made to clean a person's toilet whilst being watched, to the more compassionate experience of another client going off to make a cup of tea and allowing for that privacy – a performance of the desired *civil inattention* (Goffman, 1956). Tony has now changed roles to plan things himself. Many participants expressed the desirability of working from home as a way of ensuring this privacy and lack of surveillance. Tony's experiences as a mobile worker also show the blurring of boundaries between public and private. Tony's workplace was another person's domestic space.

Finally, what is *in* the home is also of importance. For example, knowledge not only of a private toilet, but a knowledge of where items may be in the bathroom. Where do you turn for a new roll of toilet paper? Is there a toilet brush to clean? Where is the air freshener to spray upon leaving the room? Julie explained this issue:

"...you just think, at home, you know where everything is, like the toilet paper and all the stuff, air fresheners, you name it, you know where it all is. If you go to someone else's house, they might not have those sorts of things" (Julie's interview)

This again relates to the ontological security that objects in the home can offer (Giddens, 1991). Carl discussed a similar issue of items within his own home and that of others:

"I don't really stay over at people's houses, to be honest. On the odd occasion that I have done, or I've been at my mums or whatever, and been to toilet, it's a bit embarrassing if they've not got a toilet brush, know what I mean?" (Carl's interview)

Carl's account demonstrates the intimacy of knowing *where things are* in intimate spaces within the home. The assurances obtained from knowing where things are at home and knowing how IBS symptoms *are*, leads us on to the next section where items of importance are carried from the home and into 'public' life.

8.3 INTIMATE BELONGINGS

Normally, I carry like a little emergency wash bag with me. It's got a spare pair of knickers, some wipes, some hand gel, some spray, you know, just in case. It's another reassurance.” (Carly’s interview)

As Twigg (1999: 397-8) states, ‘*Home is about privacy, security and identity. It embodies the self, both in the sense that it is the concrete extension of the self and in that it contains and shelters the self in its ultimate form of the body*’. When leaving the home, the reassurances that offer privacy and security move to the bags and pockets we have amongst our presence. This section will show how bags and pockets can provide insight, by *opening up* the private navigations of those with IBS. To facilitate this, I draw upon Buse and Twigg’s (2014) work that has explored the role of (hand)bags for women living with dementia in their care homes. Through the study of (hand)bags, Buse and Twigg (2014) drew attention to their role in negotiating identities, memories, security, and privacy. They theorise the capacities of (hand)bags through Giddens’ (1991) ontological security’. This captures an appreciation of the role of things and how they are close to us, familiar, and how they work at making us feel comfortable and safe in our everyday worlds. Miller’s (2008) title ‘*The Comfort of Things*’ feels relevant in the application of ‘stuff’ that people value and hold dear in the navigations of IBS. These material belongings often coincide with the mental planning of toilet availability and access. Participants wrote about the importance of knowing where toilets were in their diaries, but this was also made evident within the interviews as they often opened their bags and revealed the things they carry as part of this too. Many of the participants discussed carrying things around in their pockets, purses, bags, or even car boots: antidiarrheal medication, radar keys to grant access to disabled toilets, spare change, underwear, ‘safe’ foods, and peppermint tea to soothe them whilst out. To return to Miller (2008), there is something to be said for the *agency* that these objects hold, alongside the affect and reassuring capacities they carry. Namely, objects can affect us. For those with IBS, they can feel reassured in the potential and the security of having such things on their presence wherever they go.

Here I pay attention to previous theorisations of (hand)bags and their importance within public and private lives. Henderson (1975) draws upon Goffmanian terminology and

argues that (hand)bags work as ‘props’ by creating privacy in often public spaces. Buse and Twigg (2014) suggest that (hand)bags shed light on and trouble the symbolic and material divisions of public and private space within care homes. These (hand)bags hold and work to retain privacy for those they belong to. This extends to the material culture of the (hand)bags, pockets, and glove boxes of those living with IBS that also works as an important portal to feeling secure and enabling privacy whilst experiencing or anticipating symptoms in public life. Many of those who wrote diaries and spoke in interviews revealed their items of importance. Deborah was one of those who revealed this during the interview:

“Lauren: Do you always have stuff in your bag?”

Deborah: Yes. [shows me her bag] I’ve got Imodium, I’ve got Buscopan, I’ve got toilet moisture wipes, I’ve got a pad, I’ve got another pair of tights and rescue remedy. That’s all. They’re always there. I know it’s daft, even when I go to yoga, I take out my wipes and that and put them in that, but nothing ever happens, but I put them in my holdall bag that I put my blanket and everything in. But then, it’s happened the next day, it happened once where I forgot that I’d taken them and put them in my handbag. I didn’t realise until I was in town. I can’t remember what I did. I just think I went and bought some more moist wipes, that was all. That was all I did.” (Deborah’s interview)

The awareness of not having these items when bags are swapped or forgetting about them only works to reiterate the value of their presence. This echoes Scott’s (2018) work on the sociology of nothing, where thinking about what is not there requires a thought into quite the opposite. Here, the absence of the wipes and the medication in Deborah’s bag works to reiterate the importance, reassurance, and capacities of their presence. Similar to Deborah was Joyce, who wrote in her diary that she realised that upon changing (hand)bags, she kept loperamide ‘*in every bag and in some coat pockets*’. Joyce referred to this practice as her ‘*safety blanket that [she] clings on to*’, located within the uncertainty of IBS. Similarly, Julie documented that she also carries a radar key, ‘*Can’t Wait*’ card, and has additional ones in both her car and her husband’s. Julie also explained that she kept a ‘*good supply of paper towels, wet wipes, plastic bags and medicine in the car*’. Discussing this in the interview, Julie explained this practice further:

“Lauren: I noticed in your diary too you said about having the radar key and ‘Can’t Wait’ cards, in both cars as well. Do you use them a lot?”

Julie: Yes. Well, I haven’t used the card because I think really, I’m a bit ashamed of it and I don’t know how people are going to react if I go and produce it. You don’t know if those people have seen it before anyway and if they are going to go up and say, ‘what’s that?’ but yes, I have used the radar key. The place that I’ve used it most is in the station like the train station, because I used to commute, I used to commute for work, I did used to use it there. It’s just being armed; it’s just knowing you’ve got all the other things in your car or in your handbag that can help if you need them.

Lauren: So, what kind of things would you carry in your bag? And would you have them at all times?

Julie: Yes, in my handbag, I have wet wipes, tissues, things like that. I always have sheets of loperamide, those keys, just anything I can think of. I’m not as bad as I used to be since I retired, I have to say. I don’t have to worry as much, as I’m never far from home. But you know like, at work, I always had you know, underwear, all that sort of thing. Just, things that you think you might need.”
(Julie’s interview)

Here, Julie explains several important points about the things that are carried and the private nature of such. Despite having a ‘Can’t Wait’ Card, Julie explained that she has never produced this in public due to fear of what people may think. However, Julie described having both the radar key and the ‘Can’t Wait’ card as ‘being armed’. This suggests the potential for others to attack her based on the invisible nature of IBS, and thus question her legitimacy. Caroline also explained that she carries a ‘Can’t Wait’ card in her bag, explaining it as ‘not used as yet’ but ‘there for reassurance’. This feeling of ‘having’ but not ‘using’ relates to the theorisation of the dormancy of objects. Woodward (2015b) suggests that objects lie dormant because they hold within them past experiences or anticipated futures. In the objects discussed here, there is a weight of past experiences of using items for IBS symptoms, but also an active and material reassurance in their presence should symptoms arise in the future. Katie also echoed this in her interview, explaining how she carried spare tissues, wet wipes and a toilet spray, but rarely uses them. Sophie opened her bag during our interview, revealing a small toiletry pouch that contained rescue remedy spray³³, Imodium, Rennie, Gaviscon, and Buscopan. Sophie said that her wipes ‘go everywhere with [her]’ and again said,

³³ Rescue remedy is a herbal/floral supplement aimed at providing comfort in stressful situations. For more info see: <http://www.bachflower.com/rescue-remedy-information/>

'it's just one of those things, a comfort thing' that *'you don't always need but is nice to have'*. For all of them, there is an emphasis on the *presence* of objects wherever they go, and the capacity for these to negotiate their IBS establishing security by minimising disruptions and maintaining individual privacy in public spheres.

Along with the items used or carried that work to help manage toilet trips, several participants cited having particular food items stored in their bag. Carrying items of food in one's bag worked as a strategy for avoiding awkward questions around diet, as well as the prospect of being offered food that was incompatible with their IBS. For example, Stacy explained in her diary that in her bag she kept a bottle of water, small 'non-sugary' snacks, painkillers, and peppermint. Stacy has regular snacks in her bag as she feels that a strict routine regarding eating is the best way to manage her IBS. Stacy is also a lodger and when she stays at the host's house, she often takes a can of soup in case the host cooks something she cannot eat or at a time not appropriate to her routine. Similarly, Kelly described her experience:

"Lauren: I think you mentioned in your diary as well about maybe having things in your bag like spare food and stuff.

Kelly: Oh yeah, I have marmite sandwiches everywhere I go. I literally go abroad with marmite sandwiches for the plane, just in case I get hungry and there's a delay or something because I can't just go to Starbucks and get a roll, you know? There might not be anything that I can have. So, I just make sure that I've got something really simple – bread and marmite or crackers or something in my bag. Just in case I get delayed, or the journey is too long. Yeah, if I'm going somewhere and I think 'oh there might be food but there might not be' then I'll put something in my bag and I can always nip out for ten minutes and no one will miss me and I can just eat something in the car park. You know just all of these scenarios go through your mind but you kind of just have to make these contingency plans, just in case." (Kelly's interview)

Items kept *'just in case'* and items that lay dormant (Woodward, 2015b) in the privacy of people's bags offer further insights into the anticipations and uncertainties of living with IBS. Buse and Twigg (2014: 18) in their study of handbags stressed how their participants held on to their handbags, clutching them to their body in times of *vulnerability* (Hagerty, 2002). Buse and Twigg (2014) relate the security and privacy obtained from the contents of a handbag as part of *'ontological security'* (Giddens, 1991). We can draw parallels here in the accounts of IBS, whereby the contents of the

bags also work to provide comfort, privacy, and security. There in the internal pockets of the (hand)bag lie a private space in which individuals with IBS can negotiate their external world.

However, it is important to draw attention to the gendered assumptions of (hand)bags. (Hand)bags have been theorised in terms of their importance for women, further compared to the private and contained nature of their bodies and of the ‘baggage’ carried that is related to motherhood (Buse and Twigg, 2014: 16). There were nine male respondents in my study. It is important, therefore, to consider men’s experiences of their specific intimate belongings too³⁴. Tony, Shaun, Terry, and Martin all spoke of material items of importance and said that they also carried similar items, albeit in different ways. For example, Tony explained he carried medication in his suit jacket, laptop bag, car glove box, and the boot of his car. Given the context of Tony’s work that requires him to commute on long journeys regularly, the placing of these items within the private spaces of the car is significant. In this scenario, the glove box works in a similar way to how a (hand)bag might, where the door to the glove box, much like a zip or the clasp of a bag, covers a space that is otherwise *private* and *closed*. Tony and I discussed this further:

“Lauren: I noticed that you said you had peppermint tea packets on you and stuff.”

Tony: I have yeah. I’ve got some in my boot, I’ve got some in my golf bag, I have it everywhere. It’s the same with my medication. I keep tissues and stuff in my car, but I’ve never been, I’ve always found that I’ve managed to get to a toilet, so I’ve probably got a bit lax with that, but I did used to. If I go walking, sometimes I’ll bring some with me, just in case. Some walks you do you can be miles from anywhere. I probably am lax with that. I always, because of the job I do, I always have stuff like baby wipes anyway, just to freshen up if I’ve been in the car for a couple of hours.” (Tony’s interview)

Tony’s explanation of the items stored in the car draws attention to items necessary for negotiating his IBS. This illuminates the ‘*quiet materialities*’ that Pink *et al.* (2014) attend to in their discussions of hand gels and gloves in the context of workers’ safety. They suggest that these materialities and tactile ways of knowing are ‘quiet’, routine,

³⁴ I would like to stress here that I do not assume handbags are synonymous with a particular gender

and often unnoticed. So too, are the objects Tony uses for his work, but also work handily in managing his IBS.

Like many of the participants have discussed already, Shaun documented that having his radar key *'gives [him] some comfort'* and that it *'feels like a safety blanket in [his] pocket'*. Again, upon discussing this, he explained that he does not necessarily *use* his key, but it is the importance of *knowing it is there*. This shows the importance of having such items whilst being out. Again, this alludes to the private containers and material items important in navigating and maintaining privacy when moving into public spaces. On a similar note, Carl discussed this in relation to his work as a bus driver:

“Lauren: Yeah. Are there times where you’ll have tissues in your pockets or tablets if you want to take a loperamide?”

Carl: I do carry, especially on my service work. I do carry a couple of packs of loperamide in my bag. Maybe a packet of tissues because there have been times, it sounds disgusting but I’ve, there have been no toilets around, and I’ve had to go behind the nearest bush or whatever. People will laugh but I’m ex-army you know, we used to do it in a field all the time. It’s been that bad sometimes, it’s just as well that I’ve had tissues in me pocket or whatever...I mean I don’t mind; I’ll go anywhere me. I mean I even carry 20p in me pocket because at the interchange you’ve got to pay 20p to get in, which I think is ridiculous. As a driver, I don’t have to pay to get in, I can press the buzzer and go in the disabled one, but sometimes you can’t wait, I think that I can pay the 20p and get straight in and do what I’ve got to do.

Lauren: Yeah, must cost a fortune if you’ve got to go every time where you work!

Carl: I know, but it’s better than paying a fiver for some new underwear [laughs]. I don’t mind, it’s only 20p.” (Carl’s interview)

Carl draws attention to the mobility of his work and how this makes the management of his IBS pertinent. What Carl also brings to attention is how the built environment and the material relate together as he highlights tissues and the absence of toilets. As someone who is ex-army, he has known what it is like to go to the toilet without these material resources and that security. In this, there is centralising importance in objects for managing symptoms when going out. Like Carl, Martin discussed the spare change in his pocket too:

“The times I would do that is when I help run a men’s Sunday team as well so sometimes, we’ll go to other teams’ venues, so I’ll always have a loo roll in my bag just in case they haven’t left any in the toilet in the changing rooms there, kind of thing. It’s that protection almost if I needed it. When I get the train, I always have some loose change as the station has the paid toilets and stuff so it’s always useful to know you’ve got that kind of in your pocket if you need it.”
(Martin’s interview)

All of the accounts here show the negotiation of bags and pockets as holders of intimate belongings, whilst negotiating everyday life and entering public spheres. Keeping in line with ideas of private and intimate encounters, this chapter will now explore how those with IBS negotiate these moments of necessary privacy in public spaces. As we have seen, this connects mobilities with materialities, where we go and what we bring with us. However, it also brings to the fore the functions of the body in public space.

8.4 PRIVATE MOMENTS IN PUBLIC

In this final section, I work at establishing the movement into public spaces and what is at stake when IBS demands private space. This is achieved through the accounts that show the intimate geographies within public places and the return to domestic privacy in the presence of IBS. Acquiring privacy in the presence of others is not always easy. I have demonstrated this through previous accounts in the privacy of the home, the sharing between intimate others, and encounters with acquaintances. Whilst out in public, many of the participants described the strategy of returning home. For example, Kelly discussed using toilets at work in her diary:

“At least there are three cubicles in the toilet at work, although if anyone comes in after me, I like to let them leave first before I emerge, just in case there is a smell. I don’t want people at work to link me with anything negative like a bad toilet smell, so I hope they don’t know it’s me.” (Kelly’s diary)

Kelly’s feelings surrounding being known for potential smells in public spaces were also echoed in Rosie’s account of using a toilet in a public house:

“It’s awkward because I’ve had situations before a few years ago where I mistakenly went out and ate something with BBQ sauce on it, and then went to the pub afterwards. When I went to the loo, it was just your normal stalls with open tops and open bottoms and you know what girls are like, they congregate in the toilets [laughs]. I was like, ‘oh no, no this can’t be happening right now

with all these people in the bathroom' but obviously I had no choice and they...obviously it was an odorous or whatever, which in reality, everybody has the same experience at some point, it shouldn't be much of an issue but they were saying all of these really horrible things and I was just sat in the toilet for at least half an hour, and I was just like, I didn't want to leave. I don't know why these people were spending so long in the toilet and I was like 'oh no' and I think since that, that's probably the one time that sticks out in my head where I've genuinely been like, 'oh my god I'm so embarrassed' and that, it put a dampener on my evening pretty much. It was the only time that it's ever really happened. I think since then I'm more conscious that if I'm in a town that I know perhaps I would go out of my way to go to a bathroom that perhaps might have closed stalls or might have loads of stalls so you could sort of go away in the corner and not be surrounded by loads of people. Aside from that, sometimes you have no choice and whatever. If I know there's the option, I suppose I do purposely pick one over the other." (Rosie's interview, emphasis added)

What I wish to stress here is how public toilets, whilst private in some ways, do not permit the degrees of privacy that are desirable. This builds on previous work that stresses how sounds can *transgress* privacy both within the home (Gurney, 2000a) and within toilet spaces (Booth and Spencer, 2016; Cahill *et al.*, 1985). Through the boundary of the toilet door, Rosie explains how her symptoms transgressed the space to those outside who made judgements. I have elsewhere argued that accessing toilet spaces is not merely a process of a toilet simply being *there*, but how it must be sympathetic to and protective of the transgressions of sounds, smells, and sights that IBS can bring (White, 2016b). Both Kelly's and Rosie's accounts document the troublesome encounters faced when sharing the intimate spaces of public bathrooms, and the felt or enacted stigmatising (Scambler, 2009) response to symptoms of IBS. Encountering and attending to these intimate acts in public shines a light on the power and relevance of these interactions. Moreover, it is not simply a case of spatial privacy, but an appreciation of what Gurney (1998) calls '*corporeal vulnerability*'. For Gurney (1998) this captures the necessities of privacy not only in the divisions of space, but in the body and the self. Even in the 'private' singular toilet cubicle, privacy can be transgressed, and individuals can feel disrupted as they experience symptoms of IBS. Many participants described the strategy of returning home after being out in public. Amy's account explained this:

"I have had a couple of nights out where I've literally had to get a taxi home, go to the toilet, and then get a taxi back into town and just tell friends that I was

feeling a bit ill but I'd come back out again and them nights are very rough, but I didn't want to miss out because why should I? Just because of that. Then again, I'm paying a taxi, the expense of a taxi, in and out, back into town, just to go into the toilet in my house, just because I can't go to the toilet in public.” (Amy's interview)

Molly explained a similar scenario whilst out in her local supermarket. The sudden need to go to the toilet meant that she rushed home.

“I once went to Netto, and I walked up here and I was fine, got in Netto and had a few things in trolley and I thought ‘Oh no’ I'd got this horrible pain, I saw one of the blokes that I knew next door at the time, and he came and I said, ‘Here, take that trolley, I'm off, I don't feel very well’ he said ‘Right’ but bless him, he called back down with his pound from trolley and said ‘Are you alright?’ I said, ‘yes I'm fine thank you, just got a stomach ache and needed to come home’ he said ‘oh, I got you the pound out’ I said ‘oh, you can have that’ [laughs]. I felt awful, I needed to just dash out.” (Molly's interview)

Here in Molly's account, a fragment of everyday life is captured. It presents the importance of ‘fleeting encounters’ (Morgan, 2009) seen with Molly and her neighbour, but the moment of care and intimacy established as he returned the pound and she declared why she returned home. These intimate encounters, often intertwined with kindness (Brownlie and Anderson, 2017), recognise the need for privacy in public, privacy negotiated with others, and allow for a corporeal vulnerability (Gurney, 2000). As Henderson (1975) notes, privacy is obtained not only from ourselves but also on how we rely upon others to work with us for this sense of security. I develop this idea in further encounters discussed shortly.

One particular place that came up regularly in the diaries and discussions was the hairdresser's. This works as a useful case study for a public, yet often very intimate and personal space. Ward *et al.* (2016) focus on specific bodywork drawing upon Twigg's (2000) conceptualisations, extending this to hairdressing for those living with dementia. Ward *et al.* (2016) argue that the embodied dimension of hairdressing has been neglected within research, suggesting that there has traditionally been a focus on the social interactions and identities within a salon. The experiences of attending the hairdresser's for those with IBS are not necessarily a focus on social interactions nor are they about the bodywork performed as they have their hair done. Rather, it is about the experiences of their *own body* and of privacy in a public yet intimate space. The hairdresser's works as a public yet intimate space where the orderings of privacy and

embodied performances come to the fore, as one sits in the mirror anticipating such disruption. To demonstrate, here is an account from Ellie's diary:

“Saturday 20th Jan: Wasn't feeling great when I woke up but had to go to the hairdresser's to get my hair coloured and cut. All in all, it takes around 3 hours to do and so when I'm not feeling well beforehand it makes me really nervous and anxious. I go to someone who has cut my hair since I was tiny and so it's slightly better, but she just works from an extension in her house. Whilst there is a toilet, it literally right next to where she works and so if I had any urgent need to go, I would be incredibly embarrassed. When I got there, I still wasn't feeling 100% so took a Buscopan and an Imodium just as a precautionary measure.

“Sunday 21st Jan: The Imodium I took yesterday had a bit of an impact and so when I went to the toilet it was slightly uncomfortable, however it is worth it for being ok yesterday at the hairdresser's.” (Ellie's diary)

In Ellie's interview, we discussed the trip to the hairdresser's further...

“Lauren: I noticed in your diary you talked about the trip to the hairdresser's, I just wondered if you could say a bit more about that.

Ellie: Yes, it's not so bad now because my IBS is better but a couple of years ago there was couple of times when I was due to go to the hairdresser's and then in the morning, I just couldn't leave the toilet I'd be ready to go and then have to go to the toilet again. It has led me to be late a couple of times. I am lucky that the hairdresser is a lady in my parent's village that has done my hair forever. She does it in her home but she has a special room for it but the toilet is next to it and it's such a small room so I really wouldn't want to go there. It's also that I'm there nearly three hours to have my hair coloured. If I go there already not feeling great again it's that anxiety of thinking 'Am I going to need the toilet?' It would be very difficult if she was in the middle of doing my hair because she's also timing it as well. She times it so when my colour is on, she will be seeing to someone else so I can't mess her timetable up and everyone else's. If the toilet was in a different room, I don't think I would feel as bad. Also, because she's the only person there it's kind of that she would be waiting for me whereas if you were at a salon and went to the toilet and there's loads of people in there it's not as bad.” (Ellie's interview, emphasis added)

Ellie explains how she has her hair done at someone's house, as is the case with many hairdresser's. Similarly, Amy has her nails done at someone's house and recounts similar anxiety. This anxiety results in her avoiding food before her trip due to the time it takes to get to the house, have her nails done, and then travel back home. As seen in the previous chapter, the timings of tasks are significant in the practices that support them. As with Tony's work where he visited someone else's home, there is an

acknowledgement of the tensions of entering a domestic space that is not your own and what it means to use their toilet. Explicitly, what are the connotations for using someone else's toilet when having IBS? Hairdressing is an intimate practice done in often intimate spaces. Often, like Ellie who says she has had the same hairdresser '*forever*', we choose or stay with hairdressers who are familiar and whom we trust with such 'bodywork' (Ward *et al.*, 2016). Sophie told the other side of the story as she works in a salon and reflected on the intimacies and negotiated privacies within this:

“Lauren: So, is there a few of you that work in the salon?”

Sophie: Yeah. Everyone knows what I'm like [laughs]. I just think you've got to be open about stuff like that. Even though some people don't like to talk about it. To be fair, most of the women that come into our salon, I think they appreciate us being quite honest about things like that. Like I do semi-permanent makeup as well so a lot of my clients that are coming in are very nervous, so even before we start, I'll say, 'do you need to nip to the loo?' whatever they need to do. Some people will say to me 'oh god yeah I need a nervous poo' and they'll just say it, and they'll say it out loud, and I'll just say, 'yeah that's fine' even nervous weeing, to give people that option before, it's just nice isn't it? A bit of a comfort thing. I think that's because I know what I'd be like.” (Sophie's interview)

Related to Sophie's work within a salon, Cohen (2010) discusses the emotional labour and friendliness given in salon settings. However, what is also pertinent in Sophie's account of being a salon worker, is how she makes the 'corporeal vulnerability' (Gurney, 1998) present to her clients. This openness within the salon was also echoed in Deborah's experience. In Deborah's diary, she discussed anxiety around visiting the hairdresser's, for fear of needing to go whilst being in the middle of having her hair washed. It is only *after* her appointment that Deborah feels ok. We discussed this in her interview:

“Lauren: In your diary, you talked about the hairdresser's.”

Deborah: I know, I don't know what it is. I don't know why it is, but it still affects me. It happens with my nails as well. I have told me the person that does my nails, it's not always her though, but when I have her, you can tell because your body changes doesn't it? She's asked what the problem is, and I've told her before and she said, 'don't worry, if you have to go, you go. We just stop what we're doing and that's it', and you shut the door. She has it, IBS. It's a salon that just does nails. What quite often happens there, I've always been alright, it's just, and again in the hairdresser's I think once I had to go to the

toilet. I've got the same hairdresser, but I've never told her, I've only told the lady who does my nails, but it's not always her." (Deborah's interview)

Deborah explained that her nail technician knows of her IBS, offering reassurance that she can go if she needs to, but discussed how this was a process of obtaining trust. This gives weight to the vulnerability that these intimate practices and places contain. Through Deborah's account, we see what Jamieson calls (1999) '*privileged knowledge*' and the trust her nail technician comes to have as she learns of Deborah's IBS. This demonstrates the intimate and close associations of the hairdresser's and the nail salons, and why they are significant in their geographical and embodied intimacies. Whilst hairdressing and salons seem at first hand a specific example to focus on, the accounts demonstrate practices enacted in what can be seen as an intimate space for the body where the boundaries of privacy are brought into focus. This works in two ways. First, the intimate geographies that the hair salon often holds as a place where privacy cannot always be guaranteed as one sits in the chair with toilets often far from ideal and lacking seclusion. Second, precisely because of the intimate work that goes on with hairdresser's and nail salons, we see the privileged knowledge (Jamieson, 1999) of coming to know about IBS because of its sensitivity to bodies and '*corporeal vulnerability*' (Gurney, 1998).

8.5 CONCLUSION

This chapter has sought to show the day-to-day negotiations of living with IBS through an engagement in the more private and intimate aspects of everyday life. I have looked at the '*ordering of privacy*' (Twigg, 1999) in both 'public' and 'private' spaces. In the first section, I have explored the geographies of the home and sharing by considering how privacy is negotiated throughout the home and between those who come to share domestic space. This builds on previous work on houses that are shared and the connotations of this (Heath *et al.*, 2017). I have also unpicked what it means to enter a home that is *not your own*, thinking about how the line between domesticity and the public can become blurred. This is seen with Tony's previous work in domestic settings and through the hairdressers who work from home and are visited by those experiencing IBS.

Secondly, I followed the path to privacy that is established from the home and into the (hand)bag. Opening up the (hand)bag has provided an insight into the things that are carried, the journeys these go on, and their central importance in the reassurances of those living with IBS. In particular, this section draws upon the work of Buse and Twigg (2014) in their work on handbags and the '*ontological security*' (Giddens, 1991) they hold, with the contents inside working to provide privacy and self-assurance. This privacy and self-assurance are ever more important when living with a health condition that is taboo, private, uncertain and unpredictable. Importantly though, I highlight the alternative ways in which participants, including male participants, in this study carry objects. The men in the study also stressed the objects they took with them on their journeys to work, particularly those who work on the move, such as Tony and Carl. Similarly, I wished to highlight that whilst these materialities may be '*quiet*' (Pink *et al.*, 2014) in their work and are routine, they are taken-for-granted, but often essential. Similarly, these objects may lie '*dormant*' (Woodward, 2015b). This reiterates the importance of presence even in the case of non-use for reasons of reassurance and '*ontological security*' (Giddens, 1991), *especially* in light of unpredictability, discreditable symptoms, and contestation.

Thirdly, in continuing the move to the public encounters in social life, attention was turned to moments of intimacy whereby there were potential transgressions of privacy (Gurney, 2000a). These became actively negotiated moments by those with IBS, or by those who gained an intimate understanding and kindness in their public encounters. Accounts were given of the experiences of public spaces and the moments where privacy was transgressed in sensory ways (Gurney, 2000a). There were also examples given of participants' retreat to home in search of privacy, as with Molly rushing home from the supermarket. This is intimately connected to questions of accessibility, discussed in the next chapter. Here too, it became important to notice the small acts of kindness (Brownlie and Anderson, 2017) that situated these experiences, especially when there were moments of stigmatisation, discrimination, and othering in public and 'domestic' space. In this section, I took a closer look at a space that is public yet intimate, and one which came up several times in individuals' accounts – the hairdresser's. The hairdresser's worked as an example that showed how the intimate spaces brought to attention the intimate proximities between the chair and the toilet. Here there is the reminder of the anticipated fears and negotiations of going to the

hairdresser's, the fears of privacy being transgressed (Gurney, 2000a), but also how intimate knowledge can be accumulated, or trust can be gained (Jamieson, 1999). What ties these three sections together is the *ordering* of privacy (Twigg, 1999) from the home to the (hand)bag, and through to the public, yet intimate spaces. However, this chapter also brings to the fore how the functions of the body and IBS specifically, meet with the intersection of the geographical and the material. Specifically, how this privacy is sought out and IBS symptoms are kept to oneself – achieved through the upstairs/downstairs bathroom orientation, the tissues kept in the car boot, or the trip back home to use the toilet felt to be most private.

This chapter has built upon literature that engages with the geographical organisation of intimacy and privacy (Twigg, 1999). It has drawn attention to the sharing of bathrooms, and the divisions in spite of intimate associations (Lewis, 2011). Secondly, it has contributed to the important material ways in which privacy and security is established through (hand)bags (Buse and Twigg, 2014), and thinking about how these material objects are important for '*ontological security*' (Giddens, 1991). There has been a look into the blurred boundaries and privacy of homes and domestic spaces (see for example Allan and Crow, 1989; Madigan and Munro, 1999; Gurney, 2000a, 2000b; Mallett, 2004; Robinson *et al.*, 2004). In particular, there has been a consideration of what is at stake when these spaces are shared (Heath *et al.*, 2017). I have brought to attention through intimate geographies and material things to '*privileged knowledges*' (Jamieson, 1999) and intimate associations, as IBS requires privacy to be reimagined. Here, I have offered a unique contribution in relation to IBS, drawing upon the intersection of how searching for privacy brings to the fore the places, spaces, things, and people that make a difference. Everyday accounts of living with IBS tell a story of the boundaries of intimacies and the search for privacy in spatial and material ways. However, it also brings to light not only the orderings and boundaries of private space, but of the felt experience of bodies and their vulnerabilities as smells, sounds, and sights can transgress beyond the cubicle door of the nail salon or the guest house Airbnb. This chapter has pursued a shift from private to more 'public' spheres of daily life and the intimate geographies of these. This links us on to the next chapter which accounts for the mobilities in public life.

CHAPTER NINE

“I HAVE TO KNOW WHERE I CAN GO”: NEGOTIATIONS OF TOILET ACCESS AND MOBILITIES

“It’s hard, it makes it hard for people doesn’t it? If they haven’t got a toilet on bus or whatever they’re going on, then they’re snookered...sometimes someone will say, ‘oh shall we go so and so?’ and I think ‘shall I, or shan’t I?’ you know.”
(Molly’s interview)

9.1 INTRODUCTION

Molly’s account above and the questioning of whether she feels she can go to a place or not draws attention to the journeys we take, how we take them, and what is publicly at stake in navigating IBS. Needing to know where to ‘go’ often becomes a priority for those living with IBS. Toilets are at the forefront of conscious thought for many with IBS, shaping some of the most intimate encounters with our bodies, with other people, and our broader social environment. The diary guidance asked respondents to detail the *importance* of toilets and bathrooms in their everyday lives, paying particular attention to the location and knowledge of toilets, and the characteristics of such spaces. In this research, diary guidance encouraged participants to share accounts of how their IBS affected travel including going on public transport, travelling on trains, and the times of their journeys. Many participants have said, ‘*the first thing [to] check is where the toilets are*’, demonstrating the need to know *where* toilets are, and the effect of this on the *mobilities* of everyday life. In this chapter, I will explore how those with IBS experience and navigate toilet access when seeking to manage the symptoms, as part of participating in everyday life. I will argue that toilets are increasingly a crucial social *space* and *place* (Gieryn, 2000). For Gieryn (2000) space captures geometry whereas place embodies the feelings, materialities, and interactions that happen within. With this in mind, I will argue that it is not a matter of toilets simply being there as in a space to be used, but how toilets work as a place that is bound up with social interactions, material objects that enable or constrain, and how sights, sounds and smells come to

constitute the experience of being in one. In light of this, I will suggest that accessing appropriate toilets become a conscious feature of everyday life, demonstrated through the processes of mapping, mobilities and access.

Firstly, this chapter will explore toilet mapping – the practical issue of *knowing* where toilets *are*. Specifically, the knowledge acquired by those who have IBS or their intimate others, of where toilets are. This knowledge engages with the geographies of everyday ‘public’ life, particularly the common and often commercial places that are called upon in times of need. Secondly, this chapter explores how participants negotiate toilets whilst travelling, offering insights into the importance of mobilities in everyday life. It calls upon accounts related to journeys via planes, trains, and cars. This considers the feelings and negotiations of IBS symptoms in terms of location – the places people go, but also what occurs when on the move or ‘in-between’ places. This section draws attention to the importance of feelings whilst travelling – what Sheller (2004) calls ‘*emotional geographies*’. Being on the move brings to attention the importance of toilets whilst between places, together with the modes of travel that facilitate this. Finally, this chapter demonstrates how the *knowledge* of toilet locations, together with the issue of *getting to them*, also bring to attention questions of *accessibility*. Specifically, I will illuminate how accessibility can be considered in terms of physical access, but also in terms of the felt experiences of such spaces and particularly disabled toilets. The accounts portray the invisibility of IBS at surface level and how feelings of illegitimacy play out in accessing toilets, capturing the *felt* and *enacted* responses as well as processes in which those with IBS seek to pass, not as ‘normal’, but as having a legitimate illness (Goffman, 1963).

More broadly, the accounts further allude to how the environments one might travel to can have the capacity to affect the symptoms of IBS. The practical exclusions in public life and in public toilets come to affect the body by changing the nature of symptoms. This involves limiting food and drink to prevent toilet usage in public life. Cooper *et al.* (2000) refer to this as ‘*the bladders leash*’, although I extend this to the bowel. By illuminating accessibility as an issue for individuals with IBS, this chapter speaks to the literature on sociology of toilets (see for example, Pickering *et al.*, 2019; Molotch and Noren, 2010), space and mobilities (Sheller and Urry, 2006; Sheller, 2004), and questions of toilet accessibility (Wiseman, 2019; Kitchin and Law, 2001). The chapter

will offer reflections on individual mobilities and access to toilets by highlighting toilets as an important feature in the constitution of our social environment. The threads of mapping, travel, and in/accessibility appear to address the broader question of the negotiation of IBS symptoms. They provide a lens to understanding where one can/not go, feeling (il)legitimate, and the processes which make inclusion matter in everyday public life.

9.2 MAPPING OUT SPACE: TOILET MAPPING

Carl explained that he has to know ‘*where [he] can go*’ and by this he means having the knowledge of toilet locations. In my previous discussions on IBS and toilets, I understand ‘toilet mapping’ as the mental notes of toilets. These toilets are dependent upon proximity, time taken to get to them, as well as preferential toilets based on matters to do with anonymity, cleanliness, and accessibility. This knowledge is also being underpinned by feelings of safety and relief in an emotive and embodied sense (White, 2017). Within the term ‘accessibility’, I include not only physical space, but issues related to cleanliness, the availability of a window, hand dryers, and the number of cubicles that enable privacy. However, these broader conceptualisations of accessibility that are related to sensory and emotive experience are not without the problematic associations of covering and stigma (Goffman, 1963). I will explore later understandings of accessibility and experiences of this in this chapter. This relates to Gregory and Urry’s (1985: 3) advocacy that spaces are ‘*not merely...an area in which social life unfolds, but rather...a medium through which social relations are produced and reproduced*’. The topic of toilet mapping also contributes to understandings of the important sphere of, and *turn* to, mobilities (Urry, 2007) as an area of sociological inquiry.

Toilet mapping was a priority, for most, if not all, participants in this study. Those with IBS often have heightened knowledge and expertise of toilet locations. This comes in the main from the process of *toilet mapping*. Diaries articulated the ‘mental mapping’ of toilet locations as something that is part and parcel of the ‘doing’ of everyday life for many who live with IBS. To illuminate this, Rosie’s diary documented that, for her, visiting a new place meant that ‘*the first thing on [her] agenda was to work out where*

the toilet was'. Similarly, Martin described being conscious whilst on a night out of *'where [he] is going, what food [he] is going to have, how much drink [he] can have'*. These factors led to checking the toilet locations on arrival:

"I mean I think certainly I'm conscious about when I go out for a night out, I'll be conscious of where we're going and what food I'm going to have and how much drink I can have and almost like subconsciously when you first go into a bar or restaurant, you just have a quick glance around to make sure you know where the toilets is, even if you might not be having a bad day at all, you kind of still almost kind of do that to check what's around you and everything like that really." (Martin's Interview)

Kelly also discussed her knowledge of toilet locations in her daily routine, particularly in relation to her working life. In Kelly's diary, she explained the journey she takes to work every morning. Kelly lives in another town and commutes to work. She takes her car halfway, parks at a shopping outlet, and then takes the tram to her destination of work. Kelly's diary documented how her mid-stop, a park and ride, has a nearby Starbucks Coffee Shop with a toilet that she can access if she needs to during her journey to work. Kelly explained that sometimes she has used the toilet in Starbucks but explained how she feels *'conscious to buy something on the way out'*. On occasions, she has bought a small biscuit from the front of the counter, feeling that she must justify herself for using the toilet as a non-customer and the anxieties of *'being seen'*. Following this, Kelly explained the *'map in [her] head'* of all of the toilets near her place of work. Her account demonstrates not only the availability and accessibility of toilets in a literal and physical sense, but raises questions about, and stresses the importance of, which toilets are *'good'*. This means the toilets that provide privacy and limit instances of social interaction:

"I know where I can go to the toilet if I need to when I park my car and then once I get off the tram, I have a map in my head of all the toilets in the area near work, and in town, although town is limited in the early mornings. I know which toilets are good, i.e. those with lots of cubicles where you can remain undisturbed and anonymous." (Kelly's diary)

Kelly and I discussed this further:

"I know where all of the toilets are that I can use. You know where you can just walk in and use a toilet – department stores, public toilets, cafes, pubs. I know which places have got toilets where you don't have to walk past the bar or

anything, you can just sneak into the toilet. I would say that probably throughout and around the university and in the centre of town at least, I know where the toilets are. My town centre – I know where the toilets are...Anywhere that I go regularly, I do have a picture in my mind of where I can go to the toilet. Obviously, going to a new place is difficult and I tend to check out before I go at least where public toilets are. It is quite difficult, but it is something that I try to do. Journeys as well, if I'm on my way somewhere I'll think 'oh there's a garden centre where I can go to the toilet', just places along the way that you know you can stop...Starbucks opens quite early so you can go there, although I'm quite conscious that I'd probably needed to buy something on my way out, but I have done that before I think. I've used the toilet there in the morning and then I've just gone and bought one of the biscuit things at the counter and then taken that away with me because I just think 'Oh they'll see me going in and out' and think 'oh, she's just been to the toilet'. Apart from that, well there's McDonald's, but it's quite a bit from where I park up because it's around the corner. Again, I think McDonald's have always been places where you feel like you can just sneak in and go to the toilet, but I suppose it depends how busy it is as to whether or not you'll feel like people are noticing you." (Kelly's interview)

Kelly's account demonstrates her knowledge, hidden work, and preparation for embarking on her route to work, with toilets as an important feature. However, it also speaks to the broader issues of the knowledge of mapping toilets of particular kinds. For example, Kelly highlights the importance of opening times of public places, spaces that are 'open' to visitors that may not necessarily be customers, but also broader insights into key commercial spaces in the context of toilet availability. Jones *et al.* (2015), in their paper on cafes and conviviality, describe commercial cafes as important spaces in the urban and multicultural landscape. Instead of dismissing corporate spaces, like Starbucks, as '*commercial, globalised spaces of soulless homogeneity*', Jones *et al.* (2015: 644) argue that that these spaces actually provide room to generate familiarity, ethnic mixity, mundane co-presence and inattentive forms of conviviality. Whilst Jones *et al.* (2015) focus on ethnicity, the idea of commercial, globalised spaces being convivial has echoes with the issue of toilet mapping. Participants reflected upon their reliance on commercial spaces, such as Starbucks and McDonalds, that transcend localities and tend to have available toilets, even if their access is questionable. In the context of toilet mapping, in both familiar and unfamiliar territory, commercial businesses like McDonalds and Starbucks in their uniformity can be a welcome sign and a crucial reference point.

Returning again to Carl, he explained that with the routes of his bus journey as a bus driver, the most challenging aspect of accessing toilets is the *time* of day. Carl sometimes works at four or five in the morning and, for him, knowing that toilets may not be open makes the anticipation of symptoms increasingly difficult. However, Carl explained that McDonald's is a place that is most likely to be open at all times:

“Carl: When I'm on a service bus, we do a variety of routes so I have to know where I can go and where all of the toilets are. Early in the morning the only place is McDonald's otherwise through the day, usually at every terminus, or we've got a bookies shop, they're usually quite good to us [bus drivers] letting us in. Down where I live, I've got a Tesco's garage that's got a toilet. One of the routes goes past my house so if needs be, I can just nip home and go to toilet there.”

Lauren: On your routes, do you have mental notes of the next stop with the toilet?

Carl: Yes, I do. Say we're coming from such a place, the shop it depends who's on, then my next one would be the garage or the bookies outside the stop, then the next one would be the depot then after that, it wouldn't be until town. We stop outside a police station, and a couple of drivers have been in there, I haven't personally but they said they usually let you use the toilet, and then the next one after that probably isn't until the doctors. On every route I do have a mental note of where the nearest toilet is.

Lauren: Do you talk about that with the other bus drivers?

Carl: Yeah because there's a couple of others that have medical conditions that they need to go to the toilet whether it be the bowels or their bladder so they kinda know where to go as well. It's like 'oh yeah, the DIY shop, he's an ex bus driver, he lets us use toilet', you know, stuff like that. We talk about it between ourselves. We'll be like, 'I've had a flare up this morning, I've had rate gut wrench' and all that. There's a couple of us that suffer with the same sort of problem.” (Carl's interview)

Carl's account of his bus journey at work reminds us again of the permeance and importance of places such as McDonald's in their reliability of being a place to call upon, day or night. This is similar to Kelly's example of the importance of Starbucks in being a place to call upon for toilet access. Carl's account also demonstrates the plotting of places whilst on route and the knowledge of where he can stop and go if necessary. Through the conversation with Carl, this is not isolated or hidden knowledge, but mutual and almost shared with fellow bus drivers. He also explains that he goes to

the ‘bookies’ (betting shop) as a place that often has a toilet. Shaun also described using betting shops and recounts ‘instances in the past where they say its customer only toilets’. He has ended up ‘writing a quick bet’ which he described as ‘virtually paying to go to the toilet’.

Furthermore, it is important to draw attention to the fact that it is not simply a case of knowing that there is a toilet *there*, but the nature of the toilets available. During an interview with Katie, she noted her preferences for particular toilets. Katie stated that she preferred it when there are multiple toilets due to the stress of imagining people queuing, the time to use the toilet, and the potential response of others questioning ‘what are you doing in there?’. This relates to Blumenthal’s (2014: 102-3) suggestion that there are rules in the bathroom that include *minimising time* taken and to *uptake as little space* as possible. Amy began her diary by explaining that upon visiting a restaurant to meet a friend, the first thing she checked was where the toilet was ‘just in case’ she needed to go urgently. Amy explained that this is not an isolated occasion but is a practice that she engages in everywhere she goes. This could be her checking, or her husband finding out the location and availability of toilets for her. Moving beyond this, Amy’s diary later documented the morning routine and mapping of toilets in relation to work and her office, but also highlighted the particularities of specific toilets:

“Wednesday 22nd November: I feel that I need to go to the toilet before work but after sitting there for 20 minutes, it is clear that it isn’t happening. I check if I have my normal stash of Imodium and Buscopan in my handbag and set off for work. As soon as I park up at work, I feel a more urgent need to poo, so I head for some further away toilets which I have found are quieter and less used, so it is easier to avoid embarrassment.” (Amy’s Diary)

Amy’s deliberate target of the toilet furthest away captures the importance of the sensorial experience – toilets being quieter, with less intrusion, and less frequented. Again, this highlights the importance not only of toilets being ‘placed’, but experienced and felt beyond their *location*. Choosing of toilets is not merely based on local proximity and convenience but based on the desire for privacy and limited social interaction. Cahill *et al.* (1985: 36) stressed that it is not just the creation of a dedicated physical space of privacy that a toilet stall offers, but it is also the boundary that signals particular behaviours appropriate to the given space. Similarly, Lea (2001: 91) argues

that the backstage region of the toilet is very much part of performing the self, particularly within a place of work, where there is the possibility of someone else entering the space. Amy's diary entry documents how the hidden work of accessing toilets sits alongside further practices of having to hand material items of importance as further work to manage IBS, discussed in the previous chapter.

Similar to Kelly's account of planning the route to work and the potential stops along the way, many other participants spoke of mapping toilets as an important part of route planning in their everyday journeys. In Ellie's diary, she documented how she had an hour-long journey home in a friend's car, and the journey was an unfamiliar one. Ellie explained that she thought about where the toilets might be on the way home, '*just in case*' she might need them. Ellie explained:

"When I go on any long journeys, I like to know where the potential toilet stops are – certain routes I know exactly where they are, and also the stretches where it wouldn't be possible to make it to one. The same occurs when I am out – certain outdoor events, festivals, and markets make me nervous because I don't know where the toilets will be or how long the queue will be." (Ellie's Diary)

What Ellie's account also demonstrates is the temporal distance and the '*stretch*' of moving from one toilet to another – or preparing for not having a toilet or knowing when the next one will be, whether this be for necessity or assurance. It speaks not only to the knowledge of toilets but also where the toilets are on particular journeys and the intervals of time that sit between one toilet stop and another. On a similar note, Carl took me through his journey on an average day at work, where mapping and stops are integral to his work. Carl works as a bus driver so as well as knowing the routes, times, and destinations for the journeys required for the particular bus route, he also knows the toilets. Before work, he tries to go to the toilet. If he does not manage to go, he will take Imodium '*just in case*' to prevent him from needing the toilet whilst out on the road. If Carl needs the toilet whilst out on route, he explained that his routes often have the centre of town as the halfway point. This becomes a time when he knows he has likely access to a toilet. Carl also explained that he reminded himself that any journey at work was never '*more than an hour from a [bus] terminus with a toilet at least*' and took this as reassurance for how long he should have to wait should he ever need to go.

Carl's account speaks as 'being in the driving seat' in a literal sense. However, the topic of *travel* and being *on the move* is a key feature in the negotiation of IBS.

9.3 MOVING THROUGH SPACE: TRAVELLING VIA PLANES AND TRAINS

An earlier account from Kelly talked us through the imagining of toilets on route on her journey to work. This journey and mode of transport became pertinent in the negotiations of IBS in daily life. Sheller (2004: 4) talks about the '*emotional geographies*' in her work '*feeling the car*'. Here, she describes the broader automotive industry but as part of this there is a reflection on the 'driving body' as an *embodied social practice*. I extend this idea of the embodied and felt experience of being in a car or anticipating a journey within the lives of those with IBS. In particular, one must reflect upon the felt experiences of what a car journey, a flight, or a train can evoke when IBS is added into the equation. Within her diary, Amy expressed the feeling of being '*always on the edge*' on a journey home after a meal. This is due to having past negative experiences where she has felt '*trapped in the car, miles from home and desperate to go to the toilet whilst [her] husband tries to get us home as fast as he can with the windows down in an attempt to soothe the accompanying sweaty flushes*'. I asked Amy about what she found most difficult whilst living with IBS. She said food was a key feature, but that travelling and its anxieties were significant:

"I also find travelling difficult. I think I'm ok with my commute now, its 25 minutes so I'm not too bad, I generally know that I go to the toilet or I've got time to get to work and be able to get to the toilet if I need to there but I do find that a longer journey or travelling abroad because you're up at different times and that can put my stomach on edge and obviously the thought of being...we travel to Australia fairly often because we have family there, like that panics me a lot that obviously I'm trapped on a plane in a tiny toilet with the potential of having IBS...in a car or on a train, especially on a train, I'm panicking about using the train's toilet because people just wait outside, they're small, they're not very private. I would say the main thing is travelling, whether that be travelling abroad or even just day to day commuting or getting somewhere. If I am getting the train somewhere, I'll quite often probably take Imodium before I go because I'm just very conscious of having to use the train toilets, so it does impact and alter the way that I go about travelling or doing things day to day."
(Amy's interview)

As Amy alludes to, aeroplane journeys were a problem for many. Amy described the fear of being *'trapped on a plane in a tiny toilet with the potential of having IBS'*. Aeroplanes are spaces that are often tight and 'closed off' to the social world. In particular, their toilets are tight and bounded spaces. Plane toilets are often singular, small and frequently with a queue waiting outside in the case of economy travel. The bounded nature of such space within aeroplane travel and the regulation of bodies in set spaces has been explored in Bias' (2016) *'flying while fat'* animation, demonstrating how bodies can cross the boundaries of architecturally designed spaces of individualised containment. In terms of the negotiation of IBS symptoms whilst flying, Terry's diary documented that whenever he went abroad with his family, he would avoid eating the day before they were due to fly, alongside taking a precautionary Imodium. He wrote that *'the thought of having a bowel movement on a plane made me anxious'*. Terry told me of his routine when flying:

"It's like when we used to go on holiday abroad and we were leaving at 6 o'clock in the morning or something, I would starve myself the day before, take Imodium, the last thing I want to do is have a bowel movement on an aeroplane, do you know what I mean? All those kinds of issues that it's affected." (Terry's interview), *emphasis added*)

Molly explained her experience similar to that of Terry's:

"I don't go to toilets on plane I don't move, I don't get out of my seat apart from to stand up and have a couple of minutes. But then I know that when I get there there's toilets in airport. So, I know that I'm alright in short bursts, you know what I mean... I've been twice to Australia and not eaten until I've got there, and it takes 24 hours...But you sleep, you watch television. Have a sweet or whatever. With me, you just programme yourself that you're not eating, and it doesn't matter" (Molly's interview)

As stated by both Terry and Molly, the limitation or avoidance of food and drink often coincided with travelling. Molly said that twice she has travelled from the UK to Australia. She chose not to eat until she arrived – a journey that takes up to twenty-four hours. Molly explained that she avoids food whilst travelling, differentiating between the plane toilet and the airport toilets. These are distinguishable in terms of the openness of the space and the opportunity for privacy. What is important again to flag up here is the *duration* of travelling with an uncomfortable 'public' toilet, leading to avoiding

food for fear of symptoms. In an earlier chapter, we also saw how Molly avoids food by sucking a sweet and sticking to water on days where she volunteers on coach trips to the seaside. Furthermore, Kelly described similar feelings to Terry and Molly. Here is an extract from her diary on the anticipation of travelling via planes:

“Thursday 2nd November: I have booked a holiday for next year. It’s exciting, it’s my first ever long-haul flight but this brings many concerns. Can I get any suitable food on the plane? Can I bring enough food with me? I’d prefer not to eat when travelling but if I don’t eat, I get light-headed, feel faint and get headaches. I wish you could just take a tablet or have a cup of tea that made you feel full and gave you enough nutrients to keep you well. I always take two Imodium comfort plus when I’m going on holiday, even if it’s just in this country. I get up early and take it before I go, this time though I will need to be aware that I might need another dose later in the day as it’s a long journey. Toilets in airports are fine if they are UK airports but I’ve always been OK if I take Imodium. It would be dreadful to have an attack on the plane mainly because there is only a small number of toilets so you could end up with a queue outside. It’s never happened but I’ve never gone long haul. I hope it will be fine. I have been doing some research into public toilets where we are going, and I may well take Imodium most days.” (Kelly’s diary)

Kelly’s diary account demonstrates not only the anxieties related to flying, but the avoidance and fear of food whilst travelling, directly related to the confinement of space that plane toilets offer. Kelly’s fear and actual avoidance of food whilst flying, alongside Terry’s and Molly’s, resonates with Slater and Jones’ (2018) findings from their ‘*Around the Toilet*’ project. Their participants also stressed how a lack of accessible toilets can prevent them from going out or result in them restricting food and drink for ‘*up to 18 hours a day*’. Through these accounts, I have sought to demonstrate the feelings and practices of anticipating travel, specifically in relation to flying. The participant accounts show the importance of considering space in terms of the architectural and temporal constructions of modes of travel. In particular, the accounts demonstrate how spaces and places of travel can exclude or limit social participation for those living with IBS, due to the inaccessibility of toilets that can result in behaviours in order to avoid toilet usage. I will now draw attention to other modes of transport that illuminate the importance of toilet access within these that shape the negotiations of IBS.

Tony completed an audio diary, and most of the daily entries were recorded in his car on his journey *to* and *from* work. As I listened, I heard the sounds of traffic, the audio of movement as he spoke to his hands-free set on his commute. As commuting is such a big part of Tony's daily life, negotiating his IBS becomes part and parcel of the journey. He recorded:

"I've skipped breakfast because it's a 60-70-mile journey over a pass where there's not many places or services to stop that have toilets. One reason why I skipped breakfast was that I find if I've got a long drive making sure there's toilet breaks but also, I know the journey I normally take is normally bad traffic so this morning it took me three hours to do an hour journey so it can cause a bit of stress and anxiety. What I tend to do is skip my breakfast, set off a bit earlier to miss those symptoms which luckily I didn't get upset." (Tony's audio diary)

Again, Tony's account demonstrates the avoidance of food whilst travelling to work as he maps out the sixty to seventy-mile journey where there are limited points at which he can stop and access a toilet. His account highlights the toiletry time pressures of travelling, alongside the everyday pressures of getting to work on time. These time pressures change the practices of managing the body to limit or prevent symptoms. Driving has seen attention from several authors (see for example, Sheller, 2004; Sheller and Urry, 2000; Lupton, 1999). Sheller's (2004) '*emotional geographies*' that derive from the phenomenological experience of cars is useful in this context as it locates them in the broader material relations and the spaces in which they pass. However, Merriman (2004) argues that few academics have provided critical accounts of the geographies and sociologies of driving along such roads or landscapes, with an appreciation for the subjective, material, temporal, and spatial facets of driving. In particular, he acknowledges how driving speaks to the materialities of cars, bodies, roads, and surroundings. Merriman (2004) argues that previously spaces that involve travel and mobility have been suggested to be 'placeless'. However, in his exploration of motorways, Merriman (2004) suggests that the very placement of motorways is borne out of the opposite. Motorways require an understanding of place in their connections from one place to another, and what is or is not present (such as a service station and toilets) as part of this. Specifically, roads and motorways in their deliberate design are often a 'long road ahead' if a toilet is not immediately available and thus make the

experience of them as a *place* important. Where a person is, the mode of travel, and the journey time all become important factors when IBS comes into play.

Trains, like planes, can evoke similar anxieties on the boundedness and limited access to private and accessible toilets whilst on the move. Katie wrote in her diary about her day travelling up from the south to the north of the country, and how this was characterised by the uncertainty of train travel. Below is an extract from Katie's diary:

“Our train journey was a nightmare. The train was terminated at a station that I didn't know, so I didn't know if there were toilets and the train had been packed. So, we were suddenly in a huge crowd not knowing how to get to our destination! We were told to get on a tram, but it was so busy I was too anxious to get it. I got on the next but had a panic attack and had to get off as there was no way I'd be able to reach the toilet. We eventually got a quieter train, but I made sure we were near the toilet, just to make me feel better. However, that train then got really busy and I was panicky about there being so many people outside the toilet, in case I couldn't get in or people would hear me. Our next train was also packed, as the two before it had been cancelled, so people were standing in the aisles so there was no access to the toilet. I didn't even know if there was a toilet. Something I normally always check.” (Katie's Diary)

Katie's diary demonstrates the anxieties faced whilst travelling but in particular via trains. Katie had mapped out her journey to include toilet locations and their proximities to ensure her journey was a smooth one. However, the everyday changes of train travel disrupted this. Similarly, Stacy's account in her diary documents how she booked on a particular service on her journey to work that had '*decent toilets*'. This also coincided with the stress and disruptions of everyday journeys.

“Friday 1st December, 22:00: I really needed the toilet when I got the bus to the train station on the way home. Then the bus got stuck in traffic and I ended up having to bail on it and run the rest of the way to the station. I almost missed my train so couldn't even go to the toilet in the station. Thankfully, I was booked on a service with decent toilets, plus it was one which starts and ends at a station I know. That means it was clean and the toilets have been replenished with toilet paper, soap etc so it wasn't too bad in the end.” (Stacy's Diary)

Stacy and I discussed train travel and commuting to work. Stacy elaborated on not only the mapping of toilets, but also the '*earmarking*' of specific ones whilst commuting via trains. This reminds us again of the importance of toilets not only in terms of physical

access, but also in terms of how they are designed and change the way we feel. The quality of toilets in places of travel again draws attention to this. Furthermore, Stacy explained her knowledge of seeking a free toilet space that she described as ‘secret’. This has changed her experience of accessing toilets once reaching the train platform.

“So, at the moment I’m going on the train three times a week and driving a couple of days a week. It’s not a problem when I drive just because it’s quite short but when I get the train, it’s like, it can be like two hours so the main thing that I do is just like, earmark particular toilets that I know are going to be or are hopefully going to be ok. Actually, once you find them, it’s not too bad. There are ones. I remember first thinking, it’s going to be awful in the train station because the only ones I knew about were the ones on the concourse where I knew you had to pay and this kind of stuff. Then I just figured out this secret toilet on platform 9 so that’s changed my life [laughs]! Since then, that’s been fine. I hate it in winter just because they don’t have hot water in the taps and the dryers are always cold so that annoys me, and the toilets are cold and they are always small, and you don’t have the space to get your coat on.”
(Stacy’s interview)

As well as the account above, Stacy explained how she had considered the unequal access to toilet spaces, with train stations and their platforms providing a prime example of such inequality. In particular, this can be seen in the deliberate architectural design of publicly available toilets and how this intersects with who is a paying traveller and who is not. This leads on to issues of accessibility and the issues faced by being granted access to such spaces, and the barriers often faced by those living with IBS. There is the question of who is entitled to a particular space, and who is not, and how those with IBS might negotiate this in daily practice.

9.4 BOUNDED SPACES: IN/ACCESSIBILITY

As previous sections have shown, knowing where toilets are and the journeys we take to get to them go beyond the spaces in which they are placed. The experiences of toilets are relational, felt and thus affect the negotiations of IBS in everyday life. There is a degree of expertise and resourcefulness exercised in mapping and earmarking toilets. However, whilst one can appreciate this expertise, there must be a questioning of how these built environments affect those with IBS. Lefebvre (1991) has argued that space is often a site of struggle; this was the case for respondents in this study, particularly

around issues of access. Bates (2018: 985) draws upon Lefebvre's (1996) '*rights to the city*' suggesting that '*barriers to urban life are both a universal and an everyday experience, tainted by struggles with the physical environment as well as with societal attitudes*'. Kitchin and Law (2001) talked about the socio-spatial exclusions of disabled people when it comes to toilets and suggests that their construction and lack of provision limits social participation. Importantly too, they draw upon Cooper *et al.*'s (2000) notion of '*the bladders leash*', demonstrating the idea that one should be able to hold it in whilst out in public. Thinking about questions of (in)accessibility of toilets is attended to in the participants' accounts.

Alongside feeling able to use particular toilet spaces, there is a very practical issue of public and council funded toilets being in decline. Slater and Jones (2018) have argued that on top of the lack of funding for toilets, a standardised model of toilet provision means that for some disabled, trans, and chronically ill people, leaving the house is unachievable or bound up with constant anxiety. For the toilets that are available, there are questions of the nature of such space and who, and what conduct, is welcome. As public or council-funded toilets have decreased and, in some cases, completely vanished (see report by BBC, 2018), spaces mentioned previously such as McDonalds, Starbucks, Debenhams, and John Lewis are increasingly relied upon. However, these do not come without critical questioning. We can celebrate them for their universal nature and the knowledge of their being there in towns unfamiliar to us, but the micro-interactions and social divisions within such spaces are still ever-present. Here, Ellie's account of visiting a festival with friends describes the experience of needing to go to the toilet, knowing where they are, but simply not being able to get to one.

“Last Summer me and my friends went to a free Music Festival. We decided to all meet up there where we come from as one lives further away now, and we were also meeting my friend's boyfriend. We just went for the experience. I ordered a steak but what I didn't realise they had put some sort of spices on it. When I was eating it, I realised there was something on it. We then went outside, and I started thinking ‘I don't feel good’. Because it was like a massive festival that was on there was queues like everywhere. I then tried to get back in the gig we had left, I told the guy on the door I was desperate, in fact I lied to him I told him I had Crohns because I thought he might understand that whereas if I said I have IBS he might not know what that is. He said, ‘Err no sorry love I can't let you in’. I said ‘oh no I don't feel good’ and there was a big queue to get in so in the end I had to leave and leave that part of the town I had to leg it across town and I thought this could be the time in my life when it's going to happen

to me I'm surprised it hasn't happened before but I was in such a panic this was going to be the time I shit myself in the middle of town. Luckily, I found a bar that was open and just legged it in. My friends were texting to ask if I was ok, but I felt rubbish and I couldn't get back in the event with them. They were like 'Shall we come to you?' but I thought 'No I just need to get home'. I went home and that was when I was living with my parents and they were like 'I thought you were out?'. Yes, experiences like that are awful I knew where the toilets were, but I just couldn't get to them.' (Ellie's Interview)

What is of particular importance here, alongside the physical inaccessibility, is how Ellie describes her struggle to get access to a toilet whilst at a music festival. She attempts to gain access by arguing that she has Crohn's (IBD) *instead of* IBS, with the hope that with IBD there would be more understanding. This echoes sociological literature that delves into the role of 'passing' and the boundaries of identity work (Goffman, 1963). Whilst Crohn's is also an invisible condition with similar symptoms, the condition itself is considered 'real' and 'serious' compared to that of IBS. As such, it is utilised as a way to try to grant access. One of these divisions and micro-interactions is the judgement about *who* is entitled to use such a space. Carly, who lives with both IBD and IBS documented in her diary her visit to her local shopping centre and the conversations in the female queue to the women's toilet. Carly explained mutterings between women about the lengthy queue in Marks and Spencer's. However, she also delved into the fear of what a populated toilet meant:

"I went to do some Christmas shopping. During the visit, myself and some others spoke about how impractical it was having just one ladies' toilet in the M+S café. As such, a big queue had formed, and the waiting time was long. When it was 'my turn' I worried about making a noise that everyone in the queue outside would hear. It is always a relief when I hear the tap running or someone put the hand dryer on so I can relax and let out some wind! I feel quite comfortable in the shopping centre as I know where most of the toilets are, and there is always one within a short distance should I need to go urgently. Thinking about it, I went in another two toilets while I was there. One in a Wetherspoons pub which has multiple small cubicles and 'does the job', and then I needed to go quickly on the way out so used the disabled toilet in House of Fraser. I'm never quite sure if I should be using the disabled toilet. I look fine. It's a hidden illness. I always feel like a fraud though?" (Carly's Diary)

Carly's account describes not only the physical accessibility and availability of toilets, but also the broader perceptions of who is considered to be an appropriate user of a disabled toilet. For Carly, using disabled toilet leads her feeling a 'fraud'. Carly

explained her feelings around this in our interview, stating that she has ‘*an argument prepared in case someone says anything like “why are you there? You’re not in a wheelchair”*’. Here, it is not simply that Carly wishes to ‘pass’ as ‘normal’ or cover up her IBS and IBD identity as would be the case in traditional understandings of Goffman (1963). What the identity of IBS brings to the forefront is the legitimacy of the label itself. IBS is seen as a *questionable* illness and an *invisible* one. Similarly, Shaun described his process of using a disabled toilet and the judgement and ‘look’ he received upon leaving. He described the tensions between limited toilet availability and compromised spaces, but also how the legitimacy of IBS comes into play:

“When I was using it last year, I got an experience where there was this woman, I don’t think she was disabled herself, I don’t know, but it was that busy everyone wanted to use the toilet. She was tutting ‘what you doing in there? You’ve no right to be in there’ this kind of thing, but I just said something like ‘not all disabilities are visible’ and just carried on, but you do get a look sometimes. Sometimes I find that you can’t quite tell if there’s anybody in there, you put the key in and think it’s not turning but the red and the green has worn away, or they use it as a baby change. I mean I know it’s down to space sometimes, but you feel slightly annoyed if you’re desperate. Sometimes you feel as if you need a sticker on, you know? I don’t bother about it too much, but I suppose some people can get quite upset.” (Shaun’s Interview)

As Shaun and I discussed toilet access and using radar keys³⁵, he explained the process of coming to own one. Shaun visits sports grounds a lot as part of his work as a freelance sports journalist. These are spaces that are often male dominated and thus toilets are architecturally designed to include mostly urinals. Previous work acknowledges the gendered inequalities in toilet design focusing particularly on the queue of a female toilet (Twigg, 2006). However, Shaun’s account considers the design of male toilets and the implications of this when having IBS. Shaun described how the minimal cubicles in the male toilets were often misused or unavailable. When faced with the potential of needing the toilet due to his IBS, he needed to access a safe and available space.

“Lauren: I imagine in male toilets too there are often fewer cubicles.”

³⁵ RADAR keys, also known as NKS keys, ‘offer disabled people independent access to locked public toilets around the country’ (Disability Rights UK: <https://crm.disabilityrightsuk.org/radar-nks-key>)

Shaun: Yes, that's why I got the radar key as like I say, at the racecourse, it's so busy with the toilets, that the cubicles are usually being used for snorting cocaine and things like that, other things. I find it really; well it was quite distressing really when I needed to go, and I can't get in the cubicle because it's not being used for what it should be. I'm desperate for it. So that's when I got the radar key, as I knew I was guaranteed a toilet in a private situation. There's definitely less cubicles in a men's, probably only two. There's always someone in there, especially if you're at a big event." (Shaun's interview)

For Shaun, getting a radar key meant ensuring access to a safe, singular, and somewhat 'private' cubicle as and when was necessary for public spaces. However, we discussed the notion of the radar key further. As well as the practical use of radar keys for reasons of accessibility and granting access, Shaun described the nuances of bearing the key – the effect this had and the reassurance. However, there was still a push to use the male toilets in commercial spaces, using radar keys and disabled toilets as a last resort. I asked Shaun if he used his radar key:

"Yes, it's quite handy at railway stations. Yeah, sometimes I do need it. I don't use it a lot but it's as I've put in the diary, it's a bit of comfort thing knowing that I've got that. If I didn't have that, I'd be really stressed out. I would be avoiding going places. It gives you those options to go somewhere, I mean I've never pulled out the IBS card I must admit because you always do manage to find, say you're in a strange town or whatever, you can always find a pub or a Wetherspoons a good one, or a book makers, there's always usually somewhere. It is handy to have it; it does give you that reassurance." (Shaun's interview)

Shaun reiterates the importance again of commercial spaces prior to accessing disabled toilets or revealing the 'Can't Wait' card. His account speaks to the importance, agency, and reassurance of things that assist in the negotiation of IBS symptoms, such as radar keys and 'Can't Wait' cards. The 'ontological security' (Giddens, 1991) that 'Can't Wait' cards can offer that has been discussed earlier in this thesis. These objects allow one to go somewhere, granting access when a space and the associated social actors might not immediately facilitate this process. Shaun's account tells a story of the reassurance of radar keys and 'Can't Wait' cards to manage his symptoms of IBS.

An important feature of day-to-day practice with IBS is the mapping and availability of toilets and how this affects the body itself. This is not to say that IBS is psychosomatic, but more to draw attention to the ways in which the built social environment and temporalities of everyday life become *embodied* and thus *affect* symptoms of IBS. The

consciousness of available and accessible toilets, in turn, affects those with IBS. This can happen in a number of ways. First, the mental anticipation of going to a place can trigger or halt symptoms. Second, the social environment and temporal organisation of everyday life can also mean that individuals take steps to prevent the possibility of symptoms in the first place. For example, many participants discussed taking Imodium ‘just in case’ when going out. This is in anticipation of symptoms whilst in situ, rather than symptoms being actually present. In introducing Lucas’ diary, he described how he has his body ‘*well trained to require a bathroom late at night or early in the morning*’ and how his body is ‘*trained to wait for the moment of getting home*’, which his partner refers to as his ‘GPS’ (global positioning system). This necessity of holding on until getting home says something about the inaccessibility and personal uncomfortableness of public toilet spaces, and the social stigma of having a bowel condition. Moreover, it demonstrates how our social landscape prevents social presence and affects the body. For example, Shaun described that often when going on trips, his brain ‘*switches off his urge to go*’:

“Friday 24th November: Spent Friday pottering around the house. The usual lunchtime visit happened as per usual. It’s strange really because when I go on my trip tomorrow, I will not need the loo at lunchtime. It’s as if my brain switches off my urge to go. Probably sends signals to my bowel saying, ‘This is not a convenient time’.” (Shaun’s Diary)

Upon discussing this in the interview, Shaun explained:

“Lauren: Did it affect your symptoms? As you talked in your diary you talked about when you go somewhere it can affect things.

Shaun: Yeah. I go to France each year and I’ve been going on the coach, but I find, I don’t how your brain does this, but your mental state seems to turn it the other way. It’s strange. It turns into the constipation, which I can live with, in fact I find it a lot better, for that particular situation.” (Shaun’s interview)

Shaun describes how his body recognises that there appears to be appropriate times and places he is expected to go. As seen in the account above, going on a coach trip is not one of them. These encounters for Shaun mean that his body and his symptoms respond to the inaccessible spaces and places that do not account for IBS. This also relates to

the reduced intake of food and drink or the '*preventative Imodium*' taking that many participants describe. The accounts demonstrate how individuals can take particular actions on their bodies as a deliberate practice to prevent toilet usage in public life, because of structural inaccessibility, feelings of illegitimacy, uncertainty, and stigma. Martin *et al.* (2015) explore the role of architecture and healthcare and its place within sociology, suggesting there should be an appreciation of how buildings are constructed and experienced. This has resonance with Wright's (2019) study, who explored the '*affective landscape*' of a sexual and reproductive health clinic. Through the lens of *affect* and *atmosphere*, Wright (2019) demonstrated how architectural design can shape patient experience in the clinic. These studies both focus on healthcare and clinics in particular but are nevertheless useful. In the case of IBS situated within everyday life, we see how architecture, together with the material belongings, can in turn affect the experience and accessibility of symptoms. From the anxieties inside of the car to standing at the face of the disabled toilet door, we see the capacities of space and place, affecting bodies and feelings of belonging, legitimacy, and certainty.

9.5 CONCLUSION

'Bathrooms meet the world outside... it hooks the human body up to technology, individuals to infrastructure and private to public realms.' (Penner, 2013: 9)

The *presence of* toilets, the journeys *to* them, and the *access* and experience *within* them are all important in the daily experiences of living with IBS. This chapter has explored how individuals with IBS negotiate the places in which they can and can't go whilst living with symptoms, or anticipations of the onset of such. The accounts derived from diaries and interviews demonstrated the importance and often centrality of toilets, with their materiality as a key instructor for participation in everyday social life. In realising and paying attention to this importance, I have attached toilets and the daily experiences of them to the '*mobilities turn*' (Sheller and Urry, 2000). I have considered how toilets are not simply a geometric space, but a place where geographical location, materiality, and social interaction are important. This applies Gieryn's (2000) understandings of space and place to the context of toilets. Echoing Urry's (2001: 3) suggestion that space and place should be '*central to sociology*', I wish to place toilets on the sociological map and stress their importance within our everyday lives. In doing so, there is an acknowledgement of access requirements when illness or disability forces into question the barriers in urban life that are '*tainted by struggles with the physical environment [and] societal attitudes*' (Bates, 2018: 985). In capturing this, this chapter has approached the places people can go when toilet access is brought to attention.

First, I have acknowledged the importance of 'toilet mapping'. Here, I draw attention not only to the knowledge of toilets based on only convenience of nearby locations, but I work to stress the preferential toilets that we frequent based on the embodied experience of being in one. In realising these factors as important experiences of place, there is a recognition of the security derived from *knowing* of locations and the places in which it feels appropriate to attend for matters of relief, security, and privacy. The knowledge and planning of toilets on everyday journeys then took us to thinking about how we embark on these journeys and the modes of transport used in doing so. In

continuing to think about the mobilities of the everyday, I have considered the journeys people take via public transport, planes, and trains, unpicking what these mean in the broader experiences of space and place. Here, I have reflected on Sheller's (2004) concept of '*emotional geographies*' experienced from modes of transport. In particular, I emphasise how cars, trains, and planes provoke feelings within them. I have stressed how planes can hypersensitise us to compromised space and the boundedness of our bodies. These '*emotional geographies*', for those travelling via planes and trains, in part derive from the materiality of the space and places in which we travel.

Thirdly and finally, I turned to questions of being granted access to toilets when out and about. I began this chapter with a quote from Molly who stated that often it is a question of '*Shall I or Shan't I?*'. When embarking on daily activities, the consideration and knowledge of the presence of toilets is often at the fore of participants minds. The accounts provided in this section raise broader questions about who is granted access to such spaces, the constitutions of accessibility and how this is navigated or anticipated when it comes to IBS. This has drawn upon Cooper *et al.*'s (2000) concept of a '*bladders leash*' whereby having a bladder or bowel condition draws attention to the social divisions and inequalities in toilet design and accessibility. Furthermore, these limitations of access in public life become embodied in the limitation of food and drink. Moreover, this section highlighted the 'invisible' nature of IBS as a condition, and how this is navigated in public disabled toilets where contestation is felt. Accounts have demonstrated the processes of 'passing' (Goffman, 1963) and questions of what constitutes both an in/visible illness and an il/legitimate one. For people living with IBS, the invisibility and legitimacy of the condition is woven into the experience of accessing toilets. Individuals with IBS know their condition cannot be seen, nor do they feel that the general public have an understanding of the impact of symptoms in their daily life. These questions of accessibility and provisions of toilets offer further demonstration for conversations with public policy, such as recent changes into disabled toilet signs that state 'not every disability is visible' (Crohn's and Colitis UK, 2019) together with the recent fee waivers to public toilets located in many train stations across the UK (BBC, 2018). Slater and Jones (2018) project, 'Around the Toilet', explores the inaccessibility and unavailability of toilets that are functional, easy to locate, and safe which can restrict the journeys and places people can go, and thus limits accessibility and engagement in broader social life. I would extend their call to stress

the importance of toilets as a key feature in the constitution of our social and civic life and thus important for our sociological understandings of the everyday.

This chapter has engaged with how IBS meets the external world in space and place, through the journeys taken and being granted access based on presentations of illness and/or disability. Again, there is a reinforcement of the overarching issue of the legitimacy of the condition, how certainty is established and how we might find ways to locate oneself in daily life. This chapter seeks to contribute to bodies of literature related to space and place (Gieryn, 2000), mobilities (Sheller and Urry, 2006; Sheller, 2004), and the sociology of toilets (Pickering *et al.*, 2019; Slater and Jones, 2018; Molotch and Noren, 2010), and how the experiences of places and journeys for people living with IBS speak to questions of accessibility (Wiseman, 2019; Kitchin and Law, 2001). These everyday journeys are of value sociologically in providing both ubiquitous and unique insights into a universal and human experience.

CHAPTER TEN

CONCLUSION

10.1 INTRODUCTION

*“It’s the 19th of July 2019 and the writing of this thesis is slowly coming to an end. A newspaper headline reads “**IBS does not exist’ despite 13 million Brits having it new research suggests**”³⁶ I read the article. It tells me nothing I haven’t heard already. The scientist behind the study states that IBS is a label without a clear and consistent trajectory in terms of diagnosis and treatment. I turn from the news back to my thesis. What am I saying about the existence of IBS?” (fieldnotes)*

As I reflect on this moment, the sociologist in me goes beyond the headlines and straight to the academic research cited in the article. The research suggests that IBS is an umbrella state, which may in the future be bracketed off into other conditions as knowledge progresses and diagnostic processes improve. I believe in this somewhat, given the diversity present in many participants’ stories. However, the reason I draw upon this moment as I end my thesis is that I come full circle from the start, returning to the existential nature of the IBS diagnosis. Despite these uncertainties, the thesis has emphasised the moments and experiences of *symptoms* that make IBS very much real.

The contested and conflicting nature and meaning of IBS is a theme running throughout this thesis. I have sought, through reflecting on my own personal experiences and those of the research participants, to locate IBS in everyday practices. This approach connects to my epistemological position of valuing the lived and embodied experience of individuals as a source of knowledge (Schutz, 1972). Choosing to ground this work within the sociology of everyday life, I have also had moments of anxiety for fear of trivialising the experience of the condition and its complexity and severity. Yet, the reason I turn to the everyday is precisely to give life to the experiences of IBS of those

³⁶ See newspaper article that prompted discussions into the nature of IBS:
<https://www.mirror.co.uk/news/uk-news/ibs-does-not-exist-despite-18366621>

who have it. I have sought to do this by attending to the places people go, their daily routines, and the social and material relationships that remind us of the impact of IBS. The condition is made real within these fragments of the everyday – the meals out with friends, the morning routines before work, the bus journeys, the visits to the hairdresser’s, the contents kept in bags, and the head turns scoping out the nearest toilet. These quotidian encounters are what help us to ground IBS in the real, daily occurrences that we might otherwise take for granted. As I seek to conclude this thesis, I will revisit its overarching aim, which has been to explore the everyday lives of people with IBS. I offer final reflections on the three overarching research questions:

- How are symptoms of IBS experienced in *mundane everyday spaces*? How are these symptoms negotiated as people *move between* these *places* of the *home*, the *workplace* or the *dinner table*?
- What are the *daily routines* and navigations of *time* for those living with IBS? How might these routines be disrupted, (re)organised and (re)imagined?
- What *social* and *material* relations are at play for those with IBS? How might these relations play out in ‘*public*’ and ‘*private*’ life?

In exploring each of these questions, I have grappled with the spatial, temporal, social and material relations of everyday life. In this conclusion, I will revisit the background and conceptual framing of this thesis, using these to reflect upon the everyday themes made present from those living with IBS. In doing this, I will also demonstrate the substantive and theoretical contributions that this thesis offers. Next, I consider the common threads that weave through the chapters. I ask what parallels can be drawn between (hand)bags and toilet preferences, from family meals and privacy in the home? In particular, I will draw attention to how the ordering of the empirical chapters of this thesis have sought to capture the shifts from the intimacy of personal lives to the structural, public issues. I consider the common threads across encounters of diverse areas of everyday life: feeling legitimate, establishing certainty, and questions of accessibility. The analysis offers a number of contributions to the field of sociology. Studying the case of IBS and pursuing the approach I have taken facilitates a contribution to the field of health and illness. Through the lens of the everyday, this thesis enables a particular way of understanding and coming to know chronic living. At the same time, the thesis offers a way for the sociologies of the everyday to appreciate

and be inclusive of chronic living. Like other strands within the field of the everyday, it brings the material, relational, temporal, and spatial to the fore. However, what is crucially important in this work is the contested nature of IBS. Whilst the study extends ongoing work into chronic conditions, experiences of health and illness, and the reorganisations of narratives in line with illness, the contested and taken-for-granted nature of IBS adds another dimension. It offers an insight into how we might take seriously everyday symptoms in light of dismissal, and the way the sociology of everyday enables us to do so.

Next, I think about how this research might change practice. This includes how this research might inform dietary provision, supportive and flexible working environments, and toilet design and provisions for accessibility. These factors shed light on the inhospitableness of public spaces, domestic living conditions, and everyday routines. These have implications not only for those living with IBS but facilitate ideas about how to make everyday life more liveable by paying attention to the hidden and the unarticulated. I will reflect briefly upon the limitations of this study, and the gaps left that offer windows for future research.

10.2 THESIS STORY

Throughout this thesis, I have attended to the ways in which the symptoms of IBS are negotiated in everyday life. Despite beginning the thesis with a somewhat medicalised exploration of IBS in the introduction and pen portraits, I have shifted my focus towards the minutiae of everyday experiences. I discussed contributions from the sociology of health and illness, covering similar conditions to IBS, matters of the bowel, stigma, and broader insights into health narratives and medically unexplained symptoms. In reviewing substantive literature within the sociology of health and illness, I stressed that IBS has fallen under the sociological radar due to the stigmas of the bowel and of failing to be seen as a legitimate illness. In looking to capture the everyday experiences of a medically unexplained, private, and glossed over health condition, I have conceptually framed IBS within the everyday. This sees the narratives resonating with theories of everyday life, in as much as there is a demand to take the experiences of medically unexplained symptoms and experiential knowledge seriously. Conceptually

exploring through sociologies of the everyday also fits with a desire to capture the mundane ways in which IBS is experienced spatially, temporally, relationally, and materially. This was also done in an attempt to vitalise these experiences in the presence of contestation. The participant narratives have been told through the mealtimes, the routines, the ways in which privacy is obtained materially and geographically, and the places one can or cannot go based on toilet access. Threaded throughout these accounts are anecdotes that bring to attention the characteristics of IBS; common, rarely articulated but the effect of symptoms taken-for-granted. However, it further invokes sensibilities of how some of the daily dilemmas presented to those living with IBS may not be so unfamiliar to those who do not. By drawing upon the sociology of the everyday in order to explore experiences of IBS, we are able to grasp the unusual and the familiar simultaneously (Robinson, 2008; Highmore, 2002). In a similar vein, considering the taboo nature of IBS symptoms and the ways in which they fail to be publicly articulated, we can map the more general experiences of what Elias (1978 [1939]) termed the civilising process. Here, we see matters of the body regulated in the form of manners and a move to the private realms of the home. This means that matters of toiletry life located within the private realm of our lives are hidden, and thus fail to be discussed in a public, social agenda. This is in spite of IBS being incredibly common. Similarly, whilst this thesis has not focussed explicitly on stigma (Goffman, 1963), it is nevertheless implicit within the everyday encounters and the search for legitimacy, accessibility, and establishing certainty.

This study into IBS offers a contribution to the sociology of everyday life by demonstrating how the functions, intimacies, and bodily products are unarticulated. I align the daily experiences of IBS with the conceptual framing found within the sociology of everyday life. The sociology of everyday life takes the mundane and extraordinary seriously, theorising them simultaneously (Robinson, 2008). Likewise, I locate IBS in the common, everyday encounters whilst also revealing the extremities of how the contested, dismissed, and taken-for-granted condition comes to be experienced. Through the lens of everyday life, we see not only daily encounters but broader tensions. These include finding everyday meaning and belonging and feeling secure in one's surroundings when an identity is shunned or contested. Finally, there is an acknowledgement of how societal structures can accommodate or exclude individuals with IBS. These are not extreme circumstances, but simple daily things like

visiting the toilet and getting to work on time. What these categories do through the everyday in the context of IBS is act as a reminder of what it means to be human. Stewart (2007) argues that '*ordinary affect*' is found within the particularities, and these work at connecting people through common experiences and the moulding of public feeling. And within that human nature, there is the appearance of the key (dys)functions of what our bodies do - eat, excrete, and repeat. The various accounts from the twenty-five research participants, were telling of mundane routines, objects, places and spaces of everyday life, told *through* the lens of IBS. I will now turn to discuss each of these thematically.

From the Dinner Table to the Toilet

This thesis set out to explore how IBS symptoms are negotiated in everyday spaces and places, and the movement between them – from the home, to the (hand)bag, and through to the public sphere. Specifically, how does one experience IBS in the privacy of one's own home in contrast to experiencing symptoms in the cubicle of a very public toilet? The diary method was deliberately utilised to capture these shifts in spaces, from the public world to the private thoughts. Stacy wrote her diary on the train, whilst others kept it secret and behind closed doors, writing in the evening in the comfort of their own home. Participant accounts shed light on the spaces and places that are significant in the experience of living with IBS. There are the social trips out to restaurants that result in the shifting of the food around the plate to save face, or the complete avoidance of eating food as a protective measure in the absence of a publicly accessible toilet. I extended Murcott's (1993) notion of the *consequential* nature of food that includes excretion. I argued that this comes to the fore through the experiences of IBS and the spaces and places that allow eating and consequent excretion to happen. IBS heightens this consequence and reinforces the importance of being in a place where an accessible toilet is available. Furthermore, having IBS places importance on the experience of public toilet spaces that offer security and privacy. Eating particular foods can open up uncertainty for the onset of symptoms. In some cases, food is completely avoided if the consequence of doing so means having symptoms in a public *place* where they would not be accommodated.

Delving into the routines of daily life that structure where we go further reinforces the importance of space and place. For instance, the working week and the bodily calculations of ‘When is the next toilet trip?’ have been further contextualised through *where* one can go. Does this involve symptoms at work the following day? What happens when we reach Friday night and the symptoms of IBS are no longer so urgent in the safety of one’s home? Similarly, I have demonstrated that morning routines *within* the home, or *before* the commute to work, are significant. Getting on top of matters of the bowel are pertinent before shoes and coats are put on and one is out of the door. Going to the toilet at home offers an ease and certainty, precisely because of its *private* nature. If this does not happen, matters of going to the toilet then open up the question of accessibility, availability, privacy, and public scrutiny. This point leads on to the latter two chapters that make place and space pertinent in the shifts from intimate geographies and sharing within the home, through to the immediately public issue of toilet access and mobilities. I draw in particular here on Twigg’s (1999) ordering of privacy, considering the navigations of privacy within our homes and the sharing of domesticities whilst living with IBS. I extend this concept by reiterating the ordering as it moves from the divisions within the home, to the (hand)bag, and through to public spaces that reinforce and reiterate the importance of privacy and intimacy. These chapters pay attention to the intimate encounters in places, from the hypersensitivities of the hairdresser’s, to the retreat home when denied access to a toilet in public settings. These are not extraordinary places to find oneself in, but everyday occurrences. By asking what is at stake when negotiating IBS and how it affects the places one goes, a picture has been painted of ordinary life, *complicated* by the position of the bowel in society, and of the condition that is denied legitimacy. Thinking about the spatial performances of IBS, it is important to reflect upon how these are also bound up with questions of time. As Urry (1996) advocated, it is impossible to separate the spatial ordering of everyday life from time, which leads us on to the next reflection of the temporal organisation of IBS.

From the Morning Rush to the Anticipation of Tomorrow

Throughout the course of this thesis, I have also sought to capture everyday temporality. This is in part because it came to my attention through my previous research on toilet mapping that demonstrated a sensitivity to time (White, 2016a). However, questions of

temporality also come through the conceptual framing of exploring IBS through the lens of everyday life and the methods used to do so. The accounts from the diaries were time stamped, of the days and times that IBS came to affect participants. The more reflexive accounts recognised the days that had passed them by with an absence of symptoms, as well as the documentation of personal worries of future symptoms affecting social activities. We saw how Kelly's invite to the seaside with friends brought into question the anticipatory nature of how *long* she could share a holiday home before IBS took its toll, and how she (re)organised her lunchtime meetings to navigate symptoms. The time of journeys versus the time of the bowel is brought to attention in chapter nine. This brings to attention how *places and spaces*, the *time it takes* to get to them and *what is there* on arrival are crucial to managing IBS. Chapter seven, told an explicit story about the (re)organisation of time. This involved not just recollections of disruption, but also of heightened awareness and strategic management of navigating a '*biological clock*' (which I extend to the *bowel*) against '*social time*' (Adam, 2004). There was an acknowledgement of the periodicity of symptoms. From Shaun's Tuesday symptoms following the pub on Sunday to Amy's Thursday constipation, I drew attention to the weekly routines of the biological clock of the bowel. Leder (1990) talks about the (dys)appearing body when faced with illness and/or disability – how the body is noticed and brought to attention when something changes. For those with IBS, the body, but most noticeably the *bowel*, is illuminated. Specifically, IBS gives attention to the bowel's regularities and its disruptions, not always as polar opposites. The early morning routines with IBS brought to light some of the first practices we do at the start of the day. However, these illustrate the ways in which time is '*squeezed*' (Southerton, 2003) in relation to the societal clock, and the call for slowing down, pacing, and accommodation (Charmaz, 1991; Kafer, 2013). I contribute to sociological understandings of time by extending how our 'biological' rhythms, here of the *bowel*, are bound with and complicated by the social demands of daily living. For example, the routines of eating and sleeping have been theorised in this way by sociologists, and within health and illness. However, matters of toiletry time are no exception, with or without IBS. This everyday and universal matter is brought to attention in the course of this thesis.

From the Home to the (Hand)Bag

As I return to my final research question, I look to retrace the ways in which the social and material relations were made visible in this thesis. I asked how the topic of IBS came into conversation with family members, friends, colleagues, and passers-by. As well as personal relations, relations with material things were brought to attention as (hand)bags were opened in interviews and items were revealed. Diaries proved to be of material worth, as were the material relations presented in the interviews. Bags were opened, and ‘*Can’t Wait*’ cards revealed and exchanged. Interviews exposed the broader agencies of what these objects, that is, what participants have the capacity to do whilst living with IBS. The construction and emplacement of toilets were brought to attention, working to provide insights into the power of access that can be granted or denied through radar keys and ‘*Can’t Wait*’ cards.

We have also the social and material relations of food. We can see the acts of love and care through the material preparation of meals suited to an IBS diet, with an acknowledgement of the visceral consequences of elimination when particular foods are eaten (Murcott, 1993). Moving forward, we can see the material and relational importance of the home: who is there, how many rooms, who is sharing with whom, and what things are where. A prominent feature of social-material encounters in public and private life, is the work performed by the (hand)bag. From Julie’s multiple kits in each car to Sophie’s handbag containing medications and wet wipes, these intimate items worked to locate and navigate the private nature of IBS when going out into the public world. Drawing upon Buse and Twigg (2014), I suggest that bags and their contents lend ‘*ontological security*’ (Giddens, 1991) in a society not yet equipped or receptive to the requirements of IBS. I extend this work beyond a focus on (hand)bags to include the men who also found ways of carrying items of importance in the presence or anticipation of IBS. Finally, in Chapter nine, the social and material relations of access and mobilities are brought to attention through the accounts of accessing public toilets. Is a toilet there, how might one get to it, and how long might this take? Drawing upon concepts of space and place, I have argued that toilets are not simply a matter of space, but of being a place that evokes deeper feelings of accessibility. The last section of chapter nine reminds us again of the negotiated legitimacy of IBS in trying to get to a toilet. In the accounts, there is a process of passing, here not as ‘*normal*’ (Goffman, 1963), but of having a *legitimate* illness.

Everyday Life with IBS: Legitimacy, Certainty and Accessibility

I have attended to accounts of IBS through the presentation of pen portraits and four analytic empirical chapters. In this final reflection, I consider what insights might be gained through drawing across these chapters. I suggest three broader issues can be discerned across the analysis, which relate to feelings of legitimacy, processes of establishing certainty, and broader questions of an accessible social world.

First, threaded throughout the daily accounts and evident from the very start of this thesis, is how IBS as a health condition is punctured with feelings of illegitimacy. The everyday negotiations of a search for legitimacy can be seen in the participant biographies at the start of the thesis. Furthermore, this quest and struggle for legitimacy becomes strikingly apparent in the day-to-day scenarios. For instance, it is evident in the navigations of an IBS diet that it is characterised by questionable food intolerances that pose a '*moral threat*' (Nettleton *et al.*, 2010). I extend this '*moral threat*' of food intolerance, exploring how with IBS this is further implicated by the consequential nature of food (Murcott, 1993). These navigations of legitimacy are made visible in the protective work of the '*Can't Wait*' cards, which shielded people in confrontations around being granted access to public toilets.

Second, and related to the cushion of the '*Can't Wait*' card, certainty is established in everyday practice when it cannot be granted by either the diagnosis or the treatment. To revisit Giddens' (1991: 92) concept of '*ontological security*' as discussed by Buse and Twigg (2014) in their work on handbags, this refers to the confidence we have as human beings in the stability and consistency of social and material environments. The reliability of persons and things are basic to establishing this certainty. Giddens' (1991) concept has been made pertinent in this study in material, spatial, and temporal ways. For instance, strategic steps are demonstrated throughout the chapters such as the avoidance of food, the (re)organising of routines or giving oneself extra time to secure oneself when symptoms are likely. Likewise, the knowing of toilet locations and the intimate items of importance are not just for necessity; as we have seen they often lay dormant (Woodward, 2015b). These items are also for anticipated future scenarios when the symptoms of IBS are uncertain and contested.

Third and finally, with ‘*Can’t Wait*’ cards still in mind, are the ways in which the social world is made (*in*)*accessible* in the face of IBS. Despite the ‘*ontological security*’ (Giddens, 1991) these things can offer, they are met with a social world that queries access and questions legitimacy. This is seen in the accounts of accessing disabled toilets, and the challenges of visibility and legitimacy, *in spite of* these objects. Retracing each chapter, we can see the ways in which social responses isolate and fail to accommodate the practicalities and emotions of IBS, in mundane but incredibly important ways. First, we saw the ways in which an IBS diet has not filtered into everyday social life. I showed the challenges in articulating unusual food intolerances together with a declaration of the nature of IBS symptoms as taboo and hidden from public life. The availability and accessibility of toilets is stressed throughout this thesis. Within the toilet talk in this research, it becomes clear that toilets become accessible not only in their placing, but in the experiences of them as significant social ‘space’ (Urry, 2001; Gieryn, 2000). Within these spaces, there are significant social interactions and material objects that make a difference in the everyday experiences of IBS, seen throughout the explanations of participants in this thesis.

To return to the conceptual framing of this thesis within the sociology of the everyday, I consider the following by Neal and Murji (2015: 813):

‘It is the realm of the everyday that brings the structure-agency knot directly into view, but more than this it brings close the immediacy and intensity of being in, and part of, social worlds’

This quote is pertinent in that, within the everyday, we locate individuals within the structures in which they find themselves, but most importantly, the processes of being ‘*in, and part of, social worlds*’. In locating the experiences of those living with IBS in the sociology of the everyday, we come to see the placing of the contested condition and how important it is to secure this in spatial, temporal, social, and material ways and give life to a common, taken-for-granted, taboo health condition. More than that though, it brings into focus the importance of inclusion and belonging in our social worlds that the notions of accessibility, legitimacy, and certainty call into question.

Daily Diaries and ‘Can’t Wait’ Cards: Methodological Contributions

I have sought to reflect on my methodology and method throughout the course of this thesis. This thesis has not sought to confine methodological reflections to the methodology chapter alone but demonstrated these through the structure of the thesis and the expressions of participants' biographies. The thesis has offered a number of methodological contributions. First, I have offered a contribution to the knowledge of IBS by taking an explicit focus on the narrative, lived experience. This adds to the small number of studies that consider the condition within the realms of qualitative research. While diaries capture the private accounts of public worlds, they also encapsulate the day-to-day workings of everyday life by their very format and repetitive documentation (Plummer, 1983). Second, I have offered a contribution towards the value of diaries within both sociology and within studying everyday health. The diaries captured not only negotiations of symptoms, but personal reflections and biographical notes. These offer methodological value as a research method as they capture the multiple ways of experiencing health and the ways of knowing. This thesis and its methods demonstrated in the diversity of how diaries can be completed, and importantly, celebrated for doing so. More specifically, I have demonstrated the possibilities of diaries for what components of everyday life they can uncover. This is demonstrated through the pen portraits that offered the biographical notes, and the framing of each empirical chapter that added a different dimension of everyday life. Third and finally, the diaries and the objects presented within the interviews have further contributed to what we can learn from talking through things (Woodward, 2019). These fragments of everyday life in the diversity of diaries and the 'things' brought to attention in interview settings speak not only as methodological tools, but of the broader importance for the experiences of IBS.

10.3 INFORMING PRACTICE

I began this chapter with a personal reflection on a recent headline that brought the condition of IBS to the news. By starting with the weight of everyday experience, the thesis takes IBS as an 'everyday' or 'common' condition *seriously*, and the profound nature of IBS comes to the fore. This could be reflected and communicated to both medical professionals who encounter IBS, but also shared amongst publics. More specifically, practice and care for those with IBS could be informed by the deeper, biographical insights that give voice and recognition to the symptoms experienced.

These practices of care might also include an appreciation of complexity, contradictions, and the importance of the social, made visible in the implementation of or resistance to dietary change and/or modification. Nettleton's (2006) work on medically unexplained symptoms recognises the importance of appreciating uncertainty and an '*embodied doubt*' that those with medically unexplainable illness experience. Her work demonstrates how those on the edge who are not granted permission to be ill in the absence of diagnosis also tell a story of mainstream structures of uncertainty and risk. This thesis has also offered an insight into the locations of this uncertainty in everyday practice. Acknowledging these uncertainties in the diagnosis and consequent management of IBS offers the potential to improve clinical practice. There can be a power in clinicians declaring uncertainty to patients which is equally important in the management of the condition.

Likewise, it would be helpful if there was a broader understanding of dietary requirements for those with IBS within food cultures and provisioning. Whilst we have seen menus incorporating vegetarianism, vegan diets, and lactose and gluten free diets, accommodations of an IBS friendly diet have not made it onto the menu. Further insight into the intricacies and balances of a Low-Fodmap diet, together with a society that takes food intolerances (and their complexities) seriously, would be a welcome conversation around public provisions into dietary requirements, facilitated by these participants' accounts. Turning to the routines of everyday life for those with IBS, this work might inform how we can pace life or slow down, with this being particularly pertinent to working environments. In particular, shining a light on morning routines demonstrated the implications of a ticking social clock and getting to work *on time* versus the biological rhythms of the bowel. These temporal structures disrupt and exacerbate symptoms of IBS, as well as causing individuals to compromise and weigh up other necessities such as sleep and taking time for breakfast. Several participants spoke of symptoms improving following retirement or when work is made flexible by working from home. Whilst I do not intend to imply that those with IBS should only stay at home, there should be the facilitation in working life and occupational health structures that recognise IBS, allowing for *flexible working hours* suit those who need them. Work within the field of employment rights and disability relations could further facilitate this conversation.

The participant accounts reflect upon the impact that our built environment can have on our experiences of health and illness. With this in mind, it offers an opportunity to think about how our toilets could be improved, rooms organised, and the provisions for accessibility in public life. Reimagining our built environment might include the number of toilets present within our domestic homes, having private toilet spaces within our places of work, and toilets on trains or motorways. These speak to broader issues of toilet availability and accessibility within our social landscapes and public spaces. Martin *et al.* (2015) advocate for an appreciation of both the construction and experience of buildings in the context of health. Although their focus is on healthcare settings, this conceptual framing is pertinent in everyday spaces that influence health too, such as public toilets. Finally, Fish *et al.* (2018) explore how in everyday life small acts come to matter through their work on lesbian, gay, and bisexual (LGB) activism. They argue that small acts within people's everyday lives have the capacity to lead to larger, structural change. Through the conceptual lens of the everyday with IBS, we see the moments matter which thus provide instructors for change. Beyond this thesis and in public life, we can see this change with the '*Not Every Illness is Visible*'³⁷ sign, which is making its way onto disabled toilet doors in shopping centres, pubs, airports, and train stations. These societal developments have value for those with IBS. These visible signs in our everyday lives and our public toilets are pertinent in the lives of people with IBS who experience such invisibility. There is a further conversation to be had here with regards to the legitimacy of IBS on top of the visibility in public life. There must be further recognition of symptoms taken seriously as a health condition with a label such as IBS.

10.4 LIMITATIONS

As with all research studies, this particular project is not without its limitations. In the main, the limitations of this research are methodological. Firstly, this is a relatively small-scale study with twenty-five participants. Further research could be encouraged with a larger cohort as a way to begin to build up a bigger picture of the diversity of lives for those with IBS. The participants from this study were, for the main part, White British. Further research could aim for a more intersectional sample. On this note, I

³⁷ <https://www.crohnsandcolitis.org.uk/news/not-every-disability-is-visible-campaign-targets-restaurants-and-pubs>

would push for increasing critical engagement with gender, ethnicity, class, disability, and geographical contexts. Capturing the diversity of people in future research would further develop an understanding of the experiences of IBS for people situated within their everyday lives, their social context, and the importance of their background. There are discrete accounts offered by particular groups, such as gendered or classed experiences. These are delicately interwoven in each of the data chapters, but not explicitly brought to attention and discussed. Further examination would be encouraged in the context of IBS. A final methodological reflection would be my own preference to conduct face to face interviews rather than phone calls, although these often took place in this study. Whilst phone calls have their benefits within social research, including issues such as discussing sensitive topics and geographical convenience (Holt, 2010; Sturges, and Hanrahan, 2004), I feel personally affiliated to meeting people, gaining rapport, and doing research in this manner. However, to do this, funding is needed to allow for travel to participants, which was not always possible in this doctoral research.

10.5 FUTURE RESEARCH

In bringing this research to a close, I will now offer some reflections on where I would like this narrative to go, and what insights I think should be gleaned in regard to future research. Here are a number of suggestions:

- Working lives were threaded throughout the accounts. The research has made visible the ways in which occupational structures and their rhythms can in turn affect the body in the case of IBS. Further research that allows for more explicit attention to these working lives has the potential to inform practice and occupational health.
- Whilst I have briefly touched upon intimacies within chapter eight, there is more to be said on the intimate encounters and relationships for those living with IBS. Several participants expressed the close intimate knowledge of bodies and bowels when relationships have stood the test of time and when partners have lived in close proximities and come to know intimate and unruly bodies through care and intimacy. This topic goes beyond IBS and/or illness more generally but extends to everyday practices of the body and the intimate knowledge we have

of each other as part of everyday, intimate relationships. This suggests that further research into IBS could include partners and family members as part of the conversation.

- As seen in chapter nine, travel is significant in its consequences and its emotional effect. We have also seen the limits of architecture and design featured within the modes of transport and the journeys between places where toilets are not available. Further research discussing travel and toilets, including *travelling with* and implementing *mobile methods*, has further potential for understanding the importance of toilet access *on the move*. This is not a matter simply for those with IBS, but for everyone.
- As seen in chapter eight, (hand)bags and objects became significant in the experience and negotiations of IBS. Further methodological work can be done here to give light to both objects as elicitation tools. There is also further substantive work to be done on the material presence (particularly on the move) of objects important in managing health conditions.

These are only a few suggestions, and it is hoped that many opportunities come to light through the journey of this research and future communication.

10.6 CONCLUDING THOUGHTS AND CONTRIBUTIONS

As we reach the conclusion, I have reflected upon how the participant accounts of living with IBS resonate and connect with everyday sociology. The empirical chapters of this thesis shine a light onto dimensions of daily life. It has engaged with the research questions of how IBS is experienced and told through space, time, and socio-material relations. In reflecting on spaces including the dinner table to the toilet, on routines such as the morning rush, and on material belongings kept in the (hand)bag, I have illustrated how mundane contexts give rise to experiences of IBS. In reorienting the private experiences of a hidden condition to public realms and social landscapes, I have made a case for the sociology of everyday life to act as a facilitator for an enlivenment of understandings of IBS. This is achieved precisely because of the status that IBS occupies as a common, yet underestimated health condition.

Overall, the study offers a number of contributions into theorising health through the lens of the everyday. It also affords a unique contribution to the sociology of everyday life beyond the lives of those living with IBS. Using a particular illness as a lens, there is potential to see the unarticulated, and often hidden, practices of the everyday. As with other strands within the sociology of everyday life, this study brings the material, relational, temporal, and spatial to the fore. IBS extends these realms within sociology by adding the dimension of a common illness that demands serious attention to such matters of everyday life. I have extended the notion of the '*moral threat*' of food intolerance (Nettleton *et al.*, 2010), by linking it to the *consequential* nature of food (Murcott, 1993), combining them to reveal the double bind of legitimacy and uncertainty of symptoms. I have elaborated everyday theorisations of time and routine, through illustrating the rhythms of the bowel and the central importance of toiletry time. This contributes to sociological literature that has previously illuminated everyday patterns of eating and sleeping. I have further contributed to Twigg's (1999) ordering of privacy, considering this within the geographical divisions and demarcations pertaining to the domesticities of ourselves and others. Furthermore, the data shows how this privacy links up with material belongings (Buse and Twigg, 2014) as people move into public life. Finally, through the accounts of IBS, I have contributed to the sociology of toilets and mobilities. These narratives tell an important story of toilets as

not simply being ‘there’, but they illustrate the affective capacities of the built environment. They show how the social interactions within these renders it possible to feel certain, legitimate and able to access such a space.

Methodologically, I have contributed to the current knowledge of IBS, told through a qualitative research approach. In particular, the research approach is one that engages with matters of the everyday. The value of diaries has been demonstrated in their potential to provide an insight into everyday life and the diverse ways in which they can be implemented. I have also contributed to the material ways of knowing, through the objects revealed in interview settings that served both methodological and empirical purposes. To bring these contributions together, it is within the capturing of daily practice that the experiences of IBS come to be illuminated. Within daily practices we see how IBS can disrupt and push for a reorganisation of everyday life. The nature of IBS, and the aforementioned absence of medicine, further illustrates the importance of focusing in on the lived experience of the condition in order to understand its location within the social world.

Next, building on these empirical threads, I have considered how this work may inform practice. This encompasses shifting knowledge and the information necessary to healthcare professionals, as well as the mundane acts that are essential to contribute to public understandings of the condition. In particular, I have highlighted how these insights have the potential to build upon current conversations around accessibility at the face of the toilet door. I have then turned to some of the limitations in this study, reflecting upon participant demographics and how future research may include a more diverse sample. I reflected upon the practicalities and potential of doctoral research, within time and resource constraints. I have considered this study as a starting point and the potential for future research, including but not limited to working lives, intimacy and familial relationships, travel and mobilities, and materialities that are part of health. Beyond these academic contributions, I seek to retain and finish with the everyday accounts. Let us pause on Kelly’s park bench and look out of Shaun’s bathroom window: it is the very fragments of living that make IBS visible. Such individual accounts are at the heart of these conceptual understandings, and I have endeavoured to give respectful interpretations, through representing the everyday lives of people with IBS.

REFERENCES

- Abrahamsson, S. (2014) 'Cooking, Eating and Digesting: Notes on the Emergent Normativities of Food and Speeds', *Time and Society*, 23(3), pp.287-308.
- Adam, B. (2004) *Time*. Cambridge: Polity Press.
- Adam, B. (1998) *Timescapes of Modernity*. London: Routledge.
- Adam, B. (1995) *Timewatch: The Social Analysis of Time*. Cambridge: Polity Press.
- Adam, B. (1992) 'Modern Times: The Technology Connection and its Implications for Social Theory', *Time and Society*, 1(2), pp.175-191.
- Allan, G. and Crow, G. (Eds.) (1989) *Home and Family: Creating the Domestic Sphere*. Basingstoke: Macmillan.
- Amouretti, M., Le Pen, C., Gaudin, A-F., Bommelaer, G., Frexinos, J., Ruszniewski, P., Poynard, T., Maurel, F., Priol, G. and Hasnaoui, A. (2006) 'Impact of Irritable Bowel Syndrome (IBS) on Health-Related Quality of Life (HRQOL)' in *Gastronenterologie Clinique et Biologique (Research and Clinics in Hepatology and Gastroenterology)* 30(2), pp.241-246.
- Annandale, E. (2014) *The Sociology of Health and Medicine: A Critical Introduction*. (Second Edition) Cambridge: Polity Press.
- Appadurai, A. (1986) *The Social Life of Things: Commodities in Cultural Perspective*. Cambridge: Cambridge University Press.
- Arendell, T. (1997) 'Reflections on the Researcher-Researched Relationship: A Woman Interviewing Men', *Qualitative Sociology*, 20(3), pp.341-368.
- Arksey, H. (1998) *RSI and the Experts: The Constructions of Medical Knowledge*. London: UCL Press.
- Back, L. (2015) 'Why Everyday Life Matters: Class, Community and Making Life Livable', *Sociology*, 49(5), pp. 820–836.
- Back, L. and Puwar, N. (Eds.) (2012) *Live Methods*. Oxford: Blackwell.
- Back, L. (2010) Broken Devices and New Opportunities: Re-imagining the tools of Qualitative Research', *ESRC National Centre for Research Methods NCRM Working Paper Series*.
- Back, L. (2007) *The Art of Listening*. Oxford: Berg.
- Back, L. and Duneier, M. (2006) 'Voices from the Sidewalk: Ethnography and Writing Race', *Ethnic and Racial Studies*, 29(3), pp.543-565.
- Backett, K. (1992) 'Taboos and Excesses: Lay Health Moralities in Middle Class Families', *Sociology of Health and Illness*, 14(2), pp.255-274.
- Bartlett, R. and Milligan, C. (2015) *What is Diary Method?* Bloomsbury Press.
- Bates, C. (2019) *Vital Bodies: Living with Illness*. Bristol: Policy Press.
- Bates, C. (2018) 'Conviviality, Disability and Design in the City', *The Sociological Review Special Issue: Streetlife*, 66(5), pp.984-999.
- BBC (2018) 'Reality Check: Public Toilets Mapped' [online] available from: <https://www.bbc.co.uk/news/uk-45009337> (last accessed 7/2/19)
- Bertram, S., Kurland, M., Lydick, E., Locke, GR III and Yawn, B. P. (2001) 'The Patients Perspective of Irritable Bowel Syndrome', *Journal of Family Practice*, 50(6), pp.521-525.
- Bias, S. 'Flying while fat' [online] available from: <https://www.youtube.com/watch?v=Eoiml0Co50Y> (last accessed 7/2/20)

- Björkman, I., Simren, M., Ringstrom, G. and Jakobsson Ung, E. (2016) 'Patients Experiences of Healthcare Encounters in Severe Irritable Bowel Syndrome: An Analysis based on Narrative and Feminist Theory', *Journal of Clinical Nursing*, 25(19-20), pp.2967-2978.
- Blumenthal, D. (2014) *Little Vast Rooms of Undoing: Exploring Identity and Embodiment Through Public Toilet Spaces*. London and New York: Rowman and Littlefield International.
- Bolger, N., Davis, A., and Rafaeli, E. (2003) 'Diary Methods: Capturing Life as it is Lived', *Annual Review of Psychology*, 54, 579-616.
- Booth, E. T. and Spencer, L. G. (2016) 'Sitting in Silence: Managing Aural Body Rhetoric in Public Restrooms', *Communication Studies*, 67(2), pp.209-226.
- Boxall, K., Nyanjom, J. and Slaven, J. (2018) 'Disability, Hospitality and the New Sharing Economy', *International Journal of Contemporary Hospitality Management*, 30(1), pp.539-556.
- Brannen, J. (1995) 'Time and the Negotiation of Work-Family Boundaries: Autonomy or Illusion', *Time and Society*, 14(1), pp.113-131.
- Braun, V. and Clarke, V. (2006) 'Using Thematic Analysis in Psychology' *Qualitative Research in Psychology*, 3(2), pp.77-101.
- Brown, B., Huszar, K. and Chapman, R. (2017) 'Betwixt and Between': Liminality in Recovery Stories from People with Myalgic Encephalomyelitis (ME) or Chronic Fatigue Syndrome (CFS)', *Sociology of Health and Illness*, 39(5), pp.696-710.
- Brownlie, J. and Anderson, S. (2017) 'Thinking Sociologically about Kindness: Puncturing the Blasé in the Ordinary City', *Sociology*, 51(6), pp.1222-1238.
- Buse, C., Martin, D. and Nettleton, S. (2018) 'Conceptualising 'Materialities of Care': Making Visible Mundane Material Culture in Health and Social Care Contexts', *Sociology of Health and Illness*, 40(2), pp.243-255.
- Buse, C. and Twigg, J. (2018) 'Dressing Disrupted: Negotiating Care through the Materiality of Dress in the Context of Dementia', *Sociology of Health and Illness*, 40(2), pp.340-352.
- Buse, C. and Twigg, J. (2014) 'Women with Dementia and their Handbags: Negotiating Identity, Privacy and 'Home' through Material Culture', *Journal of Ageing Studies*, 30, pp.14-22.
- Bury, M. (2001) 'Illness Narratives: Fact or Fiction?' *Sociology of Health and Illness*, 23(3), pp.263-285.
- Bury, M. (1991) 'The Sociology of Chronic Illness A Review of Research and Prospects', *Sociology of Health and Illness*, 13(4), pp.451-468.
- Bury, M. (1982) 'Chronic Illness as Biographical Disruption', *Sociology of Health and Illness*, 4(2), pp.167-182.
- Cahill, S. E., Distler, W., Lachowetz, C., Meaney, A., Tarallo, R. and Willard, T. (1985) 'Meanwhile Backstage: Public Bathrooms and the Interaction Order', *Urban Life*, 14(1), pp.33-58.
- Caplan, P. (1997) *Food, Health and Identity*. London: Routledge.
- Carter, A. (1987) *The Sadeian Woman: An Exercise in Cultural History*. London: Virago.
- Charmaz, K. (1991) *Good Days, Bad Days: The Self in Chronic Illness and Time*. New Brunswick, New Jersey: Rutgers University Press.
- Chelvanayagam, S. (2014) 'Stigma, Taboos and Altered Bowel Function', *Gastrointestinal Nursing*, 12(1), pp.16-22.
- Cohen, R. L. (2010) 'When it Pays to be Friendly: Employment Relationships and Emotional Labour in Hairstyling', *The Sociological Review*, 58(2), pp. 197-218.
- Conrad, P. and Bury, M. (1997) 'Anselm Strauss and the Sociological Study of Chronic Illness: A Reflection and Appreciation', *Sociology of Health and Illness*, 19(3), pp.373-376.

- Cooper, L. (1997) 'Myalgic Encephalomyelitis and the Medical Encounter' in S. Nettleton and U. Gustaffson (eds) *The Sociology of Health and Illness Reader*, Cambridge: Polity.
- Cooper, A., Law, R., Malthus, J. and Wood, P. (2000) 'Rooms of their Own: Public Toilets and Gendered Citizens in a New Zealand City, 1860-1940', *Gender, Place and Culture*, 7(4), pp.417-433.
- Corbin, J. and Strauss, A. (1987) 'Accompaniments of Chronic Illness Changes in the Body, Self, Biography and Biographical Time', *Research in the Sociology of Health Care*, 6, pp.249-281.
- Coveney, C. M. (2013) 'Managing Sleep and Wakefulness in a 24-hour World', *Sociology of Health and Illness*, 36(1), pp.123-136.
- Coveney, J. (2000) *Food, Morals and Meaning. The Pleasure and Anxiety of Eating*. London: Routledge.
- Crawford, P., Brown, B., Nerlich, B. and Koteyko, N. (2010) 'Nutritional Atruism and Functional Food: Lay Discourse on Probiotics', *Sociology of Health and Illness*, 32(5), pp.745-760.
- Crawford, R. (1984) 'A Cultural Account of 'Health': Control, Release and the Social Body', in J. B. McKinlay (Ed) *Issues in the Political Economy of Health Care*. New York: Tavistock.
- Dancey, C. P. and Rutter, C. L. (2005) *Take Control! Insights into Irritable Bowel Syndrome*. Harley: TFM Publishing.
- Dancey, C. P. and Backhouse, S. (1993) 'Towards a Better Understanding of Patients with Irritable Bowel Syndrome', *Journal of Advanced Nursing*, 18(9), pp.1443-1450.
- Devault, M. (1991) *Feeding the Family: The Social Organisation of Caring*. London: The University of Chicago Press.
- Dickson-Swift, V., James, E. L., Kippen, S. and Liamputtong, P. (2009) 'Researching Sensitive Topics: Qualitative Research as Emotion Work', *Qualitative Research*, 9(1), pp.61-79.
- Douglas, M. (1966) *Purity and Danger: An Analysis of Concepts of Pollution and Taboo*. London: Routledge and Kegan Paul.
- Dumit, J. (2006) 'Illnesses you have to fight to get: Facts as Forces in Uncertain, Emergent Illnesses', *Social Science and Medicine*, 62(3), pp.577-590.
- Dwyer, S. and Buckle, J. (2009) 'The Space Between: On Being an Insider-Outsider in Qualitative Research', *International Journal of Qualitative Methods*, 8(1), pp.54-63.
- Earle, S. and Letherby, G. (2007) 'Conceiving Time? Women who do or do not Conceive', *Sociology of Health and Illness*, 29(2), pp.233-250.
- Elias, N. (1978 [1939]) *The Civilising Process: The Development of Manners*. New York, NY: Urizen Books.
- Elliott, H. (1997) 'The Use of Diaries in Sociological Research on Health Experience', *Sociological Research Online*, vol. 2(2), <http://www.socresonline.org.uk/2/2/7.html>
- Ellis, J. (2018) 'Family Food Practices: Relationships, Materiality and the Everyday at the End of Life', *Sociology of Health and Illness*, 40(2), pp.353-365.
- Ellis, J. (2010) 'Family Practices During Life-Threatening Illness: Exploring the Everyday' *Unpublished Doctoral Thesis*. The University of Sheffield.
- Faircloth, C., Boylstein, C., Rittman, M., Young, M. E. and Gubrium, J. (2004) 'Sudden Illness and Biographical Flow in Narratives of Stroke Recovery', *Sociology of Health and Illness*, 26(2), pp.242-261.
- Fine, M. (2002) *Disruptive Voices: The Possibilities for Feminist Research*. Michigan: University of Michigan Press.
- Fine, G. (1996) *Kitchens: The Culture of Restaurant Work*. Berkeley: University of California Press.

- Fischler, C. (1988) 'Food, Self and Identity', *Social Science Information*, 27(2), pp.275-292.
- Fischler, C. (1980) 'Food Habits, Social Change and the Nature/Culture Dilemma', *Social Science Information*, 19(6), pp.937-953.
- Fish, J., King, A. and Almack, K. (2018) 'Queering Activism Through the Lens of the Sociology of Everyday Life', *The Sociological Review*, 66(6), pp.1194-1208.
- Fox, N. and Alldred, P. (2018) 'The Materiality of Memory: Affects, Remembering and Food Decisions', *Cultural Sociology*, 13(1), pp.1-17.
- Frank, A. (1995) *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago, Illinois: University of Chicago Press.
- Freund, P. and Maguire, M. (1999) *Health, Illness and the Social Body: A Critical Sociology*. Prentice Hall.
- Gabb, J. (2008) *Researching Intimacy in Families. Palgrave Macmillan Studies in Family and Intimate Life*. Basingstoke, UK: Palgrave Macmillan.
- Gell, A. (1998) *Art and Agency*. Oxford: Oxford University Press.
- Gibson, V. (1995) 'An Analysis of the Use of Diaries as a Data Collection Method', *Nurse Researcher*, 3(1), pp.61-68.
- Giddens, A. (1991) *Modernity and Self Identity: Self and Society in the Late Modern Age*. California: Stanford University Press.
- Gieryn, T. F. (2000) 'A Space for Place in Sociology', *Annual Review of Sociology*, 26, pp.463-496.
- Goffman, E. (1963) *Stigma: Notes on the Management of the Spoiled Identity*. Englewood Cliffs, N. J: Prentice Hall.
- Goffman, E. (1956) *The Presentation of Self in Everyday Life*. New York: Anchor Books.
- Goffman, E. (1955) 'On Face-Work: An Analysis of Ritual Elements in Social Interaction', *Psychiatry: Interpersonal and Biological Processes*, 18(3), pp.213-231.
- Goodson, I. (2013) *Developing Narrative Theory: Life Histories and Personal Representation*. London: Routledge.
- Graham, H. (1983) 'Caring: A Labour of Love'. In J. Finch and D. Groves (Eds.) *A Labour of Love: Women, Work and Caring*. London: Routledge and Kegan Paul.
- Green, J. M., Draper, A. K. and Dowler, E. A. (2003) 'Short Cuts to Safety: Risk and 'Rules of Thumb' in Accounts of Food Choice', *Health, Risk and Society*, 5(1), pp.33-52.
- Gregory, S. (2005) 'Living with Chronic Illness in the Family Setting', *Sociology of Health and Illness*, 27(3), pp.372-392.
- Gregory, D. and Urry, J. (1985) 'Introduction' in Gregory, D. and Urry, J. (eds.) *Social Relations and Spatial Structures*. Basingstoke: Macmillan.
- Gullemin. M. and Gillam, L. (2004) 'Ethics, Reflexivity and "Ethically Important Moments" in Research', *Qualitative Inquiry*, 10(2), pp. 261-280.
- Gurney, C. M. (2000a) 'Transgressing Private-Public Boundaries in the Home: A Sociological Analysis of the Coital Noise Taboo', *Venereology*, 13(1), pp.39-45.
- Gurney, C. M. (2000b) 'Accommodating Bodies: The Organisation of Corporeal Dirt in the Embodied Home', in L. McKie and N. Watson (eds.) *Organising Bodies: Policy, Institutions and Work*, Basingstoke: Macmillan.
- Gurney, C.M. (1998) Accommodating Bodies: Theorising the Body in Housing Studies. Paper given at 1998 BSA conference, Making Sense of the Body, Edinburgh.
- Gurney, C. M. and Means, R. (1993) 'The Meaning of Home in Later Life' in S. Arber and M. Evandrou (eds.) *Ageing, Independence and the Life Course*. London: Jessica Kingsley. pp.119-131.
- GUTS UK (2019) 'Irritable Bowel Syndrome' [website] available from: <https://gutscharity.org.uk/advice-and-information/conditions/irritable-bowel-syndrome/> (last accessed 03/08/2019)

- Hagerty, B. G. S. (2002) *Handbags: A Peek Inside a Women's Most Trusted Accessory*. Philadelphia: Running Press.
- Håkanson, C., Sahlberg-Blom, E. and Ternestedt, B. M. (2010) 'Being in the Patient Position: Experiences of Healthcare Among People with Irritable Bowel Syndrome', *Qualitative Health Research*, 20(8), pp.1116-1127.
- Håkanson, C., Sahlberg-Blom, E., Nyhlin, H. and Ternestedt, B. M. (2009) 'Struggling with an Unfamiliar and Unreliable Body: The Experiences of Irritable Bowel Syndrome', *Journal of Nursing and Healthcare in Chronic Illness*, 1(1), pp.29-38.
- Hammersley, M. and Atkinson, P. (2007) *Ethnography: Principles in Practice*. (Third Edition) London: Routledge.
- Heath, S., Davies, K., Edwards, G. and Scicluna, R. M. (2017) *Shared Housing, Shared Lives: Everyday Experiences Across the Lifecourse*. Abingdon: Routledge.
- Henderson, M. (1975) 'Acquiring Privacy in Public', *Urban Life and Culture*, 3(4), pp.446-455.
- Hillia, M. T., Farkkila, N. J. and Farkkila, M. A. (2010) 'Societal Costs for Irritable Bowel Syndrome - a Population Based Study', *Scandinavian Journal of Gastroenterology*, 45(5), pp.582-591.
- Hicks, D. (2010) 'The Material-Cultural Turn: Event and Effect' in D. Hicks and M. Beaudry (Eds.) *The Oxford Handbook of Material Culture Studies*. Oxford University Press.
- Highmore, B. (2002) *Everyday Life and Cultural Theory*. London: Routledge.
- Hislop, J., Arber, S., Meadows, R. and Venn, S. (2005) 'Narratives of the Night: The Use of Audio Diaries Researching Sleep', *Sociological Research Online*, 10(4) DOI: <https://doi.org/10.5153/sro.1194>
- Hockey, J. and Robinson, V. (2011) *Masculinities in transition* (Genders and Sexualities in the Social Sciences). Houndmills, Basingstoke, Hampshire; New York: Palgrave Macmillan.
- Hockey, J., Meah, A. and Robinson, V. (2007) *Mundane Heterosexualities: From Theory to Practices*. UK: Palgrave Macmillan.
- Hockey, J. (2002) 'Interviews as ethnography? Disembodied social interaction in Britain'. In: Rapport N (ed.) *British Subjects: An Anthropology of Britain*. Oxford: Berg, 209-221.
- Holt, A. (2010) 'Using the Telephone for Narrative Interviewing: A Research Note', *Qualitative Research*, 10(1), pp.113-121.
- Inglis, D. (2000) *A Sociological History of Excretory Experience: Defecatory Manners and Toiletry Technologies*. Lewiston, UK: The Edwin Mellen Press.
- Inglis, D. and Holmes, M. (2000) 'Toiletry Time: Defecation, Temporal Strategies and the Dilemmas of Modernity', *Time and Society*, 9(2), pp.223-245.
- Jacelon, C. S. and Imperio, K. (2005) 'Participant Diaries as a Source of Data in Research with Older Adults', *Qualitative Health Research*, 15(7), pp.991-997.
- James, A., Curtis, P., and Ellis, K. (2009) 'Negotiating Family, Negotiating Food: Children as Family Participants?' in A. James., A. Kioholt and V. Tingstag. (Eds.) *Children, Food and Identity in Everyday Life*. Basingstoke: Palgrave Macmillan.
- Jamieson, L. (1999) 'Intimacy Transformed: A Critical Look at the Pure Relationship', *Sociology*, 33(3), pp.201-220.
- Jamieson, L. (1998) *Intimacy: Personal Relationships in Modern Societies*. Cambridge: Polity Press.
- Jones, H., Neale, S., Mohan, G., Cochrane, A. and Bennett, K. (2015) 'Urban Multiculture and Everyday Encounters in Semi-public, Franchised Café Spaces', *The Sociological Review*, 63(3), pp.644-661.

- Jones, M. P., Keefer, L., Bratten, J., Taft, T. H., Crowell, M. D., Levy, R. and Palsson, O. (2009) 'Development and Initial Validation of a Measure of Perceived Stigma in Irritable Bowel Syndrome', *Psychol Health Medicine*, 14(3), pp.367-374.
- Jutel, A. (2014) *Putting a Name to It: Diagnosis in Contemporary Society*. Maryland: John Hopkins University Press.
- Kafer, A. (2016) 'Other People's Shit (and Pee!)' *South Atlantic Quarterly*, 115(4), pp. 755–762.
- Kafer, A. (2013) *Feminist, Queer, Crip*. Bloomington: Indiana University Press.
- Kelly, M. P and Field, D. (1996) 'Medical Sociology, Chronic Illness and the Body', *Sociology of Health and Illness*, 18(2), pp.241-257.
- Kelly, M. P. (1992) *Colitis*. London: Routledge.
- Killien, M. and Brown, M. A. (1987) 'Women and Family Roles of Women: Sources of Stress and Coping Strategies', *Health Care for Women International*, 8(2-3), pp.169-184.
- King, P. (2004) *Private Dwelling: Contemplating the Use of Housing*. London: Routledge.
- Kitchin, R. and Law, P. (2001) 'The Socio-Spatial Construction of (In)accessible Public Toilets', *Urban Studies*, 38, pp.287-298.
- Kleinman, A. (1988) *The Illness Narratives: Suffering, Healing and the Human Condition*. New York, NY, US: Basic Books.
- Koutroulis, G. (2001) 'Soiled Identity: Memory-Work Narratives of Menstruation', *Health*, 5(2), pp.187-205.
- Latour, B. (1993) *We Have Never Been Modern*. Cambridge, MA: Harvard University Press.
- Lavis, A., Abbots, E. J. and Attala, L. (2015) 'Introduction: Reflecting on the Embodied Intersections of Eating and Caring', in E. J. Abbots., A. Lavis and L. Attala (Eds.) *Careful Eating: Bodies, Food and Care*. London: Routledge.
- Lawton, J. (2008) 'Contemporary Hospice Care: The Sequestration of the Unbounded Body and 'Dirty Dying'', *Sociology of Health and Illness*, 20(2), pp.121-143.
- Lawton, J. (2003) 'Lay Experiences of Health and Illness: Past Research and Future Agendas', *Sociology of Health and Illness*, 25(supp.), pp.23-40.
- Lea, R. (2001) *The Performance of Control and the Control of Performance: Towards a Social Anthropology of Defecation*. PhD Dissertation, Department of Anthropology, Brunel University.
- Lea, R. (1999) "'The Shitful Body": Excrement and Control', *Medische Anthropologie*, 11(1), pp.7-18.
- Leder, D. (1990) *The Absent Body*. Chicago: University of Chicago Press.
- Lefebvre, H. (1991a) *The Production of Space*. London: Wiley-Blackwell.
- Lefebvre, H. (1996) 'The right to the city' in E. Kofman, and E. Lebas (Eds.) *Writings on Cities* (pp.147-159) Cambridge, MA: Wiley-Blackwell.
- Lefebvre, H. and Régulier, C. (2014 [1985]) 'The Rhythmanalytical Project', in Lefebvre, H. *Rhythmanalysis: Space, Time and Everyday Life*. London, Bloomsbury.
- Leston, S. and Dancy, C.P. (1996) 'Nurses Perceptions of Irritable Bowel Syndrome (IBS) and Sufferers of IBS', *Journal of Advanced Nursing*, 23(5), pp.969-974.
- Lewis, J. (2015) 'Dealing with Qualitative Questionnaire Data: Studying an Online Irritable Bowel Syndrome (IBS) Support Group' [Online] Sage Datasets: Sage Publishers. Available at: <http://methods.sagepub.com/dataset/qualitative-survey-ibs> (last accessed 23/12/2019)
- Lewis, R. (2011) 'Shutting the Bathroom Door: Parents, Young Teenagers and the Negotiation of Bodily Boundaries at Home' in Holt, J. (ed.) *Geographies of Children, Youth and Families*, London: Routledge.
- Lovatt, M. (2018) 'Becoming at Home in Residential Care for Older People: A Material Culture Perspective', *Sociology of Health and Illness*, 40(2), pp.366-378.

- Lowton, K., Hiley, C., and Higgs, P. (2017) 'Constructing Embodied Identity in a "new" Ageing Population: A Qualitative Study of the Pioneer Cohort of Childhood Liver Transplant Recipients in the UK', *Social Science and Medicine*, 172(1-9), pp.1-9.
- Lupton, D. (1999) 'Monsters in Mental Cocoons: "Road Rage" and Cyborg Bodies', *Body and Society*, 5(1), pp.57-72.
- Lupton, D. (1996) *Food, The Body and The Self*. London: Sage.
- Lupton, D. (1994) 'Food, Memory and Meaning: The Symbolic and Social Nature of Food Events', *The Sociological Review*, 42(4), pp.664-685.
- Macdonald, S., Murphy, S., and Elliott, E. (2018) 'Controlling Food, Controlling Relationships: Exploring the Meanings and Dynamics of Family Food Practices through the Diary-Interview Approach', *Sociology of Health and Illness*, 40(5), pp.1-14.
- Madigan, R. and Munroe, M. (1999) "'The more we are together": Domestic Space, Gender and Privacy', in Chapman, T. and Hockey, H. (eds.) *Ideal Home? Social Change and Domestic Life*. London and New York: Routledge, pp.61-72.
- Mallett, S. (2004) 'Understanding Home: A Critical Review of the Literature', *The Sociological Review*, 52(1), pp.62-89.
- Martin, D., Nettleton, S., Buse, C., Prior, L. and Twigg, J. (2015) 'Architecture and Healthcare: A Place for Sociology', *Sociology of Health and Illness*, 37(7), pp.1007-1022.
- Mason J (2002) *Qualitative Researching* (Second Edition). London: Sage.
- Massey, D. (1994) *Space, Place and Gender*. Cambridge: Polity Press.
- McCormick, J. B. Hammer, R. R., Farrell, R. M., Geller, G., James, K. M., Loftus Jr, E. V., Mercer, M. B., Tilburt, J. C., and Charp, R. R. (2012) 'Experiences of Patients with Chronic Gastrointestinal Conditions: In their own words' *Health and Quality of Life Outcomes*, 10(25), pp.1-11.
- McQueeney, K. and Lavelle, K. M. (2017) 'Emotional Labour in Critical Ethnographic Work: In the Field and Behind the Desk', *Journal of Contemporary Ethnography*, 46(1), pp.81-107.
- Meadows, R. (2005) 'The "Negotiated Night": An Embodied Conceptual Framework for the Sociological Study of Sleep', *The Sociological Review*, 53(2), pp.240-254.
- Merriman, P. (2004) 'Driving Places: Marc Auge, Non-places, and the Geographies of England's M1 Motorway', *Theory, Culture and Society*, 21(4/5), pp.145-167.
- Meth, P. (2004) 'Using Diaries to Understand Women's Responses to Crime and Violence', *Environment and Urbanisation*, 16(2), pp.153-164.
- Miller, D. (2008) *The Comfort of Things*. Cambridge: Polity Press.
- Miller, D. (2005) *Materiality*. London: Duke University Press.
- Miller, D. (1987) *Material Culture and Mass Consumption*. Oxford: Basil Blackwell.
- Mills, C. W. (1959) *The Sociological Imagination*. Oxford: Oxford University Press.
- Molotch, H. and Noren, L. (2010) *Toilet: Public Restrooms and the Politics of Sharing*. New York: New York University Press.
- Monaghan, L. F. and Gabe, J. (2015) 'Chronic Illness as Biographical Contingency? Young People's Experience of Asthma', *Sociology of Health and Illness*, 37(8), pp.1236-53.
- Morgan, D. (2009) *Acquaintances: The Space Between Intimates and Strangers*. Maidenhead: Open University Press.
- Murcott, A. (2013) Models of Food and Eating in the United Kingdom', *Gastronomica: The Journal of Critical Food Studies*, 13(3), pp.32-41.
- Murcott, A. (2000) 'Understanding Life-Styles and Food Use: Contributions from the Social Sciences', *British Medical Bulletin*, 56(1), pp.121-132.

- Murcott, A. (1993) 'Purity and Pollution: Body Management and the Social Place of Infancy', in D. Morgan and S. Scott (Eds.) *Body Matters: Essays on the Sociology of the Body*. London: Falmer Press/Taylor Francis.
- Neal, S. and Murji, K. (2015) 'Sociologies of Everyday Life: Editors' Introduction to the Special Issue', *Sociology*, 49(5), pp.811-819.
- Nettleton, S. (2013) *The Sociology of Health and Illness*. (Third Edition) London: Polity Press.
- Nettleton, S., Neale, J. and Pickering, L. (2011) 'Techniques and Transitions: A Sociological Analysis of Sleeping Practices amongst Recovering Heroin Users', *Social Science and Medicine*, 72(8), pp.1367-1373.
- Nettleton, S. and Uprichard, E. (2011) 'A Slice of Life': Food Narratives and Menus from Mass-Observers in 1982 and 1945', *Sociological Research Online*, 16(2).
- Nettleton, S., Woods, B., Burrows, R. and Kerr, A. (2010) 'Experiencing Food Allergy and Food Intolerance: An Analysis of Lay Accounts', *Sociology*, 44(2), pp.289-305.
- Nettleton, S. (2006) "'I Just Want Permission to Be ill": Towards a Sociology of Medically Unexplained Symptoms', *Social Science and Medicine* 62(5), pp.1167-78.
- Nettleton, S. and Watson, J. (1998) *The Body in Everyday Life*. New York: Routledge.
- NHS Choices (2019) *Irritable Bowel Syndrome (IBS)* [online] available from: <http://www.nhs.uk/Conditions/Irritable-bowel-syndrome/Pages/Introduction.aspx> (last accessed 03/08/2019)
- NICE (2015) *Irritable Bowel Syndrome in Adults: Diagnosis and Management of Irritable Bowel Syndrome in Primary Care*. [online] available from: <https://www.nice.org.uk/Guidance/CG61> (03/08/2019)
- Oakley, A. (1979) *From Here to Modernity: Becoming a Mother*. Harmondsworth, England: Penguin.
- Ogden, C. (2010) 'Potential Narrative Inquiry Approach in Developing a Psychosocial Understanding of Inflammatory Bowel Disease (IBD) in Children: An Essential Addition to Health Related Quality of Life (QoL) Instruments?', *International Journal of Narrative Practice*, 2(1), pp.57-71.
- Okami, P. (2002) 'Dear Diary: A Useful but Imperfect Method' in M. Wiederman and B. E. Whitley (Eds.) *Handbook for Conducting Research on Human Sexuality*. Mahwah, NJ: Lawrence Erlbaum Associates Publishers.
- Parsons, T. (1951) *The Social System*. London: Routledge.
- Pechurina, A. (2019) 'Airbnb Homes and People: Exploring Experiences of the Users of the Online Renting Service' [Website] Available from: <http://www.annapechurina.com/airbnb-project-1> (last accessed 12/7/19)
- Penner, B. (2013) *The Bathroom*. London: Reaktion Books.
- Penny, K. I. and Smith, G. D. (2012) 'The Use of Data-Mining to Identify Indicators of Health-Related Quality of Life in Patients with Irritable Bowel Syndrome', *Journal of Clinical Nursing*, 21(19), pp.2761-2771.
- Pickering, L., Wiseman, P. and Armstrong, S. (2019) 'Down the Pan: New Directions in the Sociology of Dirt', *The Sociological Review Monograph Series*, 64(7), pp.743-927.
- Pickering, L., Neale, J. and Nettleton, S. (2013) 'Recovering a Fecal Habitus: Analysing Heroin Users' Toilet Talk', *Medical Anthropology*, 32(2), pp.95-108.
- Pierret, J. (2003) 'The Illness Experience: State of Knowledge and Perspectives for Research', *Sociology of Health and Illness*, 20(4), pp.489-506.
- Pink, S., Morgan, J. and Dainty, A. (2014) 'The Safe Hand: Gels, Water, Gloves and the Materiality of Tactile Knowing', *Journal of Material Culture*, 19(4), pp.425-442.
- Pink, S. (2012) *Situating Everyday Life: Practices and Places*. London: Sage.
- Pink, S. (2004) *Home Truths: Gender, Domestic Objects and Everyday Life*. Oxford, New York: Berg Publishers.

- Plummer, K. ([1983] 2001), *Documents of Life 2; An Invitation to Critical Humanism*. London: Sage.
- Pound, P., Gompertz, P. and Ebrahim, E. (1998) 'Illness in the Context of Older Age: The Case of Stroke', *Sociology of Health and Illness*, 20(4), pp.489-506.
- Prout, A., Hayes, L. and Gelder, L. (1999) Medicines and the Maintenance of Ordinarity in the Household Management of Childhood Asthma', *Sociology of Health and Illness*, 21(2), pp.137-162.
- Reed, K. and Ellis, J. (2019) 'Movement, Materiality and the Mortuary: Adopting Go-Along Ethnography in Research on Fetal and Neonatal Postmortem', *Journal of Contemporary Ethnography*, 48(2), pp.209-235.
- Riessman, C. (2008) *Narrative Methods for the Human Sciences*. London: Sage.
- Riessman, C. (1993) *Narrative Analysis*. London, Sage.
- Ritchie, J., Spencer, L. and O'Connor, W. (2003), 'Carrying out Qualitative Analysis', in Ritchie, J. and Lewis, J. (eds.), *Qualitative Research Practice: A Guide for Social Science Students and Researchers*, London: Sage.
- Robinson, V. (2008) *Everyday Masculinities and Extreme Sport: Male Identity and Rock Climbing*. Oxford, New York: Berg Publishers.
- Robinson, V., Hockey, J. and Meah, A. (2004) "'What I used to do on my mother's settee": Spatial and Emotional Aspects of Heterosexuality in England', *Gender, Place and Culture*, 11(3), pp.417-435.
- Rønnevig, M., Vandvik, P. O., and Bergbom, I. (2009) 'Patients Experiences of Living with Irritable Bowel Syndrome', *Journal of Advanced Nursing*, 65(8), pp.1676-1685.
- Rosner, T. T., Namazi, K. H., and Wykle, M. L. (1992) 'Health Diaries and Interviews: Consistency in Reporting by Older Adults', *Research on Ageing*, 14(2), pp.248-266.
- Sacks, H. (1987) 'You want to find out if anybody really does care' in Button, G. and Lee, J. R. E. (eds.) *Talk and Social Organisation*. Clevedon: Multilingual Matters, pp.219-25.
- Sanders, C., Donovan, J, and Dieppe, P. (2002) 'The Significance and Consequences of Having Painful and Disabled Joints in Older Age: Co-existing Accounts of Normal and Disrupted Biographies', *Sociology of Health and Illness*, 24(2), pp.227-53.
- Saunders, B. (2017) "'It Seems Like You're Going Around in Circles': Recurrent Biographical Disruption Constructed Through the Past, Present and Anticipated Future in the Narratives of Young People with Inflammatory Bowel Disease', *Sociology of Health and Illness*, 39(5), pp.726-740.
- Saunders, B. (2014) 'Stigma, Deviance and Morality in Young Adults' Accounts of Inflammatory Bowel Disease', *Sociology of Health and Illness*, 36(7), pp.1020-1036.
- Scambler, G. (2009) 'Health Related Stigma' *Sociology of Health and Illness*, 31(3), pp.441-455.
- Scambler, G. (2006) 'Sociology, Social Structures and Health-Related Stigma', *Psychology Health and Medicine*, 11(3), pp.288-295.
- Scambler, G. (2004) 'Re-framing Stigma: Felt and Enacted Stigma and Challenges to the Sociology of Chronic and Disabling Conditions', *Social Theory and Health*, 2(1), pp.29-46.
- Scambler, G. and Hopkins, A. (1986) 'Being Epileptic: Coming to Terms with Stigma', *Sociology of Health and Illness*, 8(1), pp.26-43.
- Scott, S. (2018) 'A Sociology of Nothing: Understanding the Unmarked' *Sociology*, 52(1), pp.3-19.
- Scott, S. (2009) *Making Sense of Everyday Life*. Cambridge: Polity Press.
- Schutz, A. (1972) *The Phenomenology of the Social World*. London: Heinemann.
- Sheller, M. (2004) 'Automotive Emotions: Feeling the Car', *Theory, Culture and Society*, 21(4-5), pp.221-242.

- Sheller, M, and Urry, J. (2006) 'The City and the Car', *International Journal of Urban and Regional Research*, 24(4), pp.727-757.
- Shilling, C. (1993) *The Body and Social Theory*. London: Sage.
- Sixsmith, A. (1990) 'The Meaning and Experience of "Home" in Later Life' in Bytheway, B. and Johnson, J. (eds.) *Welfare and the Ageing Experience*. Aldershot: Avebury.
- Slater, J. and Jones, C. (2018) 'Toilet talk: Why our public toilets just aren't good enough' *The Conversation* [online] available from: <http://theconversation.com/toilet-talk-why-public-loos-just-arent-good-enough-97110> (date accessed: 7/2/19)
- Smart, C. (2014) 'Fragments: Living with Other People's Lives as Analytical Practice' in C. Smart and J. Hockey (Eds.) *The Craft of Knowledge: Experiences of Living with Data*. London: Palgrave Macmillan. pp.131-148.
- Smart, C. (2007) *Personal Life*. London: Polity.
- Southerton, D., Mendez, C. D. and Warde, A. (2012) 'Behavioural Change and the Temporal Ordering of Eating Practices: A UK–Spain Comparison', *International Journal of Sociology of Agriculture and Food*, 19(1), pp.19-36.
- Southerton, D. (2006) 'Analysing the Temporal Organisation of Daily Life: Social Constraints, Practices and their Allocation', *Sociology*, 40(3), pp.435-454.
- Southerton, D. (2005) 'Pressed for Time' – the Differential Impacts of a Time Squeeze', *The Sociological Review*, 53(2), pp.215-239.
- Southerton, D. (2003) "'Squeezing Time": Allocating Practices, Co-ordinating Networks and Scheduling Society', *Time and Society*, 12(1), pp.5-25.
- Stanley, L. (1993) 'On Auto/Biographies in Sociology', *Sociology*, 27(1), pp.41-52.
- Stapleton, H. and Keenan, J. (2009) '(New) Family Formation and the Organisation of Food in Households: Who Does What and Why?' in P. Jackson (Eds.) *Changing Families, Changing Food*. Basingstoke: Palgrave Macmillan.
- Stenner, P. H. D., Dancey, C. P. and Watts, S. (2000) 'The Understanding of their Illness amongst People with Irritable Bowel Syndrome: A Q Methodological Study', *Social Science and Medicine*, 51(3), pp.439-452.
- Stewart, K. (2007) *Ordinary Affects*. Durham and London: Duke University Press.
- Strauss, A. L., Corbin, J., Fagerhaugh, S., Glaser, B. G., Maines, D., Sucek, B. and Wiener, C. (1984) *Chronic Illness and Quality of Life*. (Second Edition) St Louis: Mosby.
- Stoller, E. P. (1995) 'Symptom Reporting During Physician Consultation: Results of a Health Diary Study', *Journal of Ageing and Health*, 7(2), pp.200-232.
- Sturges, J. E. and Hanrahan, K. J. (2004) 'Comparing Telephone and Face-to-Face Qualitative Interviewing: A Research Note', *Qualitative Research*, 4(1), pp.107-118.
- Taft, T. H., Bedell, A., Naftaly, J. and Keefer, L. (2017) 'Stigmatisation toward Irritable Bowel Syndrome and Inflammatory Bowel Disease in an Online Cohort', *Neurogastroenterology and Motility*, 29(2) DOI: 10.1111/nmo.12921
- Taft, T. H., Keefer, L., Artz, C., Bratten, J. and Jones, M. P. (2011) 'Perceptions of Illness Stigma in Patients with Inflammatory Bowel Disease and Irritable Bowel Syndrome', *Quality of Life Research*, 20(9), pp.1391-1399.
- Terrani-Brown, S. (2019) 'Maps Cannot Tell the Whole Story: Interpreting the Shitscape with a Mixed Methods Approach', *The Sociological Review*, 67(4), pp.807-828.
- Terrani-Brown, S. (2013) 'Kampala's Shitscape: Exploring Urbanity and Sanitation in Uganda', *Unpublished Doctoral Thesis*. University of Edinburgh: Edinburgh, UK.
- The IBS Network (2019) *The National Charity for IBS*. [website] Available from: <https://www.theibsnetwork.org/> (Last accessed: 10/09/2019).
- The Independent (2019) 'Argos will now allow customers with bowel conditions to use staff toilets in 800 stores' [online] available from: <https://www.independent.co.uk/life->

style/health-and-families/argos-staff-toilets-crohns-colitis-uk-cant-wait-card-bowel-conditions-a9015076.html (last accessed 15/12/19).

- The Metro (2017) 'Ulcerative Colitis Sufferer 'has accident' while White Stuff Store refuses to let her use the toilet' [online] available from: <https://metro.co.uk/2017/07/26/ulcerative-colitis-sufferer-has-accident-after-white-stuff-store-refuses-to-let-her-use-the-toilet-6807428/> (last accessed 15/12/19).
- Thomas, F. (2007) 'Eliciting Emotions in HIV/AIDS Research: A Diary-Based Approach', *Area*, 39(1), pp.74-82.
- Thomas, G. (2016) 'It's Not That Bad': Stigma, Health and Place in a Post-Industrial Community' *Health and Place* DOI: <http://dx.doi.org/10.1016/j.healthplace.2015.12.00...>
- Thomas, G. and Latimer, J. (2015) 'In/Exclusion in the Clinic: Down's Syndrome, Dismorphology and the Ethics of Everyday Medical Work', *Sociology*, 49(5), pp.937-954.
- Thompson, A. (2013) "'Sometimes I think I might say too much": Dark Secrets and the Performance of Inflammatory Bowel Disease', *Symbolic Interaction*, 36(1), pp.21-39.
- Turner, B. S. (1995) *Medical Power and Social Knowledge*. (Second Edition) London: Sage.
- Twigg, J. (1999) 'The Spatial Ordering of Care: Public and Private in Bathing Support at Home', *Sociology of Health and Illness*, 21(4), pp.381-400.
- Twigg, J. (2006) *The Body in Health and Social Care*. Basingstoke: Palgrave Macmillan.
- Twigg, J. (2000) 'Carework as a form of Bodywork', *Ageing and Society*, 20(4), pp.389-411.
- Tyler, I. and Slater, T. (2018) 'Rethinking the Sociology of Stigma', *The Sociological Review*, 66(4), pp.721-743.
- Urry, J. (2001) 'The Sociology of Space and Place' in Blau, J. (ed.) *The Blackwell Companion to Sociology*, Malden, US: John Wiley and Sons. pp.3-15.
- Van Der Geest, S. (1998) 'Yesbisa Wo Fie: Growing Old and Building a House in the Akan Culture of Ghana', *Journal of Cross-Cultural Gerontology*, 13(4), pp.333-359.
- Van der Geest, S. (2002) 'The Night-Soil Collector: Bucket Latrines in Ghana', *Postcolonial Studies*, 5(2), pp.197-206.
- Veen, M., Molder, H.T., Gremmen, B. and Woerkum, C.V. (2012) 'If you can't eat what you like, like what you can: How Children with Coeliac Disease and their Families Construct Dietary Restrictions as a Matter of Choice', *Sociology of Health and Illness*, 35(4), pp.592-609.
- Verbrugge, L. M. (1985) 'Triggers of Symptoms and Health Care', *Social Science and Medicine*, 20(9), pp.855-870.
- Verbrugge, L. M. (1980) 'Health Diaries', *Medical Care*, 18(1), pp.73-95.
- Ville, I. (2005) 'Biographical Work and Returning to Employment Following a Spinal Cord Injury', *Sociology of Health and Illness*, 27(3), pp.324-350.
- Warde, A. (2016) *The Practice of Eating*. Cambridge: Polity Press.
- Ward, R., Campbell, S. and Keady, J. (2016) 'Assembling the Salon: Learning from Alternative Forms of Body Work in Dementia Care', *Sociology of Health and Illness*, 38(8), pp.1287-1302.
- Warin, M., Turner, K., Moore, V. and Davies, M. (2008) 'Bodies, Mothers and Identities: Rethinking Obesity and the BMI', *Sociology of Health and Illness*, 30(1), pp.97-111.
- Webster, M. and Gabe, J. (2015) 'Diet and Identity: Being a Good Parent in the Face of Contradictions Presented by the Ketogenic Diet', *Sociology of Health and Illness*, 38(1), pp.123-136.
- Weiner, K. and Will, C. (2018) 'Thinking with Care Infrastructures: People, Devices and the Home in Home Blood Pressure Monitoring', *Sociology of Health and Illness*, 40(2), pp.270-282.

- Wendell, S. (1996) *The Rejected Body: Feminist Philosophical Reflections on Disability*. London: Routledge and Kegan Paul.
- White, L. (2019) 'My Dear Diaries: On the Valuing and Affinities to Research Materials', *Materiality and the Everyday Conference*. University of Sheffield.
- White, L. (2017) 'Living and Looking for Lavatories', *The Guardian Science Notes and Theories*.
- White, L. (2016a) 'That Girls Got Guts: Relationships and Everyday Life for Women with Irritable Bowel Syndrome', *Reinvention: An International Journal for Undergraduate Research*, 9(2), <http://www.warwick.ac.uk/reinventionjournal/archive/volume9issue2/white> (date accessed 19/9/2019)
- White, L. (2016) 'Temporal Tricks and Toilet Trips: Mapping Everyday Life with Irritable Bowel Syndrome' Masters Dissertation. The University of Sheffield.
- Will, C. and Weiner, K. (2014) 'Sustained Multiplicity in Everyday Cholesterol Reduction: Repertoires and Practices in Talk about 'Healthy Living'', *Sociology of Health and Illness*, 36(2), pp.291-304.
- Wilk, R. (2010) 'Power at the Table: Food Fights and Happy Meals', *Cultural Studies, Critical Methodologies*, 10(6), pp.428-436.
- Williams, O. and Annandale, E. (2018) 'Obesity, Stigma and Reflexive Embodiment: *Feeling the 'Weight' of Expectation*', *Health* <https://doi.org/10.1177/1363459318812007>
- Williams, S. (2011) *The Politics of Sleep: Governing (Un)Consciousness in the Late Modern Age*. Basingstoke: Palgrave Macmillan.
- Williams, S. (2000) 'Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept', *Sociology of Health and Illness*, 22(1), pp.40-67.
- Williams, S. (1984) 'The Genesis of Chronic Illness: Narrative Reconstruction', *Sociology of Health and Illness*, 6(2), pp.175-200.
- Wiseman, P. (2019) 'Lifting the Lid: Disabled Toilets as Sites of Belonging and Embodied Citizenship', *The Sociological Review*, 67(4), pp. 788–806.
- Woodward, S. (2019) *Material Methods*. London: Sage.
- Woodward, S. (2015a) 'Object Interviews, Material Imaginings and 'Unsettling' Methods: Interdisciplinary Approaches to Understanding Materials and Material Culture', *Qualitative Research*, 16(4), pp.359-374.
- Woodward, S. (2015b) 'The Hidden Lives of Dormant Things: Accumulations in Cupboards, Lofts and Shelves' E. Casey and Y. Taylor (eds.) *Intimacies, Critical Consumption and Diverse Economies*, Palgrave Macmillan: London, pp.216-231.
- Wright, S. (2019) 'From "Holding Pen" to "A Space to Breathe": Affective Landscapes in a Newly-integrated Sexual Health Clinic' *Sociology of Health and Illness*, <https://onlinelibrary.wiley.com/doi/full/10.1111/1467-9566.12852>
- Zerubavel, E. (1981) *Hidden Rhythms: Schedules and Calendars in Social Life*. University of Chicago Press.
- Zerubavel, E. (1979) *Patterns of Hospital Life: A Sociological Perspective*. Chicago: University of Chicago Press.
- Zimmerman, D. and Weider, D. (1977) 'The Diary-Interview Method', *Urban Life*, 5(4), pp.479-498.

APPENDICES

EVERYDAY LIFE WITH IRRITABLE BOWEL SYNDROME: INFORMATION SHEET

You are invited to take part in a research project which seeks to explore the everyday experiences of people who live with Irritable Bowel Syndrome (IBS). Before you decide to take part in the research, it is important that you understand the purpose of the research and your involvement in it. Please take the time to read the following information and ask any questions should you have any.

What is the research about?

The aim of this research is to explore how people living with IBS negotiate their everyday life. This includes how you might manage your IBS based on whether you are at home, at work, or in a public space. The research will also explore how your daily routines and schedules work with your IBS symptoms. Finally, the research will explore how your IBS may affect your social relationships, and how this may be different depending on what you choose to tell people, and what you choose to keep private. This project is part of my PhD which began in October 2016 and will be completed by October 2019.

Why have I been asked to take part?

I am looking for up to 25 people who live with IBS in the South Yorkshire area. If you are an adult (aged 18 or over) and live with IBS, I would be interested in talking to you about your experiences of managing your condition and how it affects your day to day life, routines, relationships and engagement in social activities.

Do I have to take part?

Participation in this project is entirely voluntary. If you decide to take part, you will be asked to sign a consent form. You will also be free to withdraw at any time during the research without giving a reason. If you decide to withdraw from the project, it will not negatively affect you in any way.

What will happen if I take part?

If you chose to take part, I will ask you to complete a diary for two weeks, where you can tell me about how IBS affects you on a daily basis. How you complete your diary is entirely up to you, but I will provide some suggestions of things to consider.

After you have completed the diary, I would like to meet up and have a chat about how you found completing a diary about your experiences with IBS, and for us to discuss some of the experiences that you might have written about in your diary. I would like to arrange the interviews at a place and time to suit you. I anticipate that the interview will last for around an hour. If possible, I would like to record the interviews to get an accurate record of what we talk about. I will ask for your permission before I do this, and recordings will be destroyed at the end of the research.

Will my taking part in the project be confidential?

Everything you say in the interview will be kept confidential. All data will be stored in a password protected file in which only I will have access to. Any names (your name and the names of others) or places you state in your research diary and/or interview will be anonymised. Please be aware that if at any point you feel uncomfortable during the research process you have the right to withdraw and any information you have given will be discounted from the study.

What are possible disadvantages of taking part in this study?

I do not foresee any disadvantages to you from taking part in this study. In the unlikely event that you become upset or distressed you may choose to withdraw from the study at any time. I may wish to quote some of the things you say during our discussion in the reports that will be produced from the study, but no one will be able to identify these as your words. Whatever you tell me will be treated as confidential and, if necessary, I will disguise your identity. You will have the right to stop the recorder at any point, and have the recording wiped clean, without any reason. Nothing recorded from our conversation will be traceable back to you.

What are the possible advantages of taking part in this study?

You will not benefit immediately or directly from taking part in this study but it is hoped that this study will contribute to understandings of what it is like to live with IBS on a daily basis.

What if there is a problem or something goes wrong?

If you have any problems or concerns during the research, please contact myself using the details below. However, if you feel unable to do this, you can also contact one of my supervisors, using their details below.

What will happen to the results of the project?

The findings from the project will contribute to my PhD, alongside future presentations and publications. If you decide to take part, you will also be kept informed of the findings and conclusions made from the study.

About the Researcher

I am a PhD student in the Department of Sociological Studies at The University of Sheffield. I am interested in Irritable Bowel Syndrome and how the condition affects everyday life. You can find more about my work here:

<https://www.sheffield.ac.uk/socstudies/postgraduate-research-students/lauren-white>

The project has been reviewed by the Department of Sociological Studies Research Ethics Committee at the University of Sheffield. This PhD study is funded by the Economic and Social Research Council (ESRC).

How to get involved

If you are interested in taking part in this research, please contact myself using the details provided below. I will be happy to answer any questions.

Lauren White
Department of Sociological Studies,
Elmfield Building,
Northumberland Road,
Sheffield, S10 2TU

lwhite2@sheffield.ac.uk
Telephone: 07722054147

Project Supervisors

Dr Kate Reed (contact: k.reed@sheffield.ac.uk)
Dr Kate Weiner (Contact: k.weiner@sheffield.ac.uk)

Thank you for taking your time to read this information. You will be given a copy of this information sheet and a signed consent form for you to keep. Thank you for taking your time in this project.

CONSENT FORM



Negotiating Everyday Life with Irritable Bowel Syndrome

I confirm that I have read the information sheet for this study and have had an opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time.

I am willing for a recording to be made of the interview, and for it to be transcribed / written out and included in the research.

I understand that my details will be made anonymous in order to protect my identity (i.e. names and other identifying features will be altered) and that all data will be treated as personal under the 1998 Data Protection Act, and will be stored securely.

I am aware that my words may be quoted in written work, reports, presentations and organisations that may be interested in the research, and may be used for research training.

I understand that I may contact the researcher or supervisor if I require further information about the research.

Name of Participant

Signature

Date

I understand that my anonymised transcript and diary entries may be stored as part of the UK Data Service, and other researchers may use my words if they agree to preserve confidentiality and the other terms agreed on this form.

Name of Participant

Signature

Date

I confirm, as a research student, that I agree to keep the undertakings in this contract.

Researcher

Signature

Date

Contact Details:
Lauren White

DIARY GUIDANCE

Everyday Life with Irritable Bowel Syndrome GUIDANCE ON KEEPING YOUR DIARY

This research seeks to explore what it is like to live with Irritable Bowel Syndrome (IBS) and how symptoms are managed on a day to day basis. In particular, how managing your symptoms may be affected by where you are, the time of day, who you are with, or whether you are in a public or at home, for example.

It is entirely up to you how you wish to complete your diary. You might want to begin with something along the lines of:

Tell me about your day with IBS

However, here are a few pointers you can refer to:

- How your IBS might affect your daily routine e.g. getting up in the morning
- How you might have to factor time into your day e.g. toilet time, travel time
- How your IBS may affect travelling e.g. going on buses, trains, the times of journeys
- How you feel and manage your IBS at home, versus out and about - the places you go, the places you don't/can't
- How toilets/bathrooms may affect day to day life e.g. knowing where the toilets are and what they are like
- The known aboutness of your IBS to others - this could be a partner or spouse, family members, children, parents, friends, work colleagues and even 'strangers'
- What objects/things are important when managing your IBS? E.g. toilet roll, spare change, Imodium, particular foods that you might carry in your bag
- How breakfast/lunch/dinner time may affect you

Please remember that every activity, thoughts or feelings are important, even if it seems small and mundane to you.

If possible, please add to your diary regularly for two weeks from receiving it and carry it around with you. I will keep in touch and request that you post the diary materials after this period, with a pre-paid envelope to return to me. After I have received the diary, I will look at your entries and ask to meet for an informal interview (at your convenience) to discuss how you found keeping the diary, and to discuss what you wrote about, and why.

If you have any questions, please feel free to email me at lwhite2@sheffield.ac.uk or phone 07722054147

Thank you for dedicating your time and for sharing your story