

# Telling the untellable stories of women living with Irritable Bowel Syndrome (IBS)

Devina Lister

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Department of Psychology

Manchester Metropolitan University

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## Abstract

Irritable Bowel Syndrome (IBS) is a common, chronic bowel illness involving the presence of unpleasant bodily sensations and pain. In the current research the 'stories' women living with IBS had to tell were studied as part of a multi-layered narrative 'bricolage' (Kincholoe, 1991) analysis. The language used to discuss women living with IBS in a primarily scientific and deductive literature, was argued to be problematic, and reinforce gendered notions of IBS as a 'women's disease' (Dixon-Woods and Critchley, 2008). Informed by the researcher's positioning as a feminist and a woman living with IBS based in the UK, this feminist-narrative study was carried out and placed women's standpoints (Harding, 1991) at the forefront of IBS research.

Participants who volunteered to take part were women living with IBS and who were based in 'Western' countries, such as the UK, USA and Australia. Each of the participants completed a diary for one-week, completing at least one entry per day by writing or drawing about what was meaningful to them, reflecting upon their everyday lives and experiences of IBS and illness. Diaries were used as a means of conducting narrative inquiry, which takes human experiences seriously as the phenomena of interest (Clandinin and Connelly, 2006). The diary method also facilitated adopting a stance on illness as 'embodied' experiences, transcending a divide between the mind and body (see for example, Bendelow, 2009).

The research aims were to explore stories the women had to tell about their lives, whilst also considering if Western ‘cultural scripts’ (Miller, 2005) of femininities and of chronic illness informed the personal story constructions.

The interpretations presented how the diverse and nuanced accounts explored embodied experiences of bodily shame, suffering, hope to ‘be positive’, and efforts to keep going when faced with the challenges of living with a chronic illness. Consistent with past literature (Björkman et al., 2013) illness was emplotted into the women’s stories in gendered and culturally meaningful ways, such as by drawing upon narrow Western feminine body-ideals. Whilst the women could not contain their ‘leaky bodies’ (Shildrick, 1994), this did not prevent them constructing stories about trying to keep up an appearance of normalcy and able-bodiedness.

In addition to providing valuable new knowledge about stories of IBS, illness and gendered embodiment, this research showed the promise of adopting a creative and playful approach to conducting feminist research. The thesis itself was conceptualised by the ‘insider’ researcher as having been symbolic of what it was like to complete a PhD when experiencing intermittent illness. Poetry-as-method thus provided a valuable vehicle for the research during the interpretative process, but also in realising the potentials of artful research in creating space for innovative and politicised social action.

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## List of abbreviations

CFS – Chronic Fatigue Syndrome

FGID – Functional Gastrointestinal/Bowel Disorder

GI - Gastrointestinal

IBS – Irritable Bowel Syndrome

IBD - Inflammatory Bowel Disease

WHO – World Health Organisation

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# Chapter 1: Normative accounts of

## Irritable Bowel Syndrome (IBS)

Dixon-Woods and Critchley (2008) carried out research exploring doctors' perceptions of IBS patients amongst general practitioners and specialist gastrointestinal system doctors (gastroenterologists). In response to their research one of the specialist doctors stated that they felt there was a specific type of patient that has IBS:

Patients tend to be women, middle-aged, worriers, anal[sic] retentive people who think a lot about health and bowels...[they are] stressed, obviously twitchy, [and] quite neurotic. (Dixon-Woods and Critchley, 2008:109, parentheses added)

Not all health professionals have such pejorative views of the 'worrying' and 'anally retentive' patients with IBS (Harkness et al., 2013). Yet, Chang et al., (2006:1441) noted that there are denigrating views of IBS patients because of persisting 'societal myths' connected with illnesses like IBS. Research carried out by Letson and Dancey (1996:969) that involved interviews about IBS perceptions by nurses in the UK found that IBS patients were stereotyped as 'demanding, unable to cope with life...and waste doctors' time'. Perceptions of chronic bowel illness like IBS by friends, colleagues and loved ones are not

much better than this, according to past research, which has repeatedly found people avoid disclosing bowel illness status and experiences for fear of embarrassment and judgement by others (Dancey and Backhouse, 1993; Schneider and Fletcher, 2008; Taft et al., 2011; Barned et al., 2016).

## **Contentious, culturally constructed illness**

### *Not 'all in your head'*

It is possible to see why IBS can involve unique challenges because of negative attitudes about an illness perceived as 'trivial or unimportant; [with] symptoms...all in the person's head' (Chang et al., 2006:1441, parenthesis added). My personal experience as a woman who experiences chronic bowel issues that have been diagnosed as 'IBS', is that such views persist. This is not a unique experience, and with the rise of increasing amounts of health information available online (see for example, Hardey, 2010), people no longer necessarily need to go to their doctor for a diagnosis. This is one reason why IBS is contentious as a diagnostic category, but the negative attitudes and perceptions of IBS can also have ripple effect on the everyday lives and social relationships of women living with IBS (see for example, Dancey and Backhouse, 1993; Schneider and Fletcher, 2008; Lee, 2011; Spencer, 2014).

The contestation surrounding IBS as a diagnostic category (see for example, Camilleri, 2012) arrives from a lack of medically detectable

pathophysiology, or evidence of biological disease. Subsequently, IBS is sometimes known as a 'medically unexplained' illness rather than a 'medically explained' illness with scientifically identified biological markers (Edwards et al., 2010; Jutel, 2010; Corsetti et al., 2014). IBS is therefore one a number of illnesses that challenges the grand narrative of the power of Western medicine to identify, manage or cure all. The medical context is therefore critical in framing IBS as contentious, as Conrad and Barker (2010:69) argued, bridging the divide between personal and cultural meanings of illness:

Contested illnesses are a category of disorders that, by definition, have a very particular cultural meaning. These are illnesses where sufferers claim to have a specific disease that many physicians do not recognize or acknowledge as distinctly medical. Contested illnesses, including chronic fatigue syndrome, fibromyalgia syndrome, irritable bowel syndrome, and multiple chemical sensitivity are medically suspect because they are not associated with any known physical abnormality. These illnesses showcase the tension between lay and medical knowledge with respect to the cultural legitimization of symptoms and suffering. (Conrad and Barker, 2010:69)

Conrad and Barker highlighted the ‘tensions between lay and medical knowledge’ (ibid.) and this is of relevance within the current research. Rather than carrying out deductive research, the thesis explains how research was carried out that looked beyond the medicalisation of women’s bowel issues to consider how illness played out in the arena of their everyday lives, and by paying attention also to gender. The current research attended to the ‘stories’ a group of women living in ‘Western’ countries had to tell, and who drew upon their unique and socially situated knowledges (Haraway, 1988) to make sense of the world. In this way, not even the question of psychology as a ‘science’ involving objectivity was left uninterrogated, with my feminist positioning informing the design and conduct of what was aimed to be ethically-informed ‘feminist research’ (see for example, Haraway, 1988; Stanley, 1990; Harding, 1991; Wilkinson and Kitzinger, 1996).

To open this chapter I will discuss some of main themes within the past IBS research that have been carried out to provide an account of normative understandings and ‘theories’ of IBS. This includes an overview of the prevalence, medical context, and consensus on the ‘biopsychosocial’ aetiology of IBS (see for example, Drossman, 1990a; Drossman and Dumitrascu, 2006). This will move into justifying the current research reported in this thesis over the course of the next two chapters, which looked beyond the medical context to the scenes of women’s everyday lives, and to consider how personal and cultural

‘narratives’ unfolded in nuanced ‘stories’ women living with IBS had to tell.

## **Prevalence of a common chronic bowel illness**

IBS affects many people worldwide with the highest prevalence thought to be amongst women living in Western countries such as the UK, USA, and Europe (see for example, Gwee et al., 2004; Lovell and Foord, 2012; Canavan et al., 2014). IBS is considered as something more likely to be experienced by women, at a rate of two to three times as many women as men living with IBS (Masud et al., 2001; Kumano et al., 2004; Hungin et al., 2005; Chang et al., 2006; NICE, 2008; Jonefjäll et al., 2013). The UK organisation, the National Institute for Health and Care Excellence (NICE, 2008) predicted that IBS affects at least 10-20% of the UK population. Comparatively high rates are found in other Western cultures, such as in the USA and Europe (Chang, 2006; Chang et al., 2006). There appears to be a marked gender disparity in IBS prevalence, although exploring the literature more closely has shown any assumptions about prevalence are not as simple as they may at first seem.

### **IBS as a ‘women’s disease’**

According to past research, the ‘typical’ is most likely to be a woman living in a Western country who may or may not have access to financial resources and may be aged anywhere between 20-40 years

old (see for example, Canavan et al., 2014; Ford et al., 2013; Chang et al., 2006). Gwee (2005) argued that there appears to be fewer people living with IBS, with differences in the ratio of men to women living with IBS found in studies of illness rates in non-Western countries. This is in part because more studies have been carried out in Western and 'wealthy' countries such as the USA and UK, although a steadily increasing amount of research is being conducted in Asian countries (Gwee, et al., 2004; Lovell and Foord, 2012; Canavan et al., 2014). For example, in China and Singapore there has been shown to be little or no gender disparity in IBS rates (Chang and Heitkemper, 2002; Gwee et al., 2004; Gwee, 2005; Quigley et al., 2009; Gwee et al., 2010; Jung 2011a; Liu and Jou, 2011; Canavan et al., 2014). Masud et al. (2001) found that significantly more men were living with IBS in India, which they connected this to men being privileged with more financial and social resources, including better access to healthcare than women. Gwee (2005) argued that gender and culture intersect to be contributing to the spread of IBS worldwide. The uptake of Western practices such as eating processed food, Gwee (2005) determines as contributing to IBS being define as a 'civilisation disorder'.

### **Unpacking assumptions about gender, health and help-seeking**

Other reasons for gender disparities in illness rates can be connected to health practices in Western countries. The female-male ratio of IBS is less marked amongst people living with IBS in the community, and this contributes to theories that patients or people living with IBS in the



community constitute ‘sub-groups’ (Drossman et al., 1990; Drossman, 1999a; Smith et al., 2004) of the IBS population. Patient status is connected to gender disparities in prevalence, but also with a poorer overall quality of life, and more non-bowel related and ‘comorbid’ symptoms such as fatigue and anxiety, when compared to community samples of people living with (Drossman et al., 1990; 1999a; Kennedy et al., 1998; Chang and Heitkemper, 2002; Riedl et al., 2008; Cain et al., 2009; Adeyemo et al., 2010). This is an important issue when making sense of how many people are predicted to be experiencing IBS, since ‘help-seeking’ practices vary considerably not everyone chooses to seek a diagnosis and treatment for their bowel issues (see for example, Hungin et al., 2003; Hungin et al., 2005; Katsinelos et al., 2009).

### *Undiagnosed illness*

Part of the reason why IBS is not formally diagnosed is because of health inequalities that are shaped by who can afford and access healthcare, as determined by the way healthcare systems are organised (Van Doorslaer et al., 2004; Or et al., 2008; Delvaux et al., 2015). This shapes prevalence figures as different health resources are available to different women living with IBS. IBS is recognised throughout the world as a valid and diagnosable condition, but permanent residents of the UK, Spain and Australia are more fortunate in terms of their healthcare access. In these countries healthcare is provided for free at the first point-of-contact in healthcare settings, such as when visiting a GP (see for example, Consumers Health Forum of Australia, no date; Delvaux et al., 2015). By contrast, the USA has a

privatised and market-driven healthcare system with no universal healthcare provision, and so the rich and middle-class are more likely to be able to afford the private health insurance that pays for healthcare (see for example, Or et al., 2008; Ridic et al., 2013). Even though these marked differences exist between healthcare systems in different 'Western' countries, IBS is nonetheless widespread and has a high prevalence amongst patients based throughout the Western world (see for example, Gwee, 2005; Canavan et al., 2014).

## **Health and illness as gendered issues**

A World Health Organisation's report (WHO, 2008) emphasised how gender is a structural factor informing and shaping health inequalities (WHO, 2008). This is emblematic of wider acceptance that health and healthcare practices are informed by gender (Verbrugge, 1985; Connell, 1987; Courtenay, 2000; Doyal, 2001; Connell, 2012; Hankivsky, 2012), just as other health outcomes are shaped by factors such as a person's age, class, race, and sexuality (see for example, Hankivsky, 2012; Reczek and Umberson, 2012). In the IBS research it is possible to see how gender is connected with healthcare practices, with women seen to be more likely than men to seek help for IBS symptoms in healthcare settings (see for example, Chang and Heitkemper, 2002; Chang et al., 2006).

The relationship between gender and health is interactive' (Dixon-Woods et al, 2005: 236), and determines healthcare practices, and vice

versa as 'health and health behaviours are...ways of demonstrating gender. Gender and health are therefore integral to the construction of personal identity.' (Dixon-Woods et al, 2005:236) Women and men learn during gender socialisation about gender roles (Bem, 1983; Wharton, 2005), with sex and gender seen as distinct categories: 'sex' determined by biology, and 'gender' as culturally determined by 'socially constructed roles, behaviours, activities, and attributes that a given society considers appropriate for men and women' (WHO, 2015). This is relevant when considering how, as Wharton (2005:32) described this, the process of gender socialisation contributes to a person's understanding of what constitutes 'good' female/feminine and male/masculine behaviour (Bem, 1983). This has contributed to the perpetuation of a 'strong public narrative' (Hunt et al., 2012:241) that health and help-seeking are female matters (see for example, Saltonstall, 1993; Courtney, 2000). Illness is thus 'traditionally associated with weakness' (Dixon-Woods et al., 2005:245) and femininity, which can be seen historically in female 'maladies' (Showalter, 1985) such hysteria and other diseases of the 'nerves' (Showalter, 1998). Femininity and illness are subsequently dichotomised with masculinity and maleness, with the macho man who is seen 'tough[ing] it out' (Hunt et al., 2012:241, parenthesis added) and being the 'strong stoical and often silent' (Robertson, 2003:112) stereotyped as reluctant to visit their doctor and and concern himself with health matters (Holroyd, 1997; MacIntyre et al., 1999; Sabo, 2000; Gough and Robertson, 2010).). Whilst attitudes towards health are gradually changing (see for example, Gough and Robertson, 2010,

there are ongoing disadvantages to narrow, stereotypical and binary conceptions of health among cisgender (people who identify their gender with the sex they were assigned at birth) men and women. As this brief introduction to the topic highlights though, the issue of how gender informs help-seeking is far from simple (Horrocks, 2012; Hunt, 2012).

## What causes IBS?

### Theories of IBS aetiology

It is generally agreed in the literature that IBS is a chronic illness with long-term symptoms of uncomfortable or painful sensations experienced in the lower abdominal area and bowel (Quigley et al., 2009). Women (and men) often report symptoms changing over time, whether in terms of their severity and frequency, or in relation to the bowel symptoms experienced (see for example, Quigley et al., 2009; Goodwin et al., 2013; Arroll and Dancey, 2016). Pain and other sensations associated with IBS are caused by digestive ‘dysfunction’ (see for example, Surdea-Blaga et al., 2012:617), although there are other factors also involved.

### *Biopsychosocial illness*

In the past IBS was considered to be a ‘psychosomatic illness’ (Van Oudenhove et al., 2010) owing to the focus on biological versus psychological explanations within Cartesian and reductionist

biomedical understandings of illnesses such as IBS (see for example, Drossman and Dumitrascu, 2006). Stress has been correlated with causing symptoms (see for example, Blanchard et al., 2008), although there has been a shift to conceptualise IBS as a 'biopsychosocial illness' (Engel, 1977) in recent years. IBS aetiology is therefore most commonly described as involving a combination of 'factors' (Camilleri and Choi, 1997; Drossman et al., 1997; Drossman, 1999b; Drossman and Dumitrascu, 2006; Van Oudenhove et al., 2010; Surdea-Blaga, et al., 2012). There is:

A complex reciprocal interaction between biological, psychological and social factors that can be predisposing, precipitating and/or perpetuating (Van Oudenhove et al., 2010:201)

It is helpful to provide an account of the main 'factors' that form part of the 'complex reciprocal interaction' of bio-psycho-social explanations of IBS aetiology. This is by way of an introduction to the topic and is not an exhaustive list. For the reader interested in a more detailed and scientific explanation, please see Arroll and Dancey's (2016) recent publication written about IBS for a mainstream, 'non-expert' audience.

## The biology of IBS

The picture shows the parts of the body that make up the digestive system.

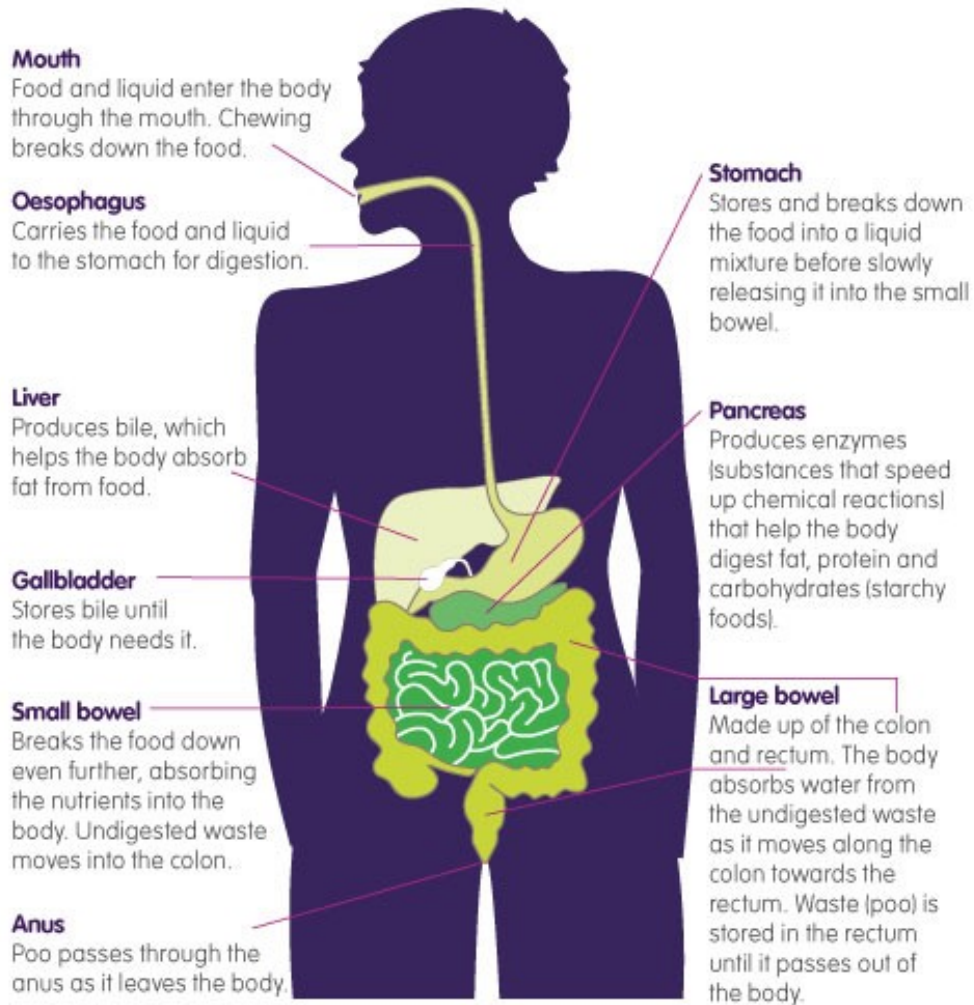


Figure 1. The digestive system and its functions (image used with permission from Bowel Cancer UK, 2017)

Figure 1 shows how complex the gastrointestinal (GI) and digestive processes are, beginning at the point at which food and liquids enter the body at the mouth, and are chewed and broken down (Bowel Cancer UK, 2017).

After being chewed in the mouth, food and liquids are swallowed, and traverses the oesophagus, before chemical digestion in the stomach begins. In total the whole process is estimated to take on average between 8 hours to 3 days, with how long this takes determining the consistency and form of excreted waste products known as stools, faeces or 'poo' in scientific and colloquial terms. For this reason, the biological process of digestion determines if a person is experiencing chronic bowel illnesses such as IBS, as informed by changes to the frequency and nature of bowel habits, and stools' consistency and form (Heaton et al., 1992).

### *Theories of 'faulty' bowels*

Enders (2014) is a European physician who wrote a mainstream text ('Gut') about the workings of the digestive system, which she describes as being 'galvanised into moving' (Enders, 2014:80) as part of the ever-continuing process of food and drink consumptions and digestive processes. Whilst the digestive system is relatively autonomous and has its own nervous system (the Enteric Nervous System), theories of biological factors in IBS argue that the process is governed by what is going on in the brain and environmental factors, with a worldwide

consensus for the 'brain-gut connection' in health literature (see for example, Surdea-Blaha et al., 2012; Kennedy et al., 2014). The brain-gut connection opens up a way of understanding the biology of IBS, drawing upon Cartesian thinking to make sense of the body and brain, or mind, as different 'parts' of a human.

### *Complex brain-gut connections*

According to 'gut motility theory' (see for example, Mantides, 2002), people living with IBS experience bowel problems because the motility of their gut is 'dysfunctional' (see for example, Surdea-Blaga et al., 2012). When the gut is not working well digestion is slowed down or speeded up, causing diarrhoea (loose stools) or constipation (hard stools) (Kennedy, et al., 2009; Van Oudenhove et al., 2010; Grenham et al., 2011). Additionally, the brain-gut connection comes into play by determining gut motility within biological explanations of IBS, with situations and experiences of stress leading to stress hormones (cortisol) being circulated around the body, causing the 'fight or flight' response that switches off, or turns on the GI system (see for example, Bartlett, 1998; Kennedy et al., 2014). In this way the stress response is closely connected with bodily processes, hereby mediating bodily functions such as digestion (see for example, Sapolsky, 2004).

## **The psychosocial nature of IBS**

Biology is understandably part of the reason why IBS occurs, though this is informed by other factors. Psychological explanations and



scientific research suggests personality may play its part, with people exhibiting certain personality traits more likely to experience IBS, according to past research (Dixon-Woods & Critchley, 2008). This is in turn understood as informed by social factors, such as a person's perceptions and beliefs of illness and their everyday life experiences.

### *Personality theories*

One theory of IBS is that people living with IBS act and think in certain ways and this has been quantified and correlated with IBS, as per theories of IBS personality traits and thought patterns (see for example, Levy et al., 1997; Jones et al., 2013). People living with IBS involved in past research are thought to be more neurotic and 'tend to be worriers...[who] have strong emotional reactions to all sorts of stimuli' (Jones et al., 2013:396). These persons who have 'neurotic personalities' are also more likely to score highly on measures of 'somatization' (Miller, 2001; North et al., 2004; Surdea-Blaga et al., 2012) as defined as 'distress in which [people] with psychosocial and emotional problems articulate their distress primarily through physical [symptoms]' (Katon et al., 1984:208, parenthesis added). People living with IBS are more likely to have other personality traits too, scoring more highly on measures of 'catastrophisation' than people living with other bowel illnesses, and 'healthy' people (Whitehead et al., 2002; Riedl et al., 2008). Catastrophisation is 'an 'exaggerated negative rumination and worry' (Jones et al., 2013: 386), and in my interpretation is another way of framing neuroticism. People living with IBS also are more likely to perceive themselves to be more 'stressed',

and have underline beliefs that contribute to more negative beliefs about illness, and feelings of anxiety and depression (see for example, Lackner et al., 2006; Creed, 2007; Spence and Moss-Morris, 2007).

I understand the psychological theories of personality traits and cognitive factors to address the aetiology of IBS, though this is done in a way that situates people living with IBS as 'neurotic' people. Like the quote cited from Dixon-Woods and Critchley's (2008) research at the beginning this chapter, there is a question as to what effect this positioning has for those living with IBS. Research now has highlighted that the 'somatizers' are a sub-group of the IBS population (see for example, Riedl et al., 2008; Whitehead et al., 2007). Scoring highly in somatization is concomitantly associated with worse health and wellbeing, with more psychological and somatic symptoms and illnesses occurring as 'comorbidities' alongside IBS (Whitehead et al., 2002; Zimmerman, 2003; North et al., 2004; Hillilä et al., 2007; Nicholl et al., 2007; Riedl et al., 2008). This is troubling when considering the positioning of people living with IBS as 'neurotic' and 'somatizers', who also happen to be more likely to be female, according to past research (see for example, Chang and Heitkemper, 2002; Payne, 2004; Bengtsson, 2006).

#### *Abuse and illness as gendered*

Further questions need asking around why psychological 'types' are connected with IBS, which some researchers have sought to explore.

For example, Delvaux et al. (1997) and Han et al. (2009) as part of research conducted in the USA, have found that between a third to half of all people living with 'medically unexplained' bowel illnesses reported experiencing sexual or physical abuse in the past. Heitkemper et al. (2011) showed how experiences of abuse also are connected with women's health and wellbeing of those who are living with IBS. In this research that included studies of sleep patterns, women who had experienced abuse or were more likely to be found to have difficulties or interrupted sleep, psychological issues and somatic symptoms. This was in comparison with another group of women living with IBS who had not reported abuse. Over time research has consistently shown repeatedly just how abuse is connected with IBS (see for example, Ali and Toner, 1997; Payne, 2004; Heitkemper, et al., 2011; Jones et al., 2011), as well as many other experiences of chronic symptoms and illnesses (Drossman et al., 1990b; Beitchman, et al., 1991; Walker et al., 1993; Leroi et al., 1995; Kendall-Tackett et al., 2003; Chitkara et al., 2008; Guthrie, 2008; Heitkemper et al., 2011; Jones et al., 2013; Surdea-Blaga et al., 2012; Halland et al., 2014).

The implications of this research that is that personality factors merely touch the surface explanations for the psychology IBS, with difficult and challenging experiences of trauma and abuse shaping how women make sense of bodily experiences, such as illness. I would add to this that considering abuse within explanations of the widespread reporting of bowel illnesses still requires further study. Abuse and violence are after all, gendered issues, with significantly more women and girls

subjected to abusive experiences worldwide (WHO, 2014). I have discussed this topic to make the point that abuse as a form of prolonged stress and trauma can, and does, have a long-lasting effect on women's health (Beitchhman et al., 1992; Putnam, 2003; Payne, 2004). Rather than labelling women patients living with IBS as highly 'neurotic', it would be more helpful for IBS to be understood as informed by gender inequalities in a cultural context; such as the greater extent to which women are subjected to trauma, abuse and sexual violence when compared to men.

### **Sensitive and 'crazy' women**

Explaining IBS is complex, and has been shown to not be easily theorised, even when adopting a deductive methods to connecting the dots between different biological, psychological and social factors. Saha (2014:6759) therefore suggested that whilst 'Many theories have been put forward...[but] the exact cause of IBS is still uncertain'. What is apparent is that, despite the vast literature, is that amidst the cloud of 'uncertainties' it is possible to get a sense of a reciprocal feedback loop between emotions, biology and psychosocial experiences and issues. Yet, these theories continue to position women as 'neurotic' who are living with IBS, which is an offensive and denigrating labelling of women already living with chronic pain and illness.

Van Oudenhove et al. (2010:209) argued that there has been a shift to a biopsychosocial understanding of bowel illnesses such as IBS, with

medical theories changing from dividing scientific versus psychological explanations, to a more integrated theory of health and illness (see for example, Engel, 1997). However, such theories are still problematic, with the connection maintained between psychiatry and GI disorders. The IBS literature uses the language of neuroscientific and psychological concepts in contemporary health and psychology research, such as of brain-gut connections and cognitive and behavioural styles, rather than psychiatric reasoning (Van Oudenhove et al., 2010). Yet, I would agree with Van Oudenhove et al. (2010) that the theories continue to quietly and implicitly perpetuate narratives of IBS being caused by stress and neuroses. One can hear the whisperings of IBS still being seen as ‘psychosomatic’, as it was previously during the 20<sup>th</sup> Century prior to the rise of the ‘biopsychosocial model’ approach to health and illness (Engel, 1984).

## Medical context

To move on now to consider how IBS is defined, first and foremost, as an illness categorised by Western medicine as a ‘Functional Bowel Disorders’ (Drossman, 1999b; Drossman and Dumitrascu, 2006). Functional bowel illnesses are identified and diagnosed on the premise of subjective and self-reported symptoms in the absence of any medically detectable signs of ‘disease’ (Manning et al., 1978). In this way medicine frames IBS and other ‘functional’ illnesses and symptoms as dichotomous with ‘medical’ disease. This has a profound effect on

how IBS is experienced and perceived, as I will discuss in more detail shortly.

## Diagnosis

Diagnosing IBS is contentious because of the lack of biological markers (Camilleri, 2012). Nonetheless, the diagnostic criteria itself is well-established and is generally considered a reliable means of identifying IBS through the presence of certain subjectively reported symptoms, as detailed below.

Table 1. Diagnostic criteria drawing upon Manning et al's (1978) and ROME III criteria (Drossman and Dumitrascu, 2006)

At least 3 days per month in the past 12 weeks of continuous or recurrent abdominal pain or discomfort *with at least 2 of the following*:

Abdominal pain and discomfort relieved by defecation

Altered stool frequency

Altered stool form

Passage of mucus

Sensation of incomplete evacuation

Onset of symptoms more than 6 months before diagnosis

Table 1 is an amalgamation of two of the published and standardised IBS diagnostic criteria, and is an adaptation from the Manning et al. (1978), and 'ROME III' (Drossman and Dumitrascu, 2006) diagnostic criteria, as described by Canavan et al. (2014). There are debates as to which of the published and validated diagnostic criteria is the most suitable for identifying IBS (Mearin et al., 2001; Lea et al., 2004; Saito et al., 2003; Dang et al., 2012). For example, the Manning Criteria (Manning et al., 1978) provides the bedrock to all IBS diagnostic tools and was the first published criteria that identified bowel symptoms and located these within a specific time frame. The next criteria by Kruis et al. (1994) extended the framing of IBS by 'stress[ing the] chronicity' (Dang et al., 2012:853, parenthesis added) of IBS symptoms. The latest criteria called the ROME III (Drossman and Dumitrascu, 2006), has since recognised people who experience intermittent and cyclical symptoms, or alternatively unrelenting symptoms.

The ROME III is one of the most recent diagnostic tools published by 'IBS experts' (Dang et al., 2012:853) the 'ROME Working Group', who named the criteria after Rome in Italy as the place of the first meetings to discuss devising criteria for Functional Bowel Disorders (Drossman et al., 2000). In these criteria, and following research, the subgroupings of the IBS population has been ever-extending, with sub-groups now identified as people living with IBS and predominantly diarrhoea, or constipation, or mixed diarrhoea/constipation symptoms. There is also a category of IBS that is 'post-infectious' (Spiller and Campbell, 2006), occurring after a bout of severe bacterial infections such as

gastroenteritis, or taking antibiotics (Beatty et al., 2014). This illustrates the diversity of IBS symptoms, which are recognised as changing from being mild to severe, frequent or continuous, over time (see for example, Drossman et al., 2006; Quigley et al., 2009). Experiences of IBS in terms of the symptoms alone are so varied and changeable that this contributes to the uncertainties of living with a bowel illness, particular given how IBS cannot be easily treated.

### **Perceptions of (dys)functional illness**

The process of diagnosing is problematic for another reason, as diagnosis also depends upon recognising if bowel symptoms such as blood in the stool and a history of bowel cancer (Dang et al., 2012). These are called ‘red flag’ symptoms in medical settings, because they are a call for urgent medical attention in potentially being signs of life threatening ‘diseases’ such as bowel cancer, Coeliac disease and Inflammatory Bowel Disease (IBD) (see for example, NICE, 2008; Quigley et al., 2009; Whitehead et al., 2006). These more ‘sinister’ (Harrington et al., 2013:95) symptoms thus can be contrasted with functional bowel symptoms with no visible signs of illness. This in turn informs perceptions of IBS as ‘less serious’ than other conditions has come into being. Western medicine is arguably responsible for medicalising unpleasant bodily sensations in order to find a way to help patients exhibiting these symptoms. However, the issue with this is the positioning of IBS and other functional or ‘medically unexplained’



illnesses, when contrasted with medical disease with a more clear-cut explanation.

Perceptions of IBS have personal and social implications upon establishing an identity as 'ill', or alternatively be considered by health professionals to be 'malingerer', and using health resources when nothing is wrong (Letson and Dancey, 1996 Chang et al., 2006; Dancey et al., 2002; Dixon-Woods and Critchley, 2008). Such a positioning is known to hold negative connotations and be stigmatised (Goffman, 1963) by people living in Western societies (see for example, Dancey et al., 2002; Taft et al., 2011). This is part of the reason why, according to Nettleton et al., (2004; 2005; 2006) and Swoboda (2008), people living with contested issues, or 'medically unexplained' illness, are greatly concerned with the issue of legitimising their status as 'really' ill. Such classifications have effects beyond the healthcare setting due to the stigma surrounding 'contested illnesses' such as IBS that lack of clear-cut scientific explanations (Conrad and Barker, 2010).

### **Assessing 'healthy' bowel habits**

Part of the process involves assessing how a person's gut is functioning through self-reported bowel function. This is done using the visual aid of the Bristol Stool Chart (see next page). The Bristol Stool Chart maps out how within Western medicine a person's bowel function is assessed by health professionals by observing the textures, form and regularity of stools. The 'gold standard' (Stewart and Stewart, 1994)








Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on its surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges (passed easily)
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces. <b>Entirely Liquid</b>

Figure 2. Diagram of the Bristol Stool Chart, taken from Heaton and Lewis (1997), based on Heaton et al. (1992). Source: Wikipedia licensed under the Creative Commons

type of stool or 'normal' type we should all be aiming for is mapped out according on the Bristol Stool Chart as a type 3-4 sausage type. These forms, consistencies and shapes of stools fall in the middle of the continuum as detailed on the stool chart. Hard stools (types 1-2) and soft/liquid stools (type 6-7) are associated with the symptoms of constipation and diarrhoea, respectively.

## Symptoms

As shown in table 1 (on page 20) the chronicity of bowel issues is especially important when defining IBS diagnostically as involving symptoms such as recurring constipation, diarrhoea, abdominal pain and discomfort, and abdominal distension or 'bloating' forms part of the IBS diagnosis (Kruis et al., 1994). There are also other bowel issues not included in the criteria but that are often reported by people living with IBS, such as frequent, smelly trapped wind (or flatulence), vomiting, nausea, and stomach noises or 'burbulence' (Arroll and Dancey, 2016).

### *Rushing to the loo*

Some symptoms are perceived as more troubling than others within the context of everyday lives. For example, sensations of hurriedness and 'urgency' to poo can be experienced as restrictive, posing challenges to taking part in everyday activities (see for example, Dancey and Backhouse, 1993; Drossman et al., 2005). This is part of the reason why people involved in IBS research have emphasised the

importance of planning eating practices, toilet access, and understanding one's own IBS through a process of learning about illness 'triggers' over time (Kennedy et al., 2003; Schneider and Fletcher, 2008; Casiday et al., 2009; Rønnevig et al., 2009; Schneider et al., 2009; White, 2016). I will discuss this in more detail in Chapter 2, as the unpredictability of bowel symptoms are perceived as not only inconvenient but also as threatening a person's 'body-self relationships' (Frank, 1995; Swoboda, 2008) through the emotional and psychosocial implications of IBS (see for example, Hall et al., 2005).

#### *Other non-bowel related symptoms*

According to Fond et al. (2014) who conducted a systematic review and meta-analysis, people living with IBS are more likely to experience additional psychological issues such as anxiety and depression when compared to 'healthy' people in control groups (see also Creed et al., 2005; Whitehead, 2007; Lee et al., 2009). Other research has also shown that people living with IBS are more likely to experience other physical and 'somatic' symptoms and illness, such as pain, chronic fatigue and women also experience more chronic pelvic pain, when comparing people living with IBS and controls (Whitehead et al., 2002; Whitehead, 2007; Riedl et al., 2008; Creed et al., 2013). It seems then that there is much literature to show that IBS is something that is often accompanied by psychological illness and 'multiple somatic symptoms' (Riedl et al., 2008).

## Gendered symptoms

Björkman et al. (2015) argued that there are more similarities than differences in terms of men's and women's experiences of IBS symptoms. Other research by contrast has suggested that women experience bowel symptoms of IBS differently to men (see for example, Payne, 2004). For instance, women living with IBS have been argued to experience more abdominal pain and discomfort, bloating symptoms, and constipation, whilst men experience more diarrhoea and do not report bloating to be a problem for them (Cain et al., 2009; Adeyemo et al., 2010; Anbardon et al., 2012). One explanation for this is that women's experiences of certain symptoms are informed by the symbolism of symptoms such as bloating within wider culture (see for example, Chang et al., 2006; Toner and Akban, 2000). Toner and Akban (2000) suggest that bloating symptoms are more reported, and experienced as more problematic for women, because of Western cultural ideas surrounding slim and toned bodies (Grogan, 2016). Past research by Björkman et al. (2013) supported this argument, having found that women living with IBS found it difficult being unable to meet cultural norms around female body ideals.

Scientific theories have been put forward that suggest women's hormones explain gender differences in IBS symptoms (Heitkemper et al., 2002), arguing that women living with IBS may experience symptoms in response to hormonal changes mediating pain perceptions during certain phases of women's reproductive and

menstrual cycles (Chang and Heitkemper, 2002; Heitkemper et al., 2003; Cain et al., 2009; Adeyemo, et al., 2010). Heitkemper and Chang (2009) propose in their literature review of gender differences in the aetiology of IBS that women's bodies produce fewer ovarian hormones during menstruation and early into the menopause, which may play a role in worsening IBS symptoms.

### *Visceral hypersensitivity theory*

Such notions of hormonal factors taps into the widely accepted 'visceral hypersensitivity theory' of IBS: that perceive pain sensations more readily and intensely than 'healthy' people (Moloney et al., 2012; Corsetti et al., 2014; Kennedy et al., 2014). This brings together the biological and psychological within hormonal theories, making claims that women are more likely to notice symptoms of abdominal pain, cramps, bloating and changes to their bowel habits as something 'healthy' women experience more readily as part of menstruation (Moore et al., 1998; Cain et al., 2009; Bernstein et al., 2014). It also provides an explanation for IBS, but there is an issue because of the way such theories position women's bodies as 'abnormal' and requiring medical theorising and interventions. Before critiquing this issue further, to briefly provide an account of how IBS is diagnosed and treated. This implicitly demonstrates how the bodies of women living with IBS are medicalised in accordance with the tools of Western medicine, which seek to categorise illnesses and diseases according to the symptoms, rather than the person.

## Treating IBS

### *Suggested interventions and tailored healthcare*

IBS is not easily treated, as is explained by the official report published by the international organisation, the World Gastroenterological Association:

there is no general agreement on the cause of IBS, it comes as no surprise that no single treatment is currently regarded throughout the world as being universally applicable to the management of all IBS patients (Quigley et al., 2009:15)

Whilst there is 'no single treatment' for IBS, tailored healthcare to individuals has become a popular way of treating IBS given the complex biopsychosocial aetiology (see for example, Surdea-Blaga et al., 2012). IBS cannot be 'cured', but it can be managed through doctors working with patients to provide tailored care (Jones et al., 2000; Fass et al., 2001; Corazziari et al., 2003; Longstreth et al., 2006; Kennedy and Robinson, 2009). There are medications that work to address specific bowel issues such as constipation and diarrhoea. For example, constipation can be treated with laxatives and a high fibre diet, whilst diarrhoea and abdominal pain can be treated with anti-diarrhoea medications or drugs that slow down digestive processes and the spasms that may result from this (see for example, NICE, 2008; Quigley et al., 2009; Østgaard et al., 2011; El-Sahy and Gunderson, 2015). Doctors

also prescribe a combination of anxiety and depression medications as part of psychological interventions (see for example, Corazziari et al., 2003; NICE, 2008; Lackner et al., 2009).

### *Mind-body treatments*

Naliboff et al. (2008) discussed how IBS can be treated as a 'mind/body' illness. Ways of coping with illness can be treated with cognitive or psychological therapies focused on changing thought patterns and ways of responding to bodily sensations. For example, 'Gut-Directed Hypnotherapy' (Whorwell et al., 1987) has been found to be effective at changing how people relate to their symptoms (Gonsalkorale and Whorwell, 2005). In the last decade, mindfulness has gained popularity in health practice and research, which provides any strategy for treating IBS through 'changing awareness and acceptance of one's own state' (Naliboff et al., 2008:46). Overall mindfulness, hypnotherapy, relaxation practices and other psychological therapies hold promise when used alongside medical treatments for GI symptoms, altering how people find ways of coping with their illness (see for example, Roemer and Orsillo, 2002; Baer, 2003).

### **Healthism and self-management**

The high degree of comorbidities with IBS, need for repeated visits to healthcare professionals, and lack amongst of a definitively effective treatment for IBS contributes to the illness being seen to be a costly business for healthcare systems (Talley et al., 1995; Levy et al., 2001;



Akehurst et al., 2002; Longstreth et al., 2003). Longstreth et al. (2003) found in their research that IBS patients took up at least 50% more healthcare resources than matched controls. This is just one example of many research studies that highlight the various costs of IBS to healthcare systems, and as indirect costs to work-places through illness-related absence (see for example, Camilleri, 2001; Akehurst et al., 2002; Gately et al., 2007; Wilson, 2011; Buono, et al., 2017).

It is possible to get a sense from this why IBS attracts such great interest within research, as part of the ongoing efforts to find effective ways of treating the illness. Yet, in the absence of a universally effective treatment, responsibility is placed on chronically ill people by policy-makers and health professionals who promote self-management, such as by adopting ways of coping and controlling symptoms by changing diet and lifestyle (Nanda et al., 1989; Stewart and Stewart, 1994; Simrén et al., 2001; 2003; Schneider et al., 2009; Williams et al., 2011; Mazzawi et al., 2013). This will be discussed within the context of past literature in Chapter 2, though to make the point that the focus on IBS self-management diminishes the power of biomedicine, and gives patients and ill people more control. However, as Radley and Bell (2007:379) suggest, we live ‘in a world where public consciousness about health maintenance is raised at every opportunity’. This is part of the ‘culture of ‘healthism’ (ibid.) within Western societies, which arguably creates amounting pressures upon people already trying to make sense of living with chronic, incurable illness.

# Summary and critique

## Medicalising women's bodies

Medicine has a long history of 'medicalising' women's bodies, this is mirrored in the negative perceptions of women living with IBS as 'neurotic' and overly sensitive to their bowels and bodily sensations (Dixon-Woods and Critchley, 2008). The hormonal and visceral hypersensitivity theories could be conceived as part of an ongoing medicalisation of women's bodies as not 'normal' when compared to male bodies (see for example, Showalter, 1988, 1995; Ussher, 2011). Scientific theories in this way position women's bodies as more attuned to abdominal pain and bloating sensations because of they are part of women's and girls' biology and experiences of menstruation (Heitkemper et al., 2003; Heitkemper and Chang, 2009).

Such an idea is argued to be problematic by Young (1983; 2005) and Showalter (1985; 1998) who take a feminist perspective on the medicalisation of women's bodies and bodily processes. Grosz (1994) suggests medicine as embedded within Western patriarchal cultures has contributed to claims of the 'healthy' and young male body being taken as the 'norm' (de Beauvoir, 1949; Gilligan, 1982; Young, 1983; 2005). In contrast to the stereotype of an unchanging male body, women's bodies may be 'culturally understood in terms of their bodily flows' (Grosz, 1994:228). In response to medicine and psychology being historically drive by male researchers and subjects (see for example, Gilligan, 1982), women's bodily processed as treated as 'different' to

the norm. Menstruation, pregnancy and menopause are reified as 'symptoms' that require medical interventions, for instance (see for example, Young, 1983; Greer, 1991; Young, 2005; Ussher, 2010). In this way, health matters within Western medicine fails to take account of women's bodies as being forever 'in-flux' (Bartky, 1990; Moss and Dyck, 2003).

Whilst times have changed, the theories of visceral hypersensitivity, and focus on sex differences, maintains the binary between male and female bodies within IBS research. Consistent with female standpoint theories (Harding, 1991), the current research sought to bring women's bodies and embodied experiences to the foreground of studies of women's accounts of living with IBS, in their own words. This contributes to reconciling the lack of attention to women's experiences as unique and informed by women's diverse backgrounds. Furthermore, focussing on experiences moves away from the already overly medical literature involving women living with IBS (see for example, Schneider and Fletcher, 2008).



## Chapter 2: Past research exploring women's experiences of IBS, illness and embodiment

A scientific and medicalised body is dissected and de-contextualised, in accordance with scientific aims to subject bodies and body parts to the scrutiny of the medical gaze (Foucault, 1963; Turner, 1984; Sampson, 1998). It has been possible to get a sense in Chapter 1 of how IBS research has generally arrived from a medical perspective, in accordance with medical and scientific goals to find ways to deduce cause, and establish ways to diagnose and treat IBS as ways of saving on the direct and indirect costs of illness within society (see for example, Stam, 1998; Murray, 2000). I have argued that this is problematic because the literature has been so distanced from women's accounts as accounts of human experiences (Schneider and Fletcher, 2008:83; Lister, 2017). This chapter will begin by situating the alternative theoretical framework adopted in the current research, which arrived from the phenomenological conception of 'embodiment' as transcending the mind-body divide of Cartesian thought, and refocusing attentions on women's embodied experiences of their 'lived bodies' (Williams and Bendelow, 1989; Bendelow and Williams, 1995a, 1995b; Bendelow, 2009).

## The body is embodied

The concept of embodiment was developed from phenomenology as a challenge to the Cartesian mind/body theory held within Western medicine and science (Stam, 1998). The issue with a dualist view of the psychic and corporeal, material realm may be understood as follows:

I believe he [Descartes] is wrong to set up a duality between body and mind on that basis...what we 'mind' only exists because we have bodies that given us the potential to be active and animate within the world, exploring, touching, seeing, hearing, wondering, explaining; and we can only become persons and selves because we are located bodily at a particular place in space and time. (Burkitt, 1999:12, parenthesis added)

Burkitt (1998; 1998) summed up the issue with Cartesian thought for me, outlining how there would be no 'mind' without the body. Human actions and sensations are situated and 'located bodily at a particular space and time'. The mind cannot be isolated from the body, which promotes a stance on embodiment rather than simply minds and bodies, since there is 'always more than the tangible, physical, corporeal object' (Waskul and Vanini, 2006:3). The body is subject and object, insofar as the material and physical body provides human senses and bodily apparatus that make it possible to perceive and make sense of the world in which we live (Waskul and van der Riet,

2002; Waskul and Vannini, 2006). In other words, the body is embodied (Waskul and van der Riet, 2002:488).

### *Pain as an embodied experience*

To provide an example to illustrate of the experience of pain, which is a useful example given that pain is experienced as subjective and personal. However, pain is also dictated by how the experience is symbolised within a culture (Good, 1994; Kugleemann, 1999; Kleinman, 1988). Pain is a physical sensation grounded in bodily experiences, but pain also transcends the mind-body divide (Kugleemann, 1999; Bendelow and Williams, 1995b). This is evidenced by human experiences of pain as something that can be vicariously experienced, such as when a person empathises with a friend or loved one's discomfort and pain. Grief also can be felt as pain, though this is not (at least initially) a corporeal experience. Jackson (1994:220) suggests this is because pain is more than sensation: it is 'a language...we know the pain of others only through expression'.

Adopting a view of women's experiences of illness and IBS as embodied better satisfied the aims of the research to expand upon scientific literature. Also a feminist endeavour, this would facilitate breaking down such binaries as the mind and body, and physical and psychological experiences grounded in women's biology as distinct from cultural meanings (see for example, Burkitt, 1999).

## Past literature exploring IBS experiences

To provide some examples of research exploring experiences of IBS as explored by women involved in past research. This literature has not encompassed the concept of embodiment and is realist and scientific, treating 'lived experiences' as accounts of human 'truths'. Nonetheless, exploring the past literature served as the starting point during the early stages of the research, which helped me to identify the gaps in the literature. This also reiterated to me just how little research had been carried out that was concerned with women's embodiment, or that took a feminist lens upon experiences of IBS.

### Bowel troubles

Studies exploring IBS-related experiences have centred on the theme of control and IBS as causing feelings of being out-of-control with illness, and a reduced quality of life (see for example, Gralnek et al., 2000; Amouretti et al., 2006; Bengtsson et al., 2007; Farndale and Roberts, 2011). The same themes have been found in the qualitative IBS literature and more widely in illness research (see for example, Schneider and Fletcher, 2008; Rønnevig et al., 2009; Schneider et al., 2009; Håkanson, 2010; Farndale and Roberts, 2011). However, qualitative studies have the advantage of providing space for participants to explore experiential knowledge and events in more detail, opening up space for in-depth meaning-making.



Casiday et al.'s (2008) explored personal experiences of IBS as part of interview research. One theme was about of pain and IBS as having held social and pragmatic consequences for the women. There were restrictions upon everyday activities that as one participant worded this, prevented doing 'normal things' (p42) like working:

I try to do the normal things even though my bowels are giving me trouble. I go into work and also attempt to do fun things. I don't want to be influenced by my IBS. If you are in pain and your stomach is giving you trouble then it is quite hard to just get on with things but I really try not to let it bother me. (Casiday et al., 2008:42)

In this quote, the participant described her IBS as giving her trouble, making it 'hard' to get things done. Yet, like other participants in Casiday et al.'s research, the people they interviewed adopted a 'stoic demeanour' (Casiday et al., 2008:42) with regards to their health, and keeping going even if 'it is quite hard...[because] your stomach is giving you trouble' (ibid., parenthesis added).

I argued in Chapter 1 as culturally stereotyped as a masculine way of approaching health matters (see page 9). Whilst this was one aspect of the IBS-related experiences, illness was also perceived as causing everyday challenges and being 'debilitating' (Casiday et al., 2008:42), which is consistent with other qualitative IBS studies (see for example,

Schneider and Fletcher, 2008; Schneider et al., 2009; Farndale and Roberts, 2011). This is also consistent with other research involving women living with different chronic illnesses, who have explored the balance between 'keeping going' and finding the uncertainty and inconvenience of being unable to control one's own body difficult (see for example, Lowery et al., 1993; Kralik, 2002; Broussard, 2005; Nosek, 2007; Swoboda, 2008; Schneider et al., 2009; Newton et al., 2012).

Research by Schneider and Fletcher (2008) and Schneider et al. (2009) explored women's experiences of living with IBS and IBD, as part of a series of Canadian interview studies. Schneider and Fletcher (2008) interpreted the theme of stress as a cause and a consequence of illness to be salient to the women's accounts of their experiences of IBS. They described this as involving a negative 'cascade of impact' that occurred as a result of feeling anxious and fearful and stressed about symptoms recurring, and IBS 'attacks' worsening as part of a stress-illness 'vicious circle' (Jones et al., 2013).

## **Strategies for coping with illness**

Self-management is not only propagated by health professionals and policy-makers for chronically ill people (see Chapter 1, 31). Finding pragmatic ways to 'cope' with illness has been described in past research as providing valuable 'coping strategies' to alleviate symptoms and create a sense of control over IBS (Kennedy and Robinson, 2003; Schneider and Fletcher, 2008; Casiday et al., 2008a; Rønnevig et al.,

2009; Schneider et al., 2009; Håkanson, 2010; Farndale and Roberts, 2011).

### *Knowing your triggers*

Schneider et al. (2009) in a second study involving the same group of women living with IBS and IBD explored how the women controlled illness as involving negotiating everyday practices. The paper explored eating practices in particular, and the way in which the participants spoke in interviews about engaging in a 'cost-benefit analysis' (Schneider et al., 2009:84). There were temptations to eat 'trigger foods and beverages' (Schneider et al., 2009:81), and at times the participants' explored indulging in these, and being in 'denial' (Schneider et al., 2009:85) about the consequences. To override fears of symptoms being caused by foods and drinks was part of the desire to be 'normal' (ibid.) One of the women in the research took for granted how normalised it was for people for drink, and so joined in because 'It was like my birthday, so I obviously drank' (ibid). Whilst this highlights weighing up the costs and benefits of consuming trigger foods and drinks, it also showed how the women had dedicated time to understanding what these triggers were in the first place.

### *Fighting illness*

I want to return to the example from Schneider and Fletcher's (2008) research about the 'cascade of impact'. This was a way in which the researchers framed the women's accounts of escalating feelings of

anxiety and stress that had a cyclical relationship with IBS symptoms (Dixon-Woods and Critchley, 2008). Biologists focus on the scientific qualities of stress and part played by Cortisol release as part of the stress-response (Herbert and Cohen, 1993). Schneider and Fletcher instead attend to the experiential realm, showing how stress and illness are indistinguishable as part of their embodied experiences of IBS. Such experiences were discursively framed in an interesting way as 'attacks' (see for example, Schneider and Fletcher, 2008). It was as if the women experienced illness as separate to themselves, and so they engaged in a 'fight' with illness to stay well (Hall et al., 2005; Bowditch, 2006; Whelan, 2007; Denny, 2004; 2009; Owton, 2013; Markle, et al., 2014).

Owton (2013:6) argued that the 'fighter attitude' featured extensively in the accounts of asthma told by sport athletes. Owton suggested such a stance showed the need for the athletes with asthma to position themselves as facing adversity and not taking things 'lying down' (ibid). This was proposed as an attitude that complemented the competitiveness and fighting spirit that characterises sporting culture. Such thinking can also be applied to considering fighting or military metaphors within the field of chronic illness experiences (see for example, Hall et al., 2005).

Swoboda (2008), Denny (2004; 2009) and Stockl (2007), for example, discussed women's 'fight' to be taken seriously by health professionals as women living with invisible and contested illnesses such as Chronic

Fatigue Syndrome and endometriosis. Not fighting meant being left in a 'diagnostic limbo' (Corbin and Strauss, 1985), rather than facing up to the challenge and 'battle' (Denny, 2009) to be heard.

## **Uncivilised bowel illness**

Beyond the medical encounters and experiences of stress as an embodied feature of living with IBS, are the emotional and social implications of bowel illnesses. Past literature has connected chronic bowel illnesses with feelings of being judged by others not only informed by IBS being a contentious diagnosis, but because the bowel issues are perceived to invite embarrassment and shame (Hall et al., 2005; Schneider and Fletcher, 2008; Rønnevig et al., 2009; Arroll and Dancey, 2016).

Rønnevig et al. (2009:1679) carried out research exploring experiences of IBS and argued that the uncontrollability of an 'undignified' and 'distrustful' body interfered with everyday activities, hereby creating uncertainties. Mary, one participant who experienced diarrhoea symptoms, described living with IBS as involving the risk of losing control of her body in public. She euphemistically discussed this within the context of not getting to a toilet in time, and so it was 'a close shave several times' (ibid.) that she would evacuate her bowels in front of others. This sense of shame was about more than losing bowel control. Her 'close shave' was about the emotional experience that was grounded in the social and cultural meanings of bowel issues, and how

having IBS constituted living with a body that could not be trusted (Håkanson et al., 2009; Håkanson, 2010). It was also a comment on everyday spaces within which it is, or is not, socially acceptable space to expel body products or perform body habits when around others (see for example, Lea, 2001). This was intimately connected with the degree of shame and embarrassment experienced.

### **Privacy and bowel functions**

Cregan (2002) described how Elias (1939) provided an account of the archaeology of manners within Western 'civilised society'. Following detailed longitudinal analysis, Elias argued that within Western cultures bodily habits are frowned upon when expressed in public. For this reason functions such as defecation is confined to the bathroom as a 'private' space to expel bodily fluids and waste products in a socially and culturally appropriate way (Lea, 2001; Cregan, 2002; Haslam, 2015). People living with Western societies are encouraged to 'conceal, hide or suppress' (Cregan, 2002:23) body habits such as 'farting, belching, guzzling, slurping, dribbling, pissing, shitting', otherwise invites disgust and fears of contamination from the others because of the risk attached to 'leaky' body (Shildrick, 1994; Ogden, 2013; Haslam, 2015; White, 2016).

This highlights one aspect of the reasons why IBS is perceived to invite feelings of shame, embarrassment and stigma because bowel issues entail uncontrollable bowels and bodies. In addition, IBS is not visible to

others as symptoms occur on the 'inside' of the body-skin barrier. This worsens the feelings of a stigma and taboo of bowel illness (see for example, Dancey and Backhouse, 1993; Schneider and Fletcher, 2008; Håkanson, 2010; Taft et al., 2011).

### *Stigmatised illness*

Goffman (1963:15) argued that people who feel stigmatised experience feelings of inferiority compared to other people: 'the normals'. Goffman theorised that this is important to a person's sense of their identity, but with notable differences between 'discreditable' and 'discredited' identities. To have been discredited means stigmatisation arrives from a visible 'defect' or undesirable and stigmatised 'attribute', in Goffman's words'; such as in the case of a facial disfigurement. To be discreditable, by contrast, involves living with a concealable and invisible identity or attribute, such as in the case of IBS. The research showing that IBS is perceived as stigmatised because of an out-of-control bowel (Jones et al., 2009; Taft et al., 2011) thus contributes to explaining part of the reason for the intrusiveness of illness in everyday life (see for example, Dancey and Backhouse, 1993; Dancey et al., 2002). To live with a concealable therefore means it is possible for the stigmatising attribute to be hidden, allowing people to 'pass' (Goffman, 1963:92) as 'normal'. That is, unless illness status is disclosed, or the out-of-control bowel reveals the person's stigmatising attribute to others.

### *Concealable illness*

In recent years there have been many studies that have explored experiences and perceptions of stigma amongst people with different identity positions that are concealable and involved 'discreditable' stigmatising attributes - such as is the case with IBS. For example, researchers have explored stigma with people living with HIV/AIDS (Persson et al., 2006) or mental health issues (Lai et al., 2001; , as well as the stigma experienced by LGBT+ communities (see for example, Persson and Richards, 2008). Waskul and van der Riet (2002) in a study of heterosexual and LGBT+ identifying palliative care patients found that the participants perceived incontinence – loss of control of one's bowels - to be the most morally incomprehensible and humiliating experience. The heterosexual women in the group experienced more shame about this when compared to the lesbian participants, and heterosexual men. Considering shame and hidden stigma from bowel issues along sexuality lines is interesting, with Weinberg and Williams (2005) suggesting their research showed how Western cultural constructions of idealised femininities intersect with the stigma of bowel functions seen in public. The heterosexual women who experienced incontinence were therefore more concerned with being unable to contain their bodies as to be 'leaky' is not attractive, desirable or in line with the idealised contained feminine body (see also Bordo, 1993).

IBS does not necessarily involve incontinence, though bowel issues of frequent and smelly wind, stomach noises, and having to urgently get



to a toilet are framed as embarrassing, shameful and stigmatising amongst women living with IBS involved (see for example, Bengtsson, 2006; Schneider and Fletcher, 2008). Consistent with Weinberg and Williams (2005), Rutter and Rutter (2002:389) found in their research with UK-based women living with IBS that there were gendered aspects of IBS-related shame. For example, 'flatulence is not considered 'ladylike' and so is something to be laughed out, just as it is the subject of 'schoolboy humour' (ibid.) amongst boys in the school playground (Haslam, 2015). There is little research that looked in more depth at the social context to IBS from a female standpoint, and so the current research sought to explore if the women's stories of illness embodiment tapped into feminine ideals in Western cultures.

## Gendered experiences of illness

### Femininity, health and IBS

Gender role theory was briefly discussed in Chapter 1 within the context of gendered help-seeking and Western gender socialisation (see pages 6-9). The notion of gender roles has also been applied within studies that looked at other ways in which gender contributed to the experiences of people living with IBS (Ali and Toner, 1997; Ali et al., 1998; Toner and Akban, 2000; Voci and Cramer, 2009). Ali et al. (1998) used gender role theory in order to explore if 'feminine gender role' was connected to health practices such as help-seeking and changing doctors. They measured the extent to which a mostly female

sample of IBS patients displayed relationship-orientated (relational) behaviours, according to participants' scores on quantitative measures of 'Communal Femininity'. This is a measure of gendered traits such as 'servility and self-subordination' (Ali et al., 1998:60) as normative and stereotypically 'feminine' behaviour in Western societies, according to Communal Femininity Scale. The results of the research found that the mostly female sample of patients scored highly on the communal femininity measures, and had greater tendencies to be 'preoccupied' (Ali et al., 1998:62) with bowel symptoms. This has echoes of the visceral hypersensitivity theory discussed previously, and how women may be more attuned to their bowel symptoms because issues such as pain and bloating are a 'normal' aspect of female embodiment.

Voci and Cramer (2009) explored stereotypically feminine 'relational' behaviour amongst people living with IBS in another study. They found that higher scores on communal and relational behaviour were associated with worse quality of life and poorer health. This was in contrast with the polarised 'masculine' behaviour of perceptions of greater agency and control. This is interesting as the research further positions women who seek help, and to whom their social relationships are important, as more likely to be diagnosed with IBS, and have a worse quality of life. Rather than critique the polarising of male versus female gendered traits however, the research inadvertently reinforced the perception of the stereotypically female and 'neurotic' IBS patient who is 'overly concerned' with their bodily sensations (Dixon-Woods and Critchley, 2008).

I offer a critique but understanding gender and illness within a cultural context is no simple matter. Ali et al. (1998) went part of the way to situating gender role and 'feminine attributes' (p60) within a cultural context. This was of interest within the current research in seeking to move beyond medicalised and normative understandings of IBS as a 'women's illness', and consider how gender informed stories women living with IBS had to tell.

#### *Unpacking the problem of gender stereotypes*

On reading the majority of the past literature that explored gender differences, I did not feel much closer to understanding women's 'gendered' experiences of IBS within a social and cultural context. If, as Ali et al. (1998) and Voci and Cramer (2009) claimed following their IBS research, women ascribed to culturally stereotyped 'feminine' behaviour and traits, how could women escape this when living in Western cultures that polarises femininity and femaleness, with masculinity and maleness? How could I situate the women living with IBS in a way that retained awareness of cultural stereotypes, but with reducing their experiences down to being 'gendered traits'? Furthermore, was gender role theory enough to theoretically frame gender given my critical stance as a feminist researcher?

## Women, self-silencing and illness

One way around this was in exploring how feminine gender roles have consequences for women by adopting a more feminist stance and utilising the concept of 'self-silencing' (Jack and Dill, 1992). The concept of 'self-silencing' has been a worthy contribution to knowledge following research conducted initially by Jack and Dill (1992) that explored women's accounts of experiences of depression. Jack and Dill (1992) argued that women in their study who identified as depressed engaged in self-silencing. Jack and Dill focussed upon on the concept of 'voice', following research exploring the moral development of women and girls by Gilligan (1982) and Brown and Gilligan (1992). Voice is conceived as 'integral to relationship, a sign of being present and engaged with others' (Gilligan, 2010: xi). The *voice* being referred to here is women's oral voices, but also 'voice' as a 'collective experience...the embodiment or one's culture' (Jack and Ali, 2010:4). In other words, women's voices tapped into cultural 'narratives' that could be 'heard' in the stories women told about their own experiences. The first-person voice ('I' and 'my' sentences) positioned the women as silencing their feelings, and this was heard in voices of experiencing 'listlessness, lifelessness, helplessness and hopelessness' (Gilligan, 2010:ix). In addition another moralistic and 'cultural scripted voice' (Gilligan, 2010:x) could be 'heard' from the third person and judgemental voice the women spoke in. The cultural pressures on women to meet gendered expectations were heard through imperatives about what 'should and should not' be being done, said, and thought. These were culturally scripted voices that were negative

self-evaluations and created feelings of worthlessness (Gilligan, 1982; Jack and Ali, 2010). The theory of self-silencing in accordance with Jack and Dill's research has been applied within the context of IBS and other illnesses. For example, Ali et al. (2000) found that women living with depression scored highly on Jack and Dill's (1992) measures of self-silencing. This was further informed by the women experiencing emotional abuse, which was connected with feelings of self-blame that they 'silenced', but which manifested as depressive symptoms.

I would argue that this literature begins to make connections between women's personal experiences and cultural norms or 'cultural scripts' (Miller, 2005) about gender and femininities within the context of illness. However, as Gilligan (1982:14) pointed out, 'it is difficult to say 'different' without saying 'better' or 'worse'. Gilligan also critiqued the way in which exploring sex differences based on role theory generally ignores the way measures have been historically arrived out from studies by male psychologists, involving male participants. Within this context, it is possible to see how from the outset women is positioned as 'Other' to man as the 'norm' (de Beauvoir, 1949).

Self-silencing theory as premised upon Gilligan's work nonetheless sought to move beyond this narrow view, situating women's 'feminine' behaviours as grounded in gender socialisation (Jack and Dill, 1992; Gilligan, 2012; Jack and Ali, 2012). 'Silencing the self' thus arrives from the promotion of women focussing on 'relationships, and particular

issues of dependency' (Gilligan, 1982:8), which are 'experienced differently by women and men' (ibid.) and so play into expressions of normative gendered traits.

## Conceptualising gender in the research

I wanted to take note from research that adopts a feminist perspective that challenges and unpacks culturally constructed gender stereotype and taken-for-granted notions of sex and gender, femininity and masculinity. Health research has generally assumed a male and female binary, and positions women as irrevocably desires to meet norms and with ideals of femininities that form part of heteronormative notions of gender (Kuhlmann and Annandale, 2012; Hammarström et al., 2014). Kuhlmann and Babitsch (2002:434) argued this creates a conundrum for feminist researchers interested in studying women's experiences as a phenomenon of interest. Such a topic is symbolically meaningful as grounded in culture and women's material and biological bodies (Benhabib et al., 1995; Birke, 1999). However, as Birke (2000:587) noted, resolving this issue is not easy, particular when trying not to frame 'men' and 'women' in an essentialist way. Kuhlmann and Annandale (2012:3, parenthesis added) amongst others, have noted that the 'gender binary' has long been a bone of contention within feminist theory. There have been: 'Numerous attempts to cross the sex-gender divide and/or expand the binary frameworks' have been made by feminist and gender researchers (see for example, Connell, 1983; West and Zimmerman, 1987; Payne, 2004; Connell, 2012;

Hammarström et al., 2014). I cannot claim to have resolved this issue either, and situated the group of interest in the research as Western adult women living with IBS. Being 'women' who are 'chronically ill' and 'living with IBS' were shared identity positions, but the women were unique and diverse as individuals, and arrived from different backgrounds. The participants were of different ages and lived across different Western countries, with different cultural resources to draw upon based on their personal and social circumstances. Given the points about problematic notions of gender, how could such issues be approached and conceptualised in a more culturally sensitive and self-conscious way in the current research?

### *Gender as performed*

My way of answering these questions was to theorise gender not in terms of gender roles, but as 'performed' within a continuum of masculinities and femininities as plural and multiplicitous rather than dichotomous categories (Connell, 1987; Butler, 1990; 2012; Kuhlmann and Annandale, 2012). I applied West and Zimmerman's (1987) ideas about 'doing gender', which recognised gender as having predated notions of 'sexed nature' or a 'natural sex'...[that is] produced and established...prior to culture' (Butler, 1990:7; parenthesis added). To illustrate this with an example of a study in the IBS field that satisfied my interests in moving beyond a gender binary, and also adopted West and Zimmerman's (1987) ideas about 'doing gender' to inform the interpretations and research.

### *IBS as a breach of femaleness/maleness*

Björkman et al's (2013) study explored how a group of IBS patients living in Scandinavia made sense of living with IBS in interview research. Nordic countries such as Sweden, where Björkman et al's research was carried out, have been found to be similar in terms of the disparity between men and women living with IBS, and high prevalence of the illness, when compared to 'Western' countries such as the UK and USA (Agréus et al., 1994; Quigley et al., 2009; Lovell and Ford, 2012). The results of the interviews were that there were 'gendered' ways IBS was explored within accounts of illness-related experiences within the context of men's and women's everyday lives.

Sexualities were not discussed in the research, although the themes tapped into ideas about the traditional heterosexual and masculine 'breadwinner', with men expressing concern with being unable to predict if they would be ill. As a result they experienced 'feelings of uselessness' (Björkman et al., 2013:5) at not being able to provide for their families, and go to work when unwell. Women living with IBS in the group struggled with feelings of guilt and shame at not being able to supportive to their loved ones when ill. This was consistent with the IBS research that explored how feminine traits were negative correlated with quality of life (Voci and Cramer, 2009). This connected the women's personal ideas of 'femaleness' as enveloped within Western stereotypical of women as more relational than men (Lips, 2004). In addition, the women participants also were the only ones to have expressed body image concerns at bloating making them feel 'fat'



(Björkman et al., 2013:5), equating slimness with being more sexually unattractive than fatness, as per Western body-ideals (see for example, Grogan, 2016). Björkman et al (2013:1) suggested that IBS prevented the men and the women from meeting the 'normative framework of femaleness and maleness', and therefore they were 'forced to abandon gender illusions'.

Björkman et al's (2013) research maintained a male/female dichotomy by studying participants by grouping them based on their sex. However, the research was firmly situated within a cultural context, and this therefore offered ideas toward the scant body of literature exploring culture as informing how gender and illness are connected as part of 'intersecting' (Crenshaw, 1991:140) social structures unfolding in people's lives. The current research was designed to add to this literature, extending knowledge by also bringing the concept of embodiment as a theoretical frame from which to explore if women told 'gendered experiences' of IBS, or not.

## Studies of women's illness narratives

This presents an overview of some of the key themes and findings in the past literature exploring women's experiences of IBS. In the current research I chose to adopt a narrative approach, and drew upon work of researchers in the field of 'illness narratives' (Kleinman, 1988). Illness narratives are first personal 'stories' people tell, within research

settings as part of interview research usually. Understanding illness narratives involves applying the concept of narrativity as an ontological and epistemological stance on 'experiences' as storied constructions that are contextualised. This will be discussed more extensively in the next chapter, although for now it is helpful for the reader to take into account how narrative theory has been applied within studies of illness-related experiences. Furthermore, the field of illness narratives is apt in exploring 'embodied' experiences of illness, such as by focussing on the way illness creates body-self disruptions, and 'biographical disruptions' (Bury, 1982:169).

### **Biographical disruptions**

According to Bury (1982), chronically ill people can no longer endorse 'taken-for-granted assumptions and behaviours' as was possible prior to illness. This is conceived as a biographical disruption, which interferes with the previous construction of identity as a 'life story' (McAdams, 2003). Illness narratives often are first-person autobiographical stories exploring how illness-related experiences unfold over time and space, according to the stories people have to tell (Kleinman, 1988). The genre of illness stories has proven a popular way in which researchers interested in 'disruptive' health-related experiences explore people's first-person accounts (Broyard, 1993; Garro, 1994; Mattingley, 1994; Frank, 1995; Charmaz, 1999; Ezzy, 2000; McAdams, 2003; Kralik et al., 2006; Whitehead, 2006; Lonardi, 2007; Roets and Goedgeluck, 2007; Smith and Sparkes, 2007;

O'Shaughnessy et al, 2014). This may be because it is possible to explore the multi-layered nature of the challenges brought about by becoming and living with illness and disease.

Lawton (2003) argued such disruptions are, with illness inviting people to ask questions about their existence in the world. For example, wondering after illness onset, 'why me?', or during the course of illness after treatment, 'why aren't I getting any better?' (Garro, 1994:780) are existential questions typically heard in accounts of illness narratives. This is typically part of the medicalised narrative when considering the hegemony of Western medicine within health and illness (see for example, Frank, 1995). Whilst medicine may not have the answers, illness narratives provide space to 'repair' (Williams, 1984) the damage caused by illness through a 'narrative reconstruction of meaning' (Murray, 1999; Williams, 1984; Lawton, 2003) following the 'assaults the body' and threat to 'the integrity of the self' (Charmaz, 1983; Charmaz, 1995:657, parenthesis added) by illness. To provide an example to illustrate, which is study concerned with exploring women's standpoint on experiences of chronic and 'contentious' illness.

### **Illness as embodied as body-problems**

Swoboda (2008) applied Frank's (1995) conceptualisation and theoretical work on illness narratives. Swoboda (2008) interviewed women living with Chronic Fatigue Syndrome (CFS) and other 'contested' illnesses. Her research followed Frank (1995) in arguing

that certain problems of embodiment were discussed in the women's stories: body-control, body-relatedness, other-relatedness and desire. Such body stories were argued as important by Swoboda, in agreeing with Frank that 'the *embodiment* of these stories: how they are told not just about the body but told through it' (Frank, 1995:3, italics in original citation). Swoboda's interpretation explored the four body-problems from Frank's theory, such as in the way the women perceived losing control of their bodies as part of stories about 'body-control', was connected with experiences of illness.

The issue of body-control follows other illness narrative studies that highlight how women struggle with the challenges of losing control of their bodies, as I have discussed in the context of IBS research earlier in this chapter consistent with wider literature exploring women's experiences of chronic illness (see for example, Kralik, 2002; Moss and Dyck, 2003; Broussard, 2005; Newton et al., 2012; Kralik et al., 2006; Nosek, 2007). Swoboda argued that the issue was also connected with the contentious nature of contested illness as illnesses that deny medical understandings, and 'that medicine cannot describe' (Swoboda, 2008:90-91). One woman living with Chronic Fatigue Syndrome showed how this in turn was enmeshed with how she felt about herself, which draws upon the embodiment of body-relatedness. The participant concerned explored how she felt a 'body-disassociation', with illness experienced as a 'struggle' (Swoboda, 2008:91) that left her feeling 'I lost me' (ibid.).

This embodied experience of illness then unfolded in participants' lives to create interconnected issues 'other-relatedness' and 'desire', leaving the women unmotivated to engage in social activities and maintain social relationships because of fatigue, pain and illness as suffering. To make sense of this, Swoboda interpreted the women's stories as positioning them as adjusting to the disruptions by reconstructing their body-self relationships in accordance with their 'ill' identities.

#### *Narratives of coping with 'fed-up-ness'*

Swoboda's (2008) research was a rich and in-depth exploration of illness narratives constructed by women about their lives living with various chronic conditions. Implicit within their stories was a courageous positioning of the women as being pragmatic, but whilst making space for reflecting upon the suffering that forms part of the ups and downs of living with chronic illness. Swoboda's research focussed on illness narratives as understood through exploring problems of embodiment. Kralik et al. (2006) adopted a different approach, moving the conversation on from questions about quality of life and coping within the context of women's experiences of chronic illness. Kralik et al. explored how the concept of resilience was of relevance to narratives women living with chronic illness had to tell. Resilience was about more than developing 'coping strategies'. It entailed accommodating the periods of sickness and 'bouncing back' from the 'good and bad days' (Charmaz, 2001). As one participant described this:

[Illness involves] continually bouncing back from feeling ill, fed-up-ness...regularly taking tablets, fatigue, disappointments and other factors or chronic illness (Kralik et al., 2006:194, parenthesis added)

This brief but meaningful quote showed the complex ways the 'bouncing back' meant psychologically make sense of all the challenges arriving from illness ('fatigue, disappointments' and so forth). Coping was not just about devising strategies such as taking medications and resting, it also necessitated being mindful of periods of struggle and suffering.

## Research aims

The research aims are to explore women's personal stories of illness, and if the stories constructed drew upon Western cultural norms, or 'cultural scripts' as I will discuss this, of illness, gender and femininities. My interest in the stigmatising and contested nature of IBS, and how this was experienced amongst women according to narrative was my initial motivation for doing the research. However, this provided just 'one story' (Milnes, 2003:116) that inspired decisions to generate new knowledge by adopting a feminist and narrative informed study involving Western women living with IBS. To summarise, the research questions were as follows:

### *Research questions*

- When asked to explore their personal stories of living with IBS, what did the women find meaningful? To what extent was IBS 'emplotted' into women's stories of their everyday lives and relationships, if at all?
- How did the women explore their gender identities in their personal stories? Did women living with IBS draw upon cultural scripts of femininities, as per Western ideals of what constitutes 'femaleness' and 'maleness'?
- To what extent did the women 'emplot' gender within their stories of their lives, and was this in any way connected to accounts of illness and IBS 'embodiment'?
- Are cultural 'scripts' of femininities and normative Western ideals of what constitutes 'femaleness' and 'maleness' drawn upon in the women's personal stories?





## Chapter 3: Narrative methodology and guiding theoretical frameworks

The previous chapter discussed the focus of the current research upon exploring women's stories of female embodiment, and of IBS as constituting embodied experiences of illness. This chapter will provide further details about another element of the theory that has informed the design and research process: the narrative methodology and relevant ontological and epistemological concerns. Chase (2011:429) argued that it may be easier to look for the 'complexities' than the 'similarities' when conducting narrative inquiry. There is a diversity of approaches to conducting of narrative research, and whilst this is an advantage of the methodology, it also makes the doing and disseminating of narrative studies of lives a difficult task (see also Riessman, 2008; Smith and Sparkes, 2008). There are commonalities, such as the focus on interpreting longer stretches of talk and text, and preserving and analysing the participants' narratives in their own words (Riessman, 1990; Murray, 1999; Riessman, 2008). Narrative researchers also agree that storytelling is a means of exploring how people go about constructing their identities as part of 'narrative construction of meaning' (Bruner, 1986; Polkinghorne, 1988; Bruner, 1991; Mattingley, 1994; Mattingley and Garro, 2000; Murray, 2000; Hiles and Cermák, 2008; Smith and Sparkes, 2008). I begin by contextualising the narrative methodology with some historical background that preceded the rise of narratives in social research and psychology.

# Background and overview to narrative inquiry

## ‘Turns’ to interpretation and meaning

There was a series of shifts in thought in the 20<sup>th</sup> Century that are often discussed by narrative researchers as a way of historically and theoretically contextualising narrative approaches in research (Pinnegar and Davies, 2007). For instance, narrative inquiry emerged in response to a number of ‘turns’ (ibid.) Scholarly critiques of scientific and experimental methods in psychology and the social sciences contributed to a ‘turn’ to interpretativism and qualitative methods (Potter and Wetherell, 1986; Crotty, 1998; Andrews et al., 2004; Kinsella, 2006). The illness narratives literature discussed in Chapter 2 is one example of a sub-discipline of narrative approaches that came about through critiques of ‘biomedical voices’ (Hyden, 1997:49) being heard over people experiencing health issues. In this way the illness narratives research aimed to explore what people living with illnesses had to say about their personal experiences first-hand (see for example, Kleinman, 1988; Frank, 1995; Koch et al., 1999).

### *Bringing human suffering to centre*

‘Taking on a medical or scientific perspective...doesn’t help us to deal with the problem of suffering’. Kleinman (1988:28) suggest as part of his critique of medical and experimental methods. Kleinman argued that the term ‘illness’ is more experiential than the medical concept of than ‘disease’. Studying narratives told by people, rather than about

them by doctors, therefore denied the objectivity and distance integral to Western medical practice. In addition to bringing first person stories to the centre of illness narratives, the researcher was also able to be situated 'in' the research. Following Mishler (1986:52) a narrative approach allowed for seeing the results of research as a 'joint construction of meaning'. Mishler's critiques were applied to engaging in more interview research, rather than the dehumanising and quantitative surveys.

Alongside concerns with experiences was the interest within narrative inquiries with interpretation and hermeneutics, as defined as the 'art of interpretation' (Willig, 2013:40). Hermeneutics focuses on the everyday, and sees interpretativism as providing the theory behind research exploring human meaning-making. As Willig (2013:40) suggested, 'interpretation happens whenever we try to understand spoken or written language or...any human acts'.

The focus in narrative research upon meanings, interpretations as contextualised and socially embedded, and positioning me (as the researcher) as active in the research process made this methodology a good fit (Henwood and Pidgeon, 1992) for the current research. I was interested in exploring what women living with IBS had to say about their lives. As a reflexive researcher, feminist, and as 'insider' I considered myself to have an 'intimate knowledge that provides a lived familiarity' (West et al., 2013:1) with the research focus on women's

stories of their lives, and of IBS. Like West et al., (2013) part of my inspiration to do the research at doctorate level was owing to this experience. It was untenable in my view, that I could ever lay claim to being distanced from the research topic given this context.

### *Reflexivity in the research process*

Lazard and McAvoy (in press) have argued that concerns with reflexivity surround questions of the degree to which researchers can, and should, stake claims to objectivity. Being reflexive ensures researchers 'foreground, and reflect upon the ways in which the person or the research is implicated in the research and its findings' (Willig, 2013:25). From my ethical standpoint it did not seem feasible to make any claims to be objective, and I did not consider my interpretations possible to be decontextualised and isolated from a social context. My way of making sense of the world and my 'subjectivity [is in this way] entangled in the lives of others' (Mauthner and Doucet, 1998:416). I took seriously feminist researchers invested interests in the 'reflexive turn' (Mauthner and Doucet, 2003:15) and therefore make my positioning and reflections part of this thesis that provides an account of the research carried out (Mauthner and Doucet, 1998; Miller, 2005; Doucet and Mauthner, 2007; Miller et al., 2012). I adopted a view of reflexivity as part of research that therefore can be seen as engaging with a relational ethics as an 'ethics of involvement' (Tillmann-Healy, 2003; Roets and Goedgeluck, 2007).

# Narrative theory and epistemologies

## Narrative Psychology

Sarbin's (1986) proposition of a 'narrative psychology', along with a series of other works published by Mishler (1986), Bruner (1986) and Polkinghorne (1988) were instrumental in introducing narrative in psychology (Hiles and Cermák, 2008). Following the critiques of experimental approaches, Sarbin (1986) made a case for narrative to be used as a root metaphor in psychology. This extended Lakoff and Johnson's (1980) work on metaphors as integral to understanding human concepts and thought processes. Narrative as a metaphor (Sarbin, 1986) therefore made space for human meaning-making as a creative process that involves imagination when making sense of experiences in the past, present and future (see for example, Sarbin, 2004). In this way the narrative application in psychology further ensured a shift ('turn') away from the experimental methods seen as using 'sterile' (Pinnegar and Davies, 2007) language of machine metaphors (Sampson, 1998).

## Narrative knowing and construction

Bruner (1986; 1991) proposed that narrative can be understood as a human sense-making process. This can be conceptualised as 'narrative ways of knowing' (Bruner, 1991; Clandinin and Rosiek, 2007). According to Bruner's ideas, knowledge and experiences are understood through two 'modes of thought': a paradigmatic mode,

and a narrative mode. The paradigmatic mode is the scientific logic of functional, which is what Sarbin (1986:9) critiqued as involving 'dead metaphors' (see also Pinnegar and Davies, 2007). Bruner argued from a different viewpoint having established himself as a cognitive psychologist before taking up an interest in the narrative turn in psychology. Bruner argued that the paradigmatic and narrative modes run in parallel and are complementary. The narrative construction of meaning thus constitutes two 'distinctive ways of ordering experience, of constructing reality' (Bruner, 1986:11). Neither mode is 'irreducible' (ibid.) and privileged over the other, in Bruner's words. I do not disagree, and this is one of the many reasons why the current research was justified. It was a way to balance the scientific literature base with research more concerned with the 'narrative mode' of knowing and understanding accounts of women's embodied experiences that are living with IBS.

Another influential person during the rise of narrative psychology as a sub-discipline was Polkinghorne (1988:13), who suggested narrative knowing offers 'a fundamental scheme for linking individual human actions and events'. For this reason, narratives are not governed by the laws of science, seeking reliability, validity and so forth. Making sense of stories and establishing their meanings is, in Bruner's (1991:4) words, a 'narrative necessity', not a means of 'empirical verification' (Bruner, 1991:4). In other words, studying narratives is less concerned with unearthing 'truths' than it is with the 'verisimilitude' of stories,

and whether the story feels 'right' to the narrator and audience (Bruner, 1986; 1991).

## Choosing an ontological and epistemological stance

### *Life as it is lived (realism)*

The issue of ontology, as understood as the study of what constitutes reality and 'being' in the world, determines the research design and claims to knowledge produced (see for example, Crotty, 1998; King and Horrocks, 2010; Willig, 2013). Past qualitative research in the IBS field involving women living with IBS has tended to adopt a realist stance (see for example, Bengtsson, 2007; Casiday et al., 2008; Schneider and Fletcher, 2008; Schneider et al., 2009; Farndale and Roberts, 2011). As Willig (2013) has discussed within the context of approaches to qualitative research, the words participants use are therefore taken at face value, with narratives considered to be accounts of 'life as it is lived' (Bolger et al., 2003). The social context and setting within which research conversations take place, and data is generated, is not interrogated within realist research.

The idea of studying women's stories devoid of the social context was far away from my reflexive position as being someone who was not 'outside' (Willig, 2001:7). Consistent with Haraway (1988) the 'God's eye view' of the distanced objective research denied my feminist standpoint and insider positioning. A social constructionist (Berger and

Luckmann, 1966; Gergen, 1985) epistemological stance was a better fit for the research, though with important caveats.

### *Life as it is told (social constructionism)*

Social constructionism recognises context, and the role of language and discourses as determining how people ‘construct’ their worlds, and make sense of experiences (see for example, Burr, 2001). From this theoretical perspective, narratives are not about lived experiences, but they are instead accounts constructed within the research setting as ‘lives as told’. In this way, narrative theory when applied within psychological and social research promotes performing in-depth interpretative analyses that see ‘stories’ as contextualised and constructed in a specific time and place (see for example, Riessman, 2008; Squire et al., 2014).

### **Language as social action**

Part of the foundations of social constructionism is in viewing language and discourses as active in constructing meanings and in shaping human subjectivities (Potter and Wetherell, 1987; Edwards and Potter, 1992; Harré and Gillett, 1994; Burr, 2001; Holtgraves, 2002). Berger and Luckmann’s (1966) work on social constructionism laid the ground for discursive approaches as closely connected with narrative psychology. Austin’s (1962) Speech Act Theory argued that discourses are intentionally ‘deployed’ within a social context in order to perform certain social functions (see for example, Potter and Wetherell,



1987). Discourses as action-orientated 'do things with words' (Holtgraves, 2002:9), such as by describing, explaining, justifying, persuading, and expressing emotional states and beliefs. Discourses are deployed in this way as a constant part of everyday life as entailing a range of social interactions (Mishler, 1986; Potter and Wetherell, 1987). In accordance with a discursive and social constructionist position, identities are not fixed (Burr, 2001). They are negotiated, constructed, and then reconstructed 'intersubjectively', which means in response to what we learn, experience and make sense of as part of our many social interactions (Gergen and Gergen, 1984; Shotter and Gergen, 1989; Crossley, 2000; Willig, 2013). Burr (2001) describes how within a social constructionist approach sees identities are seen as multiplicitous and changing and that this is connected with discourses that are 'culturally available to us'.

All objects of our consciousness...[are] constructed through language, [and] manufactured out of discourses...Our identity is constructed out of the discourses culturally available to us, and which we draw upon in our communications with other people...For each thread of our identity there is a limited number of discourses on offer out of which we fashion ourselves (Burr, 2001:105-106, parenthesis added)

The IBS literature has tended to discuss the 'types' of people that experience IBS, and personality traits connected with illness. This is not

a viewpoint compatible with the social constructionism of Burr (2001), who argued 'all objects' are made sense of and 'constructed through language'. This includes our identities, which are multiplicitous and evolving. Discourses are how people come to 'fashion ourselves', which Giddens (1991:70) has argued that is an ongoing and 'reflexive' project of modernity amongst people living within Western societies. We are forever concerned with issues of selves and identities, asking questions such as what one should do; how one should act; who one should be? For these reasons the exponential interest in narratives is thought to have come about, as people engage in self-reflection by constructing and organising stories as a way to make sense of who 'I' am (Plummer, 1995; Ochs and Capps, 2001; Stanley, 2013).

### *The structure/agency problem*

Hays (1994:57) brought attention to the 'sticky problem of culture' in a discussion of the issues of structure and agency when exploring. For example, feminists emphasise concerns with how social structures such as gender and race, act to inform the realities of the individual lives of women, and people of colour. This is set up against the issue of how people can go about their lives with agency. Hays goes on to say that the dichotomy defines the structure/agency debate, and in doing provides a way of understanding how social constructionism and discourses are limited by the role of social structures that shape which discourses and knowledge is culturally available to people:

...structure is constraint, while agency is freedom; that structure is static, while agency is active; that structure is collective, while agency is individual (Hays, 1994:57)

How then is it possible to reconcile agency and structure, with identity constructions as an active process, but institutions and cultures integral to making discourses available for human meaning-making? Furthermore, what about the concerns with embodiment and women's bodies within theory that are heavily focussed upon discourses rather than material realities?

### **Making space for bodies in theory**

The feminist psychologist Ussher has extensively explored women's experiences of health-related issues such as depression (Ussher, 2010) and pre-menstrual distress or 'PMS' (Mooney-Somers et al., 2008; Ussher and Pertz, 2017). I found it helpful looking to this body of literature in order to make sense of the 'structure-agency' problem, ensuring embodiment was part of the epistemology and methodology for the current research. Ussher (2010) subsequently argued, within the context of women's depression research, that a critical realist (Bhaskar, 1989) approach may be preferable because:

A critical-realist analysis allows us to acknowledge the 'real' of women's psychological and somatic distress, whether this distress is mild or severe, yet to

conceptualize it as a complex phenomenon that is only discursively constructed as 'depression' within a specific historical and cultural context. (Ussher, 2010:23)

This stance satisfied the aims of the current research, recognising epistemologically that women's bodies are 'real' material entities that shape women's embodied experiences. At the same way there was still space for discursive and social constructionist theory, making it possible to explore constructions of gender identities and illness as part stories that show a complex interaction between person and culture.

## Understanding narrativity

### Plotting and emplotment

In order to understand narratives requires making sense of what is meant by a story's 'plot', as well as how narrators 'emplot' events, characters, and experiences into stories (see for example, Brookes, 1984; Del Vecchio Good et al., 1994; Garro, 1994; Mattingley and Garro, 2000). The plot is what brings the 'parts' of narratives together as part of a temporal sequencing of events, which makes the story into meaningful and coherent narrative 'whole' (see for example, Brookes, 1984; Del Vecchio Good et al., 1994; Mattingley and Garro, 2000). Plots within Western stories have been seen to have a tripartite structure, seeing the sequencing of events to have a clear beginning, middle and end (Murray, 1999; Mattingley and Garro, 2000). This is a view of

narratives as linear, and that is grounded in the structuralist approach known as narratology.

Narratology (Bal, 1992; Onega and Garcia-Londa, 1997) has aimed to develop a systematic theory in order to predict the 'structures' of narratives, focussing on written forms of narrative (Bal, 1992; Onega and Garcia-Londa, 1997; McQuillan, 2000; Czarniawska, 2004). All narrative research shares concerns with a story's 'plot', although structuralist approaches to story research differentiate between the 'fabula' and 'szjuhet' (see for example, Riessman, 2008; Squire et al., 2014). The fabula or 'story' within narratology encompasses the 'parts' of narratives, such as the characters, scene of events, and episodes that threaded together create the narrative 'whole' of 'szjuhet' (Bal, 1972; 1992; McLeod, 1997; Czarniawska, 2004; Riessman, 2008). Labov (1972) proposed that all narratives involve some form of human action involving a main character of their story (the protagonist), and an evaluative or reflective point to the events that take place. In this way stories are constructed in a way that makes it worth telling to the audience, since 'how' the story is told is as important as 'what' is included within it (Riessman, 1990; 2008).

Structuralist approaches to narrative have been applied within narrative research, with the focus of research ranging from analysis of events that form part of 'an overarching storyline' (Riessman, 2008:78) to exploring 'brief embedded moments in a conversation that take a

poetic form' (ibid.). Riessman (1990) carried out narrative research in order to understand stories crafted by people who took part in interviews about their experiences of infidelity and divorce. For example one participant, Al, constructed accounts of his experiences of divorce, which preceded his wife's affair. In one story Al chose to 'tell a story about physical violence' (ibid.) to Riessman, focussing on the anger he felt about his wife's behaviour and eventual actions punching a door, rather than focussing on the details of the affair itself. Another participant called Burt constructed accounts of the series of events that contributed to his wife 'wash[ing] away everything' with alcohol' (ibid, parenthesis added). Rather than talk about the separation, for Burt it was meaningful to connect his wife's drinking problems with the gradual deterioration of Burt's health, which eventually resulted in divorce.

I make these points because Riessman's (1990) structuralist narratives study showed how much 'the same event can have contrasting meanings' (Riessman, 1990:748) for people. This research was carried out at a time in the late 20<sup>th</sup> Century when psychologists were using quantitative methods to measure effects of stress by measuring reported stressful life-events (see for example, Kessler, 1997). Her research therefore contributed to demonstrating how narrative when applied within psychological studies, provided a way of exploring uniquely meaningful, diverse stories of human experiences, such as about stress, in more depth.

## No end and no beginning

### *The 'postmodern' story*

The interconnecting thread to narratives remains the way events that are real or imagined, and may take place in the past, present or future, are organised in time and space (Ricoeur, 1985; McLeod, 1997). However, the plot to 'postmodern' stories are not conceptualised as necessarily linear and structured, as with the structuralist endeavours in narrativity (see for example, Brookes, 1984). For this reason it is argued that the concept of 'emplotment' (Del Vecchio Good et al., 1994; Mattingley, 1994; Garro, 1994) is of greater value. How narrators 'emplot' the characters into the scenes of events thus reflects how storytelling is 'active process' (Crossley, 2003:440) that is informed by the social context within which stories are told.

Thomas-MacLean (2004) analysed stories constructed by a group of women living with breast cancer who were interviewed. Thomas-MacLean found that some parts of the stories that were told over time about breast-cancer experiences 'flowed' well, such as when providing a chronological account of events that took place prior to diagnosis. Yet, other parts of the stories were fragmented and saw a 'jump from one sub-topic to another' (Thomas-MacLean, 2004:1652). For example, one of the women could easily provide an account of making a decision to get a mammogram. However, her speech changed 'into sentence fragments' (ibid.) that did not 'flow' when she discussed the experience of being diagnosed with breast cancer. Thomas-MacLean suggested

that the stories that were structured and ‘flowed’ appeared to have been ‘regularly rehearsed’ (ibid.) and told to others before. The research interview provided space for the women to tell the other stories too that were not well-rehearsed, but were deeply emotional and meaningful.

Thomas-MacLean’s research provides an example of the different ways in which the women living with breast cancer ‘emplotted’ themselves into the stories as tellers who had, or had not rehearsed their illness narratives. The stories were constructed in a way that conveyed their meanings, though these were instances of what Brookes (1984) called the postmodern narrative, insofar as some of the stories did not have a clear and linear structure (Brooks, 1984; Del Vecchio and Good, 1994). This first of all highlights how the narratologists distinctions between the fabula/story and szjuhet/narrative are of less relevance when focussing on the meaning, rather than the structure of stories (see for example, Culler, 1984; Mattingley and Garro, 2000; Squire et al., 2014). As the current research was interested in exploring what meaningful stories the women living with IBS constructed, I rejected the narrow structuralist definition of narratives. This thesis therefore uses the concept of a ‘story’ and ‘narrative’ interchangeably, as other researchers have done (McAdams, 1993; Mattingley, 1994; Riessman, 2008).



A second point is about temporality, and a 'lived time' (Ricoeur, 1985) as at the centre of narrative constructions of meaning. A number of researchers have contested the notion of narratives requiring linearity (Mattingley, 2000; Wikan, 2000; Riessman, 2015). Riessman (2015:1067) in a recent paper exploring her autobiographical experiences of being treated in hospital for Cancer argued that in her account temporality was blurred. 'Past, present and future co-mingle' in the story Riessman constructed, which she organised from the notes and bits of paper she used for writing about her experiences when in hospital. Far from being organised, her journal was seen as providing a more poignant depiction of a life as lived, which is by nature disorderly and 'messy' (ibid.). One of the functions of narratives are to provide a space for organising and constructing a coherent account of events (see for example, Ochs and Capps, 2001). However, Riessman's (2015) paper is an example of the way illness narratives do not need to have linearity. What is of greater importance to the 'postmodern' narrator is considering the audience to whom the story is being told, and allowing the narrative construction to see the narrator enveloped in the unfolding process of finding out for themselves 'what *really* will happen next' (Del Vecchio Good et al., 1994:855, italics in original citation).

## Defining narratives in the current research

### Exploring 'conversational stories'

I adopted Ochs and Capps' (2001) definition for conceptualising the personal narratives the women living with IBS had to tell in the current

research. Their interest was in conversational narratives as a way of conceptualising the everyday exchanges and interactions that form part of stories told in people's everyday lives. This type of story may be seen to bridge the gap between what could be described as the 'big' autobiographical and life stories, and the 'small' stories that are naturally occurring storytelling that is the focus of conversational analysis (Davies and Harré, 1990; Bamberg, 1997; van Langenhove and Harré, 1999; Georgakopoulou, 2006; 2007; Bamberg and Georgakopoulou, 2008; Bamberg, 2011).

I discussed examples of the 'big' life-stories earlier in this chapter, providing the example of Riessman's (1989) divorce stories research, and Thomas MacLean's (2004) study of narratives of women living with breast cancer. Such stories were retrospective accounts about experiences over time. The 'small' stories by contrast, are constructed in context as part of conversations and interactions between two or more people (see for example, Bamberg, 1997). Whilst I was interested in the small stories as focussed on the everyday scenes of the women's lives, it did not seem feasible (or ethical) to obtain conversations amongst women living with IBS without their knowledge. There were options, but I was interested less in the naturally-occurring interactions than the issue of how gender was 'performed' within stories women had to tell. Given the dearth of illness narratives literature involving people living with IBS, it would in itself be valuable new knowledge to analyse the emplotments of illness within stories the women participants constructed. Furthermore, by adopting a method such as

diaries allowed for exploring how identities are constructed ‘in-flux’ (Bamberg, 2011:7) as part of stories that unfolded as part of real-time storytelling (see Chapter 4 for a more detailed discussion of the diary method). The idea of ‘conversational narratives’ therefore was somewhere along a continuum between the spontaneous small stories, and the big life stories. To clarify, Ochs and Capps (2001) define the conversational narratives as follows:

Everyday conversational narratives of personal experience might be regarded as the country cousins of more well-wrought narratives...[The] mundane conversational narratives of personal experience constitute the prototype of narrative activity rather than the...byproduct of more artful and planned narrative discourse ... it is the most common form of narrative the world over. (Ochs and Capps, 2001:3, parenthesis added)

#### *Tellership, and listening for different ‘voices’*

Ochs and Capps (2001:24) defined ‘tellership’ as important to analysing conversational narratives. Tellership facilitates exploring how the narrator positions the storyteller (or ‘teller’), which in the case of autobiographical first-person pronoun stories is the same person. Tellership can be understood by considering the concept of dialogical stories, following Bakhtin (1981). Analysing stories dialogically involves listening for the layering of different voices within stories. Putting this

differently, stories may be understood as layered because the tellership addresses 'the thoughts and words of others who are not present' (Ochs and Capps, 2001:24), as well as the teller themselves. In this way narratives may or may be organised and constructed as part of a dialogue with the audience, or another person who may implicitly be influencing the story that is told.

The issue of tellership was relevant to the current research since I adopted a view of myself as a researcher who adopted an active stance as a 'co-constructor' of meanings. I was not going to be physically present during data collection as the stories would be told as part of diary-keeping. However, the participants knew I would be consuming and interpreting their stories in my capacity as a researcher. This issue of tellership and audience was therefore integral to interpreting the diaries as narrative data, as I discuss in more detail in Chapter 6.

### **From personal to cultural readings of narratives**

Narrative researchers often agree that stories work on number of different 'levels' (Somers, 1994; Miller, 2005; Murray, 2000). Miller (2005) described this as follows:

Narratives...exist at different levels. They are individual stories emanating from personal experience and reinterpreted and reconstructed over time and in

different contexts. They are also collective stories of discernible groups in wider society, which provide the contours of the available and, importantly, acceptable cultural scripts. It is important then to note the cultural dimensions of narratives. (Miller, 2005:11)

I have up to this point in the chapter been discussing personal narratives, although the quote above highlights there are also other cultural meanings, or 'cultural dimensions of narratives', in Miller's words. In line Miller, I refer to cultural scripts hereon in; although cultural scripts are also referred to as 'canonical scripts' (Bruner, 1991; 1996), 'master narratives' (Somers, 1994), 'ideological narratives' (Murray, 1999), and 'dominant narratives' (Milnes, 2003; Andrews, 2004).

### **Framing 'cultural scripts'**

Cultural scripts are argued by Somers (1994: 619) to be 'larger than any single individual'. The reader will recall an earlier section in this chapter discussing discourses deployed by people to construct identities and making experiences meanings as contextualised tellings, as per a social constructionist epistemological stance (see for example, Burr, 2001). Adopting a critical realist stance in the current research retained the space for seeing discourses as culturally determined, and which may also be described as 'scripted'.

### *Scripts in psychology*

Scripts have been understood in the past within psychology from a realist perspective. Cognitive psychology defined scripts as schematic clusters of information and knowledge organised together in the brain, and held within a cognitive 'schema' or 'script' (Schank and Abelson, 1977; Mandler, 1984; Polkinghorne, 1988). The scripts were narratively organised mental representations of 'stereotypical' situations and 'scenes' such as what happens when a person is in a restaurant (Schank and Abelson, 1977:422; Bruner, 1991; Emmott and Alexander, 2011). The current research eschewed cognitivism and experimental methods, although, it is a short step to see how the basis of cognitive scripts was also applied with more constructionist work with scripts.

Bruner (1986; 1991) argued that to make narratives 'worth telling' involves the breach of a well-known or 'canonical' cultural script. In his words:

Narratives require scripts but they do not constitute narrativity itself. For to be worth telling, a tale must be about how an implicit canonical script has been breached, violated, or deviated from in a manner to do violence to ... the [message of the] canonical script. (Bruner, 1991:11, parenthesis added)

Bruner extends Miller's point about the personal and cultural 'levels' of narrative, depicting the narrative that is 'tellable' (Norrick, 2005) or 'worth telling' (Bruner, 1991:11) to be one that goes up against the canonical or cultural script. Ochs and Capps (2001:34) describe this idea as part of what defines the 'tellability' of conversational stories, following Norrick (2005). Stories with 'high' tellability may perhaps be dramatic and draw the audience into the story. However, Thomas-MacLean's (2004) research that was discussed demonstrates another feature of tellability, which sees the story as more tellable (having a high tellability) if the audience is interested in what the teller has to say.

I would argue alongside Miller, and others, that there are certain cultural scripts that are privileged over others, and this in turn shapes and influences the tellability of a story for individuals (McLeod, 1997; Douglas and Carless, 2013). In the context of the current research, one Western cultural script surrounds the power of Western medicine in shaping how people make sense of their illness-related experiences. Medical knowledge and the discourses of diagnoses operate to classify and reify sensations and health experiences as 'diseases' and 'symptoms' (Foucault, 1976). This has had a powerful influence on how people conceptualise health and illness in Western societies as the IBS literature has demonstrated. Whilst cultural scripts have power, personal narratives are unique, but are not told in a cultural vacuum. Milnes' (2003) research provides an example to

illustrate how personal stories are aligned to, or contest cultural narratives.

Milnes (2003:3) conducted feminist-narrative research exploring the personal narratives 'young mothers' had to tell. Milnes interviewed a sample of young women in the UK in order to analyse the personal stories the women had to tell. Milnes also analysed the extent to which they drew upon dominant narratives of young motherhood, which has been framed as a societal 'problem' to be denigrated and shamed, as within cultural representations of teenage mums in mainstream media. One of the women (Abby) challenged an underlying assumption that contributed to the pejorative framing of young mothers as part of judgements about promiscuity within the dominant narrative of female adolescence. Abby constructed her identity as a 'masculine' and 'ladette' teenager who was an actively rebellious teenager (Milnes, 2003:173). Yet, despite being 'one of the lads' (ibid.) in her mostly male teenage friendship group, Milnes interpreted Abby to have emplotted herself into her stories as feeling the same social pressures other young women experience. The dominant narrative of female adolescence, in addition to discouraging sex outside of monogamous relationships, promoted seeking 'male approval as confirmation of her [Abby's] status and 'worth' as a woman' (ibid., parenthesis added). This is just one of many stories Abby and the women who participated in Milnes' research constructed. This example highlighted the way Abby's personal narrative was crafted in ways that were aligned with and also



contested the Western dominant narratives and 'acceptable cultural scripts' (Miller, 2005) of young women's performances of femininities.

Langellier (1999) and Bamberg and Andrews (2004) suggest that whilst cultural scripts or narratives are powerful, it is nonetheless possible to explore within personal stories instances where people contest or resist the accepted and hegemonic narrative. Milnes (2003) research provides an example of this, showing the importance of analysing cultural scripts by 'look[ing] under the covers' (Harris et al., 2001:32, parenthesis added) of what is 'normally labelled as common sense (ibid). This provided a way in which it was possible to analyse what was assumed and taken for granted by the women living with IBS in the current research as constituting 'common sense', which I argue to be the influence of Western cultural scripts.

## Summary of methodology

I have outlined in this chapter an overview of narrative theory, and how I have defined and understood narratives as concerned with storytellers' emplotments of what is meaningful to them. I have discussed in detail the relevance of critical realist epistemological approaches, as well as the incorporation of social constructionism and discursive approaches as a way to study women's stories as narratives constructed within the research setting. My position as a reflexive and feminist researcher also meant it was necessary to discuss decisions

made as to how I situated myself in the research, and considered embodiment part of the critical realist approach taken. In the next two chapters I provide details of the research process undertaken, and the diary method that was used is discussed. These chapters also attend to how I considered and approached certain ethical issues when designing and conducting the narrative study.

## Chapter 4: Exploring women's stories in 'real time': Diary method and design

I considered the ethics of doing narrative research that took as its focus women's everyday lives and experiences when designing the research. I chose to use a diary method for an array of reasons that will be discussed throughout this chapter. Diaries are used less often within qualitative research than interviews (Bartlett and Milligan, 2015). This can be seen from the field of IBS qualitative research, where the method of choice in the past has been interviews (see chapter two for examples of past qualitative research involving women living with IBS). Chapter 3 outlined how the narratives methodology rejected the realist claims to unearth truths within research. I adopted a constructionist view of stories as embedded within the social context of the research (Berger and Luckmann, 1966; Burr, 2001). In this chapter I will explore diaries as a method used for generating narratives, and explore some ethical considerations of diaries and narrative methods.

### **Defining and understanding diaries**

The broad definition of a diary is:

...a document created by an individual who has maintained a regular, personal and contemporaneous record (Alaszweski, 2006:1, parenthesis added)

Diaries can be defined as a personal ‘document of life’ (Allport, 1942; Plummer, 2001) that allows for maintaining everyday and ‘contemporaneous records’. I will use the term journal and diary interchangeably in this thesis as the temporality of the personal documents is what is at stake, rather than the linguistics of the terms.

### **Moving beyond an ‘interview society’**

Within the research setting diaries have been claimed to be a ‘poor relation’ (Bartlett and Milligan, 2015:1) of the interview as a qualitative method. Atkinson and Silverman (1997:310) claim that this is because we live in an ‘interview society’. The popularity of interviews is argued to have led to qualitative researchers become over-reliant upon method of data collection. I mentioned the ‘turn to narrative’ as one of the turns that took place in 20<sup>th</sup> century (see for example, Czarniawska, 2004). The interview society reflects the Western cultural interest in narrative forms, such as autobiographies and biographies, as discussed in Chapter 2. Documents of life are personal narratives that take a material form. They are a tangible and physical object that the diarist can carry around, and that becomes embedded within the participant’s everyday practices (Plummer, 2001; Stanley, 2013). Diaries are but one example of personal documents, with some other commonly used documents of life including objects such as passports, weekly shopping lists, to do lists, birth and marriage certificates, photographs, and medication prescriptions. However, the diaries in the current research were not like these personal documents, which highlights an important

difference between documents generated at random, or with the research context – known as ‘solicited’ and ‘unsolicited’ diaries.

## **Diaries used in research**

### *Solicited and unsolicited diaries*

Jacelon and Imperio (2005) differentiated between two types of diaries. The ‘solicited diary’, or research diary as I call this, is different to the spontaneously produced ‘unsolicited’ diary. Solicited or research diaries then can be defined as a ‘research tool that requires respondents to make regular records of daily lives and experiences’ (Wiseman, et al., 2005:394). By contrast, the unsolicited diaries are demarcated by their design for personal ‘private’ use and consumption (see for example, Mulcahy, 2007). The diary audience of the personal diary is imagined, with the minimum audience in mind of the future diarist (Bell, 1998; Jacelon and Imperio, 2005; Alaszewski, 2006; Bartlett and Milligan, 2015).

Unsolicited diaries are by design intended for personal consumption, though the reader need not look far to see examples of unsolicited diaries that have since gone on to be publicised. For example, Watson’s (2012; 2013) research analysed the diaries and a memoir of a boy called Harry Tucker who was evacuated during World War II. Watson analysed both the diaries and memoir collated using the diaries that Harry Tucker kept for many years after being evacuated. In the literary world, the diaries written by Samuel Pepys in 1660 have been compiled

by different writers over the years (Latham and Matthews, 2000). Lowe (2006) has compiled a collection of diary entries in an 'illustrated journal' of the Mexican artist Frida Kahlo (1907-1954) thoughts, poems, and drawings during the last decade of her life. These are just a few of the plethora of unsolicited diaries that have been published posthumously, or as part of personal memoirs or autobiographies.

### **Contemporary diary-writing: blogging**

Bolger et al. (2003) and Bartlett and Milligan (2015) argued that new technologies provide more opportunities for innovative diary keeping than ever before. They 'have the potential to change the meaning and nature of diary keeping and the potential medium through which diary data might be gathered' (Bartlett and Milligan, 2015:51). For example, online and internet first-person storytelling on websites, known as 'blogging', has become a prolific method of diary-keeping in contemporary society. Personal online blogs are unsolicited, but their existence in the public domain for consumption by internet users blurs the boundaries between what may be perceived as public or private (see for example, AoIR, 2012). The proliferation of internet-based sites for interaction and writing, such as with blogs, are evidence of this call to recognise the way new technologies. For these reasons, it can be argued that using online writing may be ethically complex, but are rich data that could be drawn upon within social research.

I considered the potential of using online sources of writing such as discussion forums and blogs during the design phases of the research. Researchers have taken this approach, such as Barker and Gill (2011) and Handyside (2012) who analysed an online blog called Bitchy Jones' Diary (2010). Using online writing, Handyside (2012:41) argued, 'opens up new ways of thinking'. This would have been an option, since there are various IBS blogs around. For example, Sophie Lee's website, the 'IBS tales' is a blog that Lee completed about her illness-related experiences as a person living with IBS in the USA. Having gained considerable attention over the years, Lee changed the blog to allow readers to submit their IBS stories. She wrote an autobiographical book based on her experiences, showing how diary mediums can shift and change if reconstructed for a wider audience (Lee, 2011).

Lee's blog and the autobiographical book she published using the material from her blog (Lee, 2011) transcended the online-offline boundary. If used for analysing in research this would have been a valuable source of data. However, the ethics of using writing that was not intended for research purposes was something I could not ignore. It was possible to design a study with a prospective method, with data that unfolded in 'real time', without using Lee or someone else's blogging as an example of unsolicited diary-keeping. The 'stories' written within this context would have been generated without the narrator having consented for this to be used for research. In the hypothetical scenario of the narrator/blogger having consented for

their writing to be used for research, this did not alleviate the risk of causing distress.

Researchers' have a responsibility to make effort to avoid causing participants harm (BPS, 2010). I perceived this to be a risk of using unsolicited diaries from the internet or from any other means (see for example, BPS, 2011). It would also be ethically dubious to ask women living with IBS to send me their personal diaries, and was not required in relation to the research questions as interested in stories women living with IBS had to tell within the context of research participation. Taking this into account, I chose not to use unsolicited diaries. My theoretical position on narratives (and narrating) and diary-keeping was that such activities have specific audiences in mind, and are written in certain social context. For me, this meant using a means of data collection and method that acknowledged narrative research as a deeply ethical endeavour (see for example, Ochs and Capps, 2001).

## Dilemmas, strengths and ethics of diaries

The research aims surrounded exploring everyday stories the women constructed in the research setting, and as they unfolded in 'real time' (Plummer, 2001; Alaszewski, 2006; Stanley, 2013; Bartlett and Milligan, 2015). My interest was in the everyday, a realm of experiences that is fundamental to understanding human lives (see for example, Highmore, 2002). Consistent with my feminist standpoint, I agreed the



‘personal is political’ and that exploring stories of women’s everyday lives was important. I wanted to make the process of generating the story data as easy and convenient as possible for the participants. Diary methods provided contextualised ways of exploring illness stories and accounts of women’s everyday lives, satisfying the aims of the research. Additionally though, there was the added advantage of providing new knowledge using a prospective method (Sargeant and Gross, 2011) that involved storytelling that looked towards the future, rather than providing stories of the past, as with interview studies (Watson, 2013). Diaries are completed ‘at the same time or very close to the time when events and activities occur’ (Bartlett and Milligan, 2015:16). This strength of diaries would provide new ground through which to explore women’s stories who are living with IBS. It lent the women’s stories as ‘data’ a quality of immediacy that is lacking with other methods and data generated in a ‘false’ rather than ‘naturalistic’ research setting (Plummer, 2001; Alaszewski, 2006; Stanley, 2013).

### **Space for emotional expression**

The premise of diaries as produced by participants at a comfortable distance from the researcher, and as completed at the participants’ own pace and convenience, greatly appealed to me as a researcher interested in experiential meaning-making (see for example, Bartlett and Milligan, 2015). It would be possible to explore stories as they unfolded in ‘real-time’, rather than as part of retrospective tellings. Furthermore, as Riessman (2015) argued after keeping her own illness

diary, the diary method permits exploring stories that blur the boundaries between past, present and future, with diaries moving between temporalities as a common feature of diary-writing.

### *Journalling as cathartic*

I was a child when starting my own personal diary. I am now many years older and still write and draw in a personal diary, and gain satisfaction from doing this. Whilst it was not assumed the act of diary-keeping would be appealing to participants, I did balance the benefits and limitations of diaries when used as a method during the design phases. For example, within Western cultures there is a perception that diaries are an object taken-for-granted as eliciting reflections on personal experiences, thoughts and emotions (Wiener and Rosenwald, 1993). Following Pennebaker and colleagues (Pennebaker and Beal, 1986; Pennebaker, 1989; Pennebaker, 1997), there have been claims that diaries can be cathartic by providing a space to express and release repressed, 'bottled-up' emotions about meaningful events and life experiences (Elliott, 1997; Baikie and Wilhelm, 2005). This has been my personal experience, though I do not consider the psychoanalytic views of diary-keeping as cathartic as unproblematic in suggesting an 'internal' life that is expunged through writing practice. Furthermore it would be presumptuous to assume different people would experience the practice of keeping a diary in the same way.

Within a research context Meth (2004) and Thomas (2007a) used diary methods and argued the method helped to 'give voice' to difficult and traumatic experiences of people from marginalised groups. Meth conducted feminist research involving South African women who were asked to document experiences when they were subjected to, or had witnessed, abuse or violence. In the follow-up interviews, the participants reported to Meth that they found the activity of diary-keeping positive. Subsequently, Meth concluded that the diary method has the potential of being empowering when used with marginalised groups. Thomas (2007a) also found participants living with HIV/AIDS, which is a highly tabooed topic in Namibia where the research was carried out, offered similar feedback as Meth's (2004) participants. Whilst I could not assume diary-keeping would be a 'release', like Meth and Thomas it was possible the diary method could be potentially positive, empowering, and perhaps cathartic. This may be particularly so given the context of IBS as a stigmatised illness, according to past research (Taft et al., 2011; 2014; 2017). Perhaps telling personal 'stories' of illness would be something the women enjoyed given this context?

### **An activity that is bodily/emodied**

Another advantage of the diary was in relation to the research aims and theoretical interests in narratives about illness as an embodied experience. Diaries as an object can be accommodating, and convenient, but it is also literally enmeshed as part of the diarists' daily

lives (see for example, Clandinin, 2007; Riessman, 2008). This could be argued to add authenticity to the method, which Watson (2013) suggested makes diaries different to other narrative forms. In Watson's words: the 'authenticity [of diaries] is embodied in its very material existence' (Watson, 2013:08, parenthesis added). The diary acts as a physical 'conduit which creates the illusion of direct access to the past' (ibid). This 'authenticity' makes the act of keeping a diary an embodied activity, which literally requires engaging using one's body to engage with the external world of objects using one's fingers, hands, eyes, and so forth. In this way diaries were useful as a way of exploring accounts of lived experiences, but which was approached in the current research as including stories as 'lives as told' (see Chapter 3).

### *Diaries as 'private'*

Feminist researchers such as Ribbens and Edwards (1998) have argued that the dichotomising of the public and private realms is a cultural construction, not a social 'reality'. Consistent with this argument, diary methods blur the boundaries between public and private spaces, troubling the notions of a neat and binary compartmentalisation of different domains of human lives (see for example, Bell, 1998). I would agree that the division between public and private is false, just as the stereotypical ideas of men as 'breadwinners' and women as 'homemakers' is embedded within historical notions of the 'separate spheres' (Chapman, 2004:36) within 19<sup>th</sup> Century Western ideologies about marriage. Diaries in this way facilitate exploring the meaningful 'stuff' of lives within and beyond the public versus private realms. There

are however questions about who 'owns' the data since the stories are about, and are told by participants, which is an issues that has troubled feminist and narrative researchers for decades (Stanley, 1990; Kelly et al., 1994; Wilkinson and Kitzinger, 1996; Mauthner and Doucet, 1998; 2003; Plummer, 2001; Hesse-Biber, 2012; Miller et al., 2012).

## **Risks of diary methods**

### *Research representing whose interests?*

Narrative research carries the risk of participants experiencing their accounts of their lives as having been taken over, or 'colonised' (Plummer, 2001). This can be easily done if researchers are distracted by invested interests such as research agendas, even if it is an unintentional effect of diary-keeping (see for example, Kelly et al., 1994; Miller et al., 2012). The issue of representation is something I feel no closer to resolving. As Miller et al. (2012) argued, I do however wish to convey to the reader my enthusiasm for engaging in an open and reflexive dialogue about such ethical issues as part of research endeavours (Miller et al., 2012). Whilst not easy to overcome, 'unpacking' taken-for-granted assumptions, such as about the impact of research participation of people's lives (Lazard and McAvoy, in press) is an essential component of doing 'good' research.

### *Bringing back bad memories?*

Bartlett and Milligan (2015) suggest diaries can (and likely do) make people aware of negative experiences that had been forgotten. The risk of constructing narratives about personal experiences and events could include stories that are upsetting and traumatic, which could lead to participants' ruminating and staying with emotions, thoughts and experiences after the research is completed (Laurenceau and Bolger, 2005). Bell (1998) argued that researchers come into people's lives asking them to talk and explore complex meaningful experiences and issues for research participation, before promptly exiting and leaving the participants with potentially upsetting and difficult feelings and thoughts connected to the personal stories (Kelly, 1994). Harm could also have been caused through unknown social ramifications of diary-keeping that reaches beyond the participant to their social networks and relationships. In the earlier example from Thomas' (2007) research with the people living with HIV/AIDS in Namibia, Thomas highlighted that the researcher as distanced from participants cannot know the consequences for people in their lives, and so the diary-keeping may have affected people close to the diarists:

...diaries are recorded in the private sphere of the household, [and] it is not possible to know how their recording might have impacted upon intra-household relations (Thomas, 2007a:3174, parenthesis added)

I could not ignore important ethical issues such as this, given how it could be argued exploring personal narratives is a 'sensitive' research topic (Renzetti and Lee, 1990). As a researcher it was my responsibility to work with integrity, sensitivity and respect for the deeply personal nature of the women's diaries (see especially Miller et al., 2012). I also recognised the women's commitments devoting their time and energy to research participation and hoped to produce research that would be valuable, and that the women involved would enjoy reading, and find salient and meaningful in some way.

#### *Giving participants more control*

There are risks of harm with diary methods, but there are strengths of diary methods in providing participants opportunities to complete diaries at their convenience and at their own pace, as well as being able to do this in more comfortable surroundings than interviews (see for example, Bartlett, 2011; Sargeant and Gross, 2011). Additionally, as a tangible object, diaries were documents that could be edited, and completed, at the women's convenience. This depends considerably on the way 'data' is inputted into the diary, since some software for keeping electronic diaries does not include free or easy to use functionality. Yet, this was not a concern in the current research as the diary mediums chosen meant the women could edit or change the content of their diaries if they wanted to. This autonomy was something I wanted the women to use to their advantage, and I emphasised to the women who completed diaries to feel free to delete and edit their entries before sending to me as they chose fit.

### *Burdensome method?*

One of the risks of using diaries was in requiring a time and emotional commitment from the women who took part (see for example, Johnson and Bytheway, 2001; Bartlett and Milligan, 2015). As women living with IBS, I knew fatigue could be an issue and that doing the diary could be tiring and experienced as burdensome. Sheridan (1993) and Milligan et al., (2005) found within their diary research that some people were more inclined to complete diaries than others. For some who were unfamiliar or less inclined towards diary-keeping the activity, the activity was described as a 'boring and repetitive activity...a chore to complete' (Milligan et al., 2005:1888). Diary research carried out by Jacelon and Imperio's (2005:994) also suggested some participants found diary-keeping 'got to be a bore'. This contributes to reasons why diaries are ethically positioned as a potentially burdensome method, with a risk of drop-out and attrition (Elliott, 1997; Bartlett and Milligan, 2015).

I sought to work around this by limiting the amount of time I asked the women living with IBS to complete their diaries. The supervisory team and I decided to keep the diary keeping phase to seven days, allowing sufficient time for the women to get into the task, but without requiring too much of their time. Rather than being a burden, I found that the women who took part in the current research thesis expressed an enthusiasm and willingness to complete their diaries, which I did not expect during data collection.



# Putting ethics to practice

## Ethics, research processes and decisions

I have explored some of the potentials and pitfalls of diary methods, with examples provided of specific ethical issues of interest. In agreement with Plummer (2001), Miller et al. (2012) and Stanley (2013), I treated ethical issues as ongoing, and addressed these unfolding scenarios and situations with a pragmatic attitude. Neill (2016) argues that psychological practice and research usually involves addressing ethical issues by adopting a universalistic and utilitarian approach. Regulatory practices by bodies such as the British Psychological Society (BPS, 2010) therefore call for psychologists to demonstrate adherence to certain values and principles, such as ensuring they work with 'honesty, justice and respect' (Neill, 2016:13). Consent, confidentiality, debriefing, withdrawal, and avoiding causing participants' harm also requiring addressing through devising specific ethical protocols (BPS, 2010).

As a psychological research study at Manchester Metropolitan University I was required to generate specific ethical protocols preparing for worst case scenarios. Protocols were devised and put in place, such as removing or changing identifiable information to maintain confidentiality, separating the 'raw' data from the interpretations; storing electronic information securely in encrypted and password-protected files; as well as making efforts to establish good research relationships with participants to facilitate ongoing

‘process consent’ (Eynon et al., 2008; King and Horrocks, 2010). For the reader’s benefit the ethical protocols that were generated as part of the application submitted to the University Research Ethics Committee can be found in the Appendix A. This includes the Research Information Sheet (Appendix B) that was given to any potential women living with IBS interested in taking part, the consent forms (Appendix C) and the debriefing sheet provided after research participation (Appendix D). Even though the application was prepared, ethics cannot be fully anticipated or planned, with ethical scenarios unfolding all the time within real-life situations (Plummer, 2001). For this reason ethics formed part of an ongoing dialogue throughout the thesis in seeking to make transparent any issues that arose during the research process (see for example, Plummer, 2001; Miller et al., 2012; Stanley, 2013).

### *Technical problems*

I learned a great deal as a result about using personal documents within research, and how the problems that come up can be most unexpected. Whilst the process of sending and receiving the paper diaries was relatively straightforward, I encountered some issues with the electronic diaries. More specifically, even though the encrypted memory sticks arrived in the US, Europe and Australia without any issues, the technology itself failed to unlock with the passwords that had been set. Whilst this may have been inconvenient for the participants, there was an override function that allowed for re-writing and saving the electronic diaries onto the sticks, and resetting the passwords. Other minor technical issues occurred, which highlights

how even when planning for every eventuality it is not possible to anticipate technical issues. This underlined the necessity of putting contingency plans in place when conducting research.

## **Developing collaborative research relationships**

I wanted to encourage the women to feel part of making the research, seeing them as ‘collaborators’ working with me to carry out the research (Elliott, 1997; Sargeant and Gross, 2011). Reducing the power imbalance between researcher and researched is never fully achievable, though active efforts can redress the power dynamic (see for example, Miller et al., 2012). For example, my approach to discussions with the participants was to offer plenty of opportunities for asking questions. I provided my contact details so I could advise before, during and after the data collection phase, and also encouraged the women to edit their diaries (if they wanted to). This was especially useful for the participants who not had any past experience of keeping a diary, but also for some of the women who were uncertain what to include in their diaries. In addition to making myself available for answering questions, I also tried to make the task more interesting by providing choices in terms of the type of diary they completed. Taking this approach also acknowledged that women living with IBS are a diverse group who would have different preferences and find some methods more convenient than others (see for example, Bartlett, 2011; Meth, in press). I detail in the next chapter the diary

methods chosen, with justifications for the diary design included for the remainder of this chapter.

## Diary design

### Use of diaries in health research

Diaries have been embraced by health researchers and clinicians as a way to gather information about patients and participants, with many claiming the benefits of descriptive and 'structured' diaries for recording symptoms, psychological states, health-related behaviours such as eating and exercise regimes, over a longitudinal period of time (see for example, Tennen et al, 1991; Affleck et al., 1999; Bolger et al., 2003). Health researchers have used structured diaries with closed-questions, providing participant-diarists with instructions to fill in their research diaries at certain times, or in response to certain events, such as experiencing symptoms (Bolger et al., 2003). Bartlett and Milligan (2015:18) define the structured diary as most frequently used as a time-log to record details of interest to the research, with the parameters set 'against a list of predefined actions or validated measures over a predefined period of time'. IBS research has tended to use the structured diary format most often as part of research interests in understanding the cause of IBS symptoms. For example, records may be kept of diet or symptoms as part of monitoring connections with symptoms (see for example, Levy et al., 1997), or understanding social, personal or lifestyle factors such as stress, in order to establish ways to

control or treat IBS (Shimberg, 1988; Naliboff et al., 1999; Jacobs, 2007; Kennedy and Robinson, 2009; Mazzawi et al., 2013).

Some of the participants in the current research had experience of keeping daily diaries within these contexts, although most had not completed largely unstructured diaries in conjunction with their illness-related experiences before participating. Selecting the diary method was a novel and innovative way to collect 'real-time' data that would generate new knowledge. The only prerequisite was that each of the women had an aptitude and skill at constructing 'stories' of their personal reflections, thoughts, emotions and experiences in words or drawings.

### **Why not diaries and interviews?**

The reader may be wondering why not combine interviews and diaries as others have done? There are many examples of research carried out that use a 'Diary Interview Method' (Zimmerman and Wielder, 1977), or that combines two or more different methods simultaneously (see for example, Thomas, 2007a; Worth, 2009; Kenten, 2010; Bartlett, 2011; Sargeant and Gross, 2011). Latham (2003:2012), for example, adopted a diary-photograph, diary-interview method, creatively blending methods in order to create a more organic process of data collection that brought together different mediums of storytelling. This was an option though I chose to keep the suggested diary methods simple, recognising I had limited research resources to offer

participants. I did not want to overly complicate the guidance given to the women.

I did include an interview phase in the early design of the PhD research, with two phases of diaries and interviews. However as an alternative there was going to be two phases, a diary study (phase 1) and an interview study (phase 2), involving two different groups of women living with IBS. My thinking behind this was that the data could be ‘triangulated’ (Willig, 2013), just as diaries are sometimes used to inform and supplement other data collected later into the research process. As Corti (1993) and Thomas (2007a) detailed, by the end of the diary study data collection I had an unexpectedly large and rich amount of data already. This was exciting though I felt conflicted given the depth of meaning of entries and the potential the women could regret what was included in their diaries. Diary analysis is known to be time-consuming when using the unstructured diary method (see for example, Bartlett and Milligan, 2015). It was therefore clear after data collection of ‘Phase 1’ that the volume of data made completing a second phase unfeasible within the PhD time-frames. For this reason the supervisory team and I decided it would generate valuable new knowledge by focussing exclusively on the diaries as high quality data.

### **Electronic, handwritten and mixed-media diaries**

Diary researchers have used an array of diary mediums in recent years, using traditional pen-and-paper diary methods and taking advantage of

the emergence of new digital technologies. For example, researchers have utilised video diaries (Gibson, 2005; Buchwald et al., 2009; Bates, 2011) and audio diaries (Hislop et al., 2005; Worth, 2009; Sargeant and Gross, 2011) and photo diaries (Radley and Taylor, 2003). There has also been a steadily increasing number of diary studies using a combination of methods, such as by integrating audio, photo, and video diaries to participants to allow people to choose their preferred diary medium (Holliday, 2000; Latham, 2003; Bartlett, 2011; Gibson et al., 2013). Bartlett's (2011:4) research with people living with dementia offers one example of a recent mixed diary medium study, justified by the researcher in respect of the flexibility of diary methods.

## **Largely unstructured diaries**

*'You have a choice of methods'*

I chose to use a semi- or largely unstructured diary format. My reasoning for this was so that the process of diary-keeping was as easy and convenient as possible for the women who took part, whilst also observing there were limited resources available in terms of equipment that could be offered. As Bartlett (2011) noted different people have different preferences and I accommodated this by providing some examples of well-known diary mediums (pen-and-paper, electronic and video diaries), and during informal conversations expanded on the diary instructions. This was also a useful opportunity for exploring if the women were drawn towards completing in another format, which was not the case. Whilst I had written on the Research Information Sheet

there was 'no right or wrong choice' of diary method, talking this through with each of the women was useful in getting a sense of how comfortable they were with keeping a diary.

Bartlett and Milligan (2015) defined this diary design as involving minimal instructions to the women in how they kept their diaries, and what they chose to write/draw:

In-depth semi- or unstructured diary [keeping]...is designed to encourage to write a more detailed temporal narrative, often around a loosely structured set of themes devised by the researcher...to gain a deeper understanding of a person's actions, experiences, thoughts and emotions around a particular topic (Bartlett and Milligan, 2015:21, parenthesis added)

This definition and focus was a better fit than a fixed diary format as it provided more space for the women to tell stories about their everyday lives and IBS-related experiences as the phenomena of interest in this study. Diaries are well-known for encouraging a more conversational and informal form of storytelling, and this was something I wanted to take advantage of in keeping with the focus on conversational stories told in real time, rather than as retrospective storytelling. In other words, diaries as a method would promote a 'deeper understanding' of the women's experiences when interpreting their emplotments in their stories.



### *Overcoming barriers to research participation*

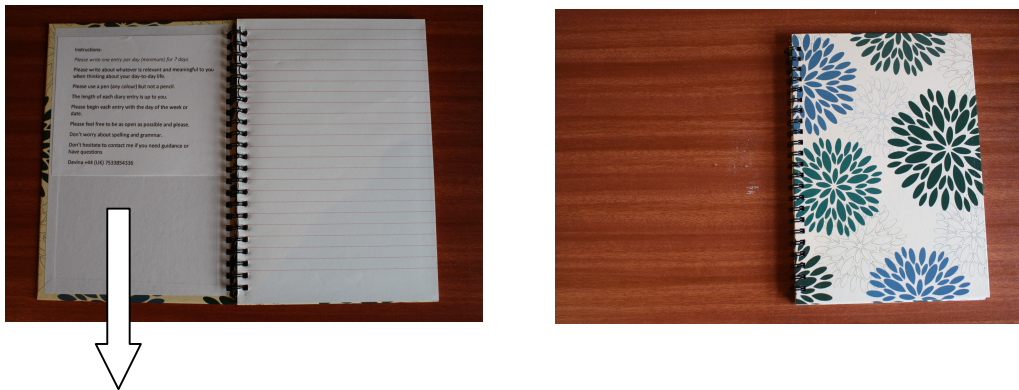
Sargeant and Gross (2005; 2011) argued that unstructured diaries are particularly well-suited to carrying out research with people living with chronic illness. They carried out audio diary research with young people living with IBD, and found the method was sensitive to their participants' having unpredictable and restrictive chronic conditions illness. A number of the young people that took part reported enjoying the process, which was likely facilitated by designing the research to accommodate the group of interest. Like IBD, IBS can involve symptoms that fluctuate and come on suddenly and without warning. For example, people involved in past IBS studies have reported how symptoms can hinder activities such as travelling, whether through the unexpected onset of symptoms or because of anxieties and concerns that this could happen (Dancey and Backhouse, 1993; Dancey et al., 2002; Casiday et al., 2008a; Håkanson, 2010). Using a diary method removed the need for travelling to interviews, and the design of the diaries to be a loosely structured encouraged the women to construct stories about whatever experiences they felt comfortable exploring in the stories crafted in their diaries.

### **Instructions for diary task**

*'Please write about what it is meaningful to you'*

The diary instructions were simple and broad, leaving space for the participants who volunteered to 'record activities and events in their

words' (Corti, 1993:2) that were meaningful to them. The following images show the diary instructions inside the handwritten diaries sent and the instructions sent to the participants that completed electronic diaries.



#### Instructions:

*Please write one entry per day (minimum) for 7 days*

Please write about whatever is relevant and meaningful to you when thinking about your day-to-day life.

Please use a pen (any colour) but not a pencil.

The length of each diary entry is up to you.

Please begin each entry with the day of the week or date.

Please feel free to be as open as possible and please.

Don't worry about spelling and grammar.

Don't hesitate to contact me if you need guidance or have questions

Devina +44 (UK) xxxxxxxxx

Figure 3. Images, and details of the instructions inside the front cover of the handwritten diaries

**'What to include in your diary:**

*Please type one diary entry per day (minimum) for 7 days using your computer.*

This is your diary, so please write about whatever is relevant and meaningful to you when thinking about your day-to-day life.

You can do more than one diary entry per day if you want to.

When typing your diary you can use any font size, colour and type of font that you like.

The length of each diary entry is up to you. You could try to do at least half a page per diary entry, or just write as much as you can in the time you have available

It would really help me if you could please type the date or the day of the week at the beginning of each diary entry. If you would not mind doing so please could you also introduce people you talk about when you first mention them: (for example) *Georgie, my grandpa*.

Please feel free to be as open as possible. I am so interested in looking at the meanings you attach to your experiences.

If you want to talk more about what to talk about when recording your video diary please do feel free to contact me. I'll call during the week to check things are going ok.

I hope you don't mind but I was planning to send you a daily reminder asking you to please do each entry. This will just be a short text or email reminder.

**What to do once you've finished your diary:**

*Once you have completed your diary, please save it on the USB stick I sent you. Please also let me know you have finished and we will arrange for a courier to pick up your USB stick.*

I will not be returning the USB stick to you so if you would like to keep your diary please save a copy of it somewhere secure on your computer. The version that I will use in the research will have any personal information removed or changed.

If you change your mind about being involved in this research, please do let me know as soon as you can. I can take your diary out of the research up until 15<sup>th</sup> November 2015. After this date I will have started the research data analysis. Any questions please do not hesitate to get in touch!

Figure 4. Image of the password-protected USB used to save the electronic diaries, and details of the instructions sent with this.

The aims of the instruction sheets was to avoid putting words and ideas 'into' the women's heads, keeping instructions short and concise, and also a reminder that we had agreed I would send reminders, since diaries can be easily forgotten amongst other daily activities ('I was

planning to send you a daily reminder asking you to please do each entry. This will just be a short text or email reminder.’) As it is possible to see from the electronic diary instructions (and in Appendix E for the full handwritten instructions), I agreed with each participant that their diary would be picked using a courier or a stamped and addressed envelope. For the women based abroad a courier was organised, whereas the UK-based participants were sent a stamped and addressed envelope with a forwarding address for the University written on it. My reasoning behind these protocols was to ensure the women did not have to incur any costs from participating, excluding having to go to a post-box or wait for a courier. Thankfully we did not have any trouble organising this, and the seven participants were all kind enough to send the diaries promptly when they were completed.

## Summary

In this chapter I have provided a dialogue about the value of using diary methods in research, more readily focussing on the solicited diary that was produced specifically for the purposes of research. There are advantages and limitations to different diary methods, and ethical issues that unfolded, as I have discussed in this chapter and will continue to do so during the remainder of the thesis. In the next chapter there will be information provided about the women who volunteered to be part of the research, dedicating their time and energy to constructed detailed narratives about their lives.



## Chapter 5: Strategies used to gather story data, and about the participants

Feminist standpoint theories (Harding, 1991) emphasised the importance of providing women with spaces to tell stories about their lives from their unique and socially situated knowledge of the world. Feminists engaging in research, or feminist researchers (Miller et al., 2012), in this way take seriously women's diverse experiences, and also situating women as having different backgrounds, skills, abilities and preferences. I have detailed in the previous chapter the diary methods used, and some ethical constraints of using narrative and diary methods. In this chapter I give an account of the process of data collection, as well as a representation of the women living with IBS that took part in the PhD diary study, is discussed.

### Process and decisions made

#### Aims for inclusivity

I gave careful consideration as to how to approach inviting women living with IBS to take part taking this into account. My aims were to be as inclusive as possible, and address the imbalance of power in the researcher-researched relationship by leaving space for the women to construct stories using a diary format that worked well for them (see for example, Stanley and Wise, 1993; Renzetti, 1997; Miller et al., 2012). I mentioned in the previous chapter (Chapter 4) that in the early

stages of doing the PhD it was necessary to complete a University ethics application, exploring the ethics of doing narrative research and using diaries. An additional consideration not already discussed is the way in which decisions were made about the sample of interest. As IBS is often undiagnosed (see for example, Hungin et al., 2003), I did not want to invite only women from certain groups, such as IBS patients who had been formally diagnosed, to take part. The stigma surrounding IBS has been part of oppressive labelling of women living with IBS as 'neurotic' by health professionals and in past research (see for example, Dancey et al., 2002; Dixon-Woods and Critchley, 2008; Håkanson, 2010). I therefore chose very broad eligibility criteria so any women who identified as living with IBS and were 'Western', living in countries such as the UK and USA, could consider research participation. This approach avoided the deductive categorising of women, such as by differentiating between their health-related practices, which was not necessary within the narrative research.

From my personal experiences as an 'insider' I knew there were many women who experienced symptoms that fit an IBS diagnosis, or who had been diagnosed by a doctor following invasive tests. My thinking during the research design stages was to avoid providing strict guidelines and inclusion/exclusion criteria as this level of detail was not necessary given the methodology did not seek to make generalisations or adopt a realist and hypothesis-driven method (Crotty, 1998; Tracy, 2013). The aims were to generate in-depth stories women constructed about their lives, and I did not need a large group of participants. In line



with qualitative research paradigms, the focus of data collection was to produce a rich and meaningful data that could be subjected to an in-depth interpretative (narrative) analysis (see for example, Smith et al., 2009; Tracy, 2013; Willig, 2013).

Against my expectations, it was far simpler to engage a small group of (seven) women living with IBS from different Western countries. I anticipated difficulties recruiting and retaining participants given warnings by other diary researchers about the risks of asking for commitment to diary-keeping and attrition (see for example, Milligan et al., 2005; Hyers et al., 2006). Instead, a combination of word-of-mouth and online advertising was sufficient in gaining the interest of 10 potential participants. Whilst three chose not to take part, the seven who did were based all around the world.

## Advertising and materials

To engage potential participants a poster was made, which was then distributed amongst my social networks via universities, and word-of-mouth. The specific wording was intended to be informal and enthusiastic, not positioning me as an IBS 'expert', but as someone interested in hearing women's stories that are living with IBS.

Table 2. Key points made in the advertising poster

- Are you a woman living with IBS?
- Would you be interested in doing a one-week diary about your experiences of illness, daily life and your personal relationships?
- My name is Devina Lister and I am conducting the 'Women's Stories of IBS Project' as part of my PhD at Manchester Metropolitan University. My personal experiences of having IBS informs my interest in the research topic.
- I will invite women involved in the research to keep a diary for one week by talking about aspects of their lives, in their own words.
- If this maybe of interest to you and would like to know more about getting involved, please do get in touch for an informal chat.

The simplest of details were included in the poster so to make this easy to read and understand (or at least this is what I hoped). I find it ironic that despite this, at the time of data collection during the first year I chose to give the project the name (Women's Stories of IBS Project). Reflecting upon this now, 4 years later, this seemed at odds with how I wanted to position myself as approachable, but situated as a PhD researcher with 'insider' knowledge of being a woman living with IBS ('My personal experiences of having IBS informs my interest in the

research topics', Table 1). This became especially apparent when utilising other means of inviting potential participants to contact.

## **Ethics of using online spaces**

### *Looking 'in' from the 'outside'?*

In addition to circulating posters I used word-of-mouth methods by sharing the poster online using the social media site 'Facebook' to share the 'post' about the research, which was then 'reposted' by my Facebook 'friends' (see Appendix F for this social media post). After gaining permissions from an online IBS support group, I posted an introduction outlining my purpose for posting in the group and my dual position as a person living with IBS and a researcher. As Pitman (2002:285) suggested, my reasons for this was to avoid to creating an 'illusion of sameness' with the other members of the group (Breen, 2007). Yet, as my naming of the project implies I struggled with the tensions of being someone that was theoretically part of the group, but who also occupied the position of being a researcher (Kanuha, 2000; DeLyser, 2001; Pitman, 2002; Breen, 2007; Burns, 2012). Pitman (2002:282, parenthesis added) captured what I think applies to my decisions in the earlier stages of the PhD, since: 'My intentions were...noble, yet my consciousness and awareness [was] limited'.

I suggest this because of an issue that unfolded after I made my presence known in the online IBS group (whose name is removed for confidentiality purposes). This was a 'closed' group, where members

requested to be accepted to participate and view discussions, which generally centred on sharing information, asking questions and exploring personal experiences in the supportive online space.

Hello all, I just wanted to introduce myself as I'm probably a bit different to the average member.

I'm a woman living with IBS but also a PhD student doing a project about the everyday lives and relationships of women living with IBS (with MMU [sic., Manchester Metropolitan University] in the UK). I would like to join the group (if it's ok with all members) to learn but also to potentially request women to take part in some informal interviews early 2015. If anyone would prefer I don't belong to the group please just 'comment' below and the administrator can take me off. (I'll not be using anything anyone says in any [way now] of course).  
Thanks a lot!

Figure 5. Post circulated in the online IBS group (2<sup>nd</sup> October 2014)

Internet-mediated research carries with it ethical considerations that researchers are required to engage with, and increasingly so given the steady rise of internet-based research following the digitisation of contemporary Western cultures (Eynon et al., 2008). Prior to posting in

the group I had spent significant time balancing out the ethical issues and benefits of approaching the various stages of the research. Yet, it was something an oversight for me to have failed to consider that, in my naivety, members of the group who read the post would *not* post their desire and interests in the research. The Association of Internet Research (AoIR; 2012) noted that researchers should be considerate of belief systems and frames of references from which people arrive and make sense of into online spaces. This plays a part in perceptions of online interactions, even if individuals have knowledge of social norms and conventions. Subsequently, even though my message aimed to be an introduction as a member who was 'a PhD student doing a project about the everyday lives and relationships of women living with IBS', some members read this post and interpreted it differently. A number of women in the group proceeded to write in the comments that they would be willing to take part, much to my horror as I watched this unfold in the semi-public online space.

To counter the action I quickly responded. I thanked the people who had come forward, and promptly asked them to send me a message or email 'offline'. I also asked if no other members could comment that they wanted to take part for confidentiality reasons. This experience taught me about the integral importance of researchers recognising the differing perceptions of online communications and online groups by individuals. Perhaps it could be said that my insider positioning helped to 'get in' (Burns et al., 2012:52) as part of the community, but also as an observer with different interests to other members. Far from

being straightforward, there are many complexities of internet-based research practices that ‘insider’ researchers should consider in advance of participant engagement (Pitman, 2002; Breen, 2007).

## About the participants

A sample of seven women living with IBS volunteered and chose to take part, agreeing to do so by completing consent forms and in subsequent communications to check for ‘process consent’ prior to the withdrawal deadline. Six of the women were friends or acquaintances who found out about the research through advertising word-of-mouth online and in-person amongst my social networks. One of the women was recruited via the IBS group. Overall the participants were based all across the world, providing a diverse group of women living with IBS based in Western cultures.

I have not included a detailed breakdown of demographic information as I chose not to ask the women too many details about themselves, beyond their illness status, location, and age. Asking the women about themselves, beyond asking if they identified as a ‘woman living with IBS’, was not something relevant to the research questions. What was of greater concern was how the women constructed their identity positions through their emplotments in the stories in their diaries? In accordance with feminist standpoint theory, I do not want to treat the group as sharing qualities of sameness and homogeneity (see for

example, Stanley and Wise, 1993; Wilkinson and Kitinger, 1996). This assumption of diversity and uniqueness was realised as the women emplotted themselves as having unique personal stories to tell, as informed by their diverse backgrounds and social circumstances (see Chapters 7-9).

### **Diverse group of Western women living with IBS**

What I did notice was that the women were very different ages, ranging from retirement age (60-70 years old) to women in early adulthood (20s-30s). This was decipherable from a few of the diaries, and for this reason I chose to ask all of the women how old they were within a ten year age bracket. My thinking behind this was to get a sense of the women's culturally contextualised attitudes, beliefs, and personal resources. Did the women grow up in a time when feminist activism had contributed to changing attitudes towards women's roles as caregivers and homemakers? Was IBS a relatively new concept for any of the women who had experienced the bowel symptoms synonymous with an IBS diagnosis as it is medically defined in the late 20<sup>th</sup>/early 21<sup>st</sup> Century? Were some of the women part of contemporary Western cultures insofar as they had established skills in utilising digital new technologies, providing access to information and communities not available in the past? These were some questions that arose when I was considering the how the cultural resources available to the women would be shaped by experiences of events in Western history.

### *Sexual identities, relationships and subjectivities*

Each of the women chose to explore relationships in their diaries, and for the sake of consistency I requested one of the women (Eliza) to tell me about her sexuality and relationships. Namely, I asked Eliza if was comfortable telling me how whether she was involved in an intimate relationships, and about her sexual identity (as straight or LGBT+ identifying, for example) at the time of the research. A number of the women told stories in their diaries about boyfriends (Alice), ex-boyfriends (Adele), and husbands (Helen, Georgiana and Maria). Eliza shared with me that she was not involved in a long-term relationship at the time of the research, as was also the case with Diana. Eliza was different in terms of her decision not to put her sexual identity into a predefined category (e.g. as straight, gay or bisexual). This was in contrast with other women who emplotted themselves into their stories as women looking for, or involved in heterosexual relationships.

### **Participant profiles**

The remainder of this chapter gives some information about the participants in terms of the identities they constructed through the stories they told. The representations are written to represent each of the women in a balanced way, whilst staying loyal to the information they chose to share in the diaries. All names and personal details have been changed so it is not possible to identify anyone.



*Georgiana* lives in Portugal in Europe having emigrated there from the UK. Georgiana was in her 40s when she took part in the research, and often emplotted into stories accounts of her husband (Tom) and two children (Martin and Emma). At the time she took part in the research Georgiana was working full-time in a busy job. Georgiana chose to complete an electronic diary.

*Diana* lives in the UK and was in her 20s at the time she completed her diary. She lived at home with her parents and was working part-time, as well as studying for an undergraduate degree in a social science subject. Diana positioned herself as interested in having a heterosexual relationship with 'boys', and emplotted many friends, peers, and family into her diary. Diana completed a handwritten diary, and included a mixture of written entries and drawings.

*Adele* lives in the UK and was in her 20s when she completed her diary. She positioned herself as a woman involved in a heterosexual relationship with 'Jonas' in her diary, and emplotted family and flatmates into stories she told. At the time of the research Adele was studying for a professional health-related doctorate. She chose to complete an electronic diary.

*Maria* lives in the east coast of the USA. She was in her 40s and was working full-time in a busy job. Maria emplotted her husband (Joseph),

her Mother, and her children into the stories she constructed. Maria chose to complete an electronic diary.

*Eliza* lives in the UK and was in her 30s at the time she took part in the research. Eliza was studying full-time for a doctorate in a biological sciences subject. Eliza chose not to discuss her sexual identity and did not emplot others into her diary, except for brief emplotments of friends and colleagues into stories told. She discussed experiencing anxiety as interconnected with her experience of IBS. Eliza chose to write a handwritten diary, and interspersed the text with small drawings – symbols for emotions known as ‘emojis’ – and structured her diary with prose and bullet points to separate paragraphs of writing.

*Helen* lives in Australia and was in her 50s when took part in the research. She emplotted her husband (Edgar), and children (Leah and Kenneth), and also a number of her friends into the stories she told. She also explored experiences of living with chronic pain, as well as chronic bowel issues associated with IBS. Helen’s diary was handwritten.

*Alice* lives in the UK and at the time of the research was completing a doctorate in a humanities subject. Alice emplotted her boyfriend (Edward), and friends and her Mother into the stories she constructed. Alice’s diary was handwritten.

## Summary

In this chapter I have discussed the participants of the research, and the process of data collection. This took about 4 months in total, with some additional time for the diaries that travelled a great distance back to the UK where I am based. Proceeding chapters will move into the analysis and interpretations of the diaries, which were fascinating accounts of a week in the lives of the diverse group of women.



## Chapter 6: Retaining the ‘mess’ in

### method: Multi-layered analytical

### approach taken

To recap, I outlined in Chapter 4 information about the process of data gathering, and in Chapter 5, details of how and who took part in the research and how. Whilst I have provided an overview of the participants and the diaries they produced, this does not do justice to the level of detail and nuance of each diary. They were all very different, in terms of the content and structure. Some of the diary entries included emplotments of many ‘characters’, everyday events and reflections into the stories that looked beyond illness-related experiences. Other diary entries focussed on accounts of the women’s embodied experiences of IBS and illness. The only detail the diaries shared was in having been completed at least once per day for a week in either the electronic (typed) or pen-and-paper (handwritten or drawn) diary formats. For these reasons it would not be out of place to say analysis felt like a daunting task.

As Holstein and Gubrium (2012:6) pointed out, ‘Methods of analysis do not emerge out of thin air’. The flexibility of diaries and narratives made for a diverse and mixed medium collection of meaningful diary-based narrative data. Therefore no prescribed and linear method of analysis would ‘fit’ (Henwood and Pidgeon, 1992) the data and provide

a means of conducting 'good' qualitative research. This was positive in opening up space to explore the many 'varieties of narrative analysis' (Holstein and Gubrium, 2012) in order to fulfil the current research' aims. However, the analytical approach was required to do a number of tasks, as discussed in Chapter 3. I was interested in the nature of the stories constructed as emplotments of personally meaningful experiences, reflections, and relationships with people in the women's lives. Additionally, as narratives exist on a number of 'levels' (see for example, Somers, 1994; Murray, 2000; Miller, 2005), I wanted to interpret the personal meaning-making, but also how the women could aligned themselves to, or contested Western cultural scripts. For example, did the women's emplotments of illness reiterate and reinforce messages from past IBS literature about the importance of finding ways of coping and controlling their 'ill' bodies. Did the women construct gendered stories of illness when exploring experiences of illness embodiment and their everyday lives? If so, to what extent did the personal stories tap into Western culturally scripted ideals about femininities as constituting women containing their 'leaky bodies' (Shildrick, 1994)?

## Interpretation as interactive process

### Conceptualising multi-layered analysis

In order to explain how I went about the interpreting the diaries I offer a step-by-step account, although the task was not linear. It was iterative (see for example, Willig, 2001; 2013) and the interpretations

moved between the 'parts' of the data and the 'whole' data set, as a fluid interpretative and hermeneutic process (see for example, Smith et al., 2009:27-28; Willig, 2013). I did not want to lose sight of my role as researcher who was active in the process of co-constructing the interpretations, or lose the 'authenticity' of the women's stories by changing them. Therefore in agreement with Riessman (2008:144) I found that narrative analysis entailed 'Multiple readings...[as] potential in all narrative work'. Some of the stories were more structured, and constructed a linear account of events, whilst others lacked structure and had no clear-cut ending, consistent with the 'postmodern' narrative, as discussed in Chapter 3 (see for example, Wikan, 2000; Ochs and Capps, 2001; Riessman, 2015). I conceded that to reconstruct the narratives as part of the interpretative process, without taking into account the women's words and stories as contextualised tellings would be tantamount to 'colonising' the data (Plummer, 2001). My task doing the research was to complete my thesis, but at the same time I wanted to conduct a study that was ethical, feminist and reflexive. To this end I applied the concept of a narrative 'bricolage' to conceptualise the process of analysing the data.

### **Narrative 'bricolage' approach**

Worth (2009) drew upon the Deleuzean concept of assemblage 'as a collage of sometimes incompatible parts that is by definition active' (Law, 2004). Worth (2009) applied assemblage to explore narratives told by young people living with visual impairments about their

transitions into adulthood. The analysis of audio diary data was carried out by Worth by treating the interpretations as a means of 'method assemblage', which in doing so eschewed established qualitative and 'conventional methods that produce results that are deceptively ordered and complete' (Worth, 2009). I framed the analytical process along similar lines having found the concept of a narrative 'bricolage' as an example of 'method assemblage' an interesting and interdisciplinary way to conduct artful qualitative research (see for example, Denzin and Lincoln, 1994; Knowles and Cole, 2008; Tracy, 2013; Douglas and Carless, 2016).

### *Researcher bricoleur*

The researcher-as-bricoleur idea is a contemporary application of the bricolage concept, which originally was derived as a French word that means 'to arrange, to potter' (Leach, 2011:351) In my interpretation, assemblage and bricolage are complementary concepts, although it is helpful to focus on bricolage as conceived as a layered analyses, and 'sort of toolbox' (Keats, 2013:5) (Denzin and Lincoln, 1994; Lincoln and Denzin, 2000; Steinberg, 2006). Furthermore, as Kincheloe (2001) argued:

The bricoleur becomes an expert on the relationship connecting cultural context, meaning making, power, and oppression within disciplinary boundaries. Their rigorous understanding of these dynamics possibly



makes them more aware of the influence of such factors  
on the everyday practices (Kincheloe, 2001:84)

Given this context as troubling the 'disciplinary boundaries' and providing new knowledge that explores multi-layered analyses, the notion of my role as researcher as bricoleur was well-suited within the current research. Whilst Hammersley (1999) has argued that bricolage is too eclectic and involves ideas and theory that 'do not fit together' (Hammersley, 1999:578), I would disagree. Using artful and innovative approaches progresses research practices, and offers a valuable means of approaching a multi-levelled narrative analysis. The following 'layers' of the narrative bricolage are represented in this thesis in a linear way, although the reader is reminded this for the pragmatic purposes. The interpretations were iterative and interactive.

## **'Layers' of the narrative analysis**

Holstein and Gubrium (2012:7) suggest a place to start with a narrative analysis is by studying the 'hows' and 'whats' of stories. The 'hows' of stories are the ways they are told by narrators, with exploration of the structure, plot, and emplotments, sequencing of events, and characters in the stories. Questions of how the story is told in a way that persuades the audience to listen, such as by including evaluative points (Labov, 1972) can be studied as part of a structuralist analysis, for example (Riessman, 1990; 2008).

The 'whats' of stories constitutes analysis of 'the storied content of personal narratives' (Holstein and Gubrium, 2012: 7) such as the story-themes (McAdams, 1993). Lieblich et al. (1998) and Riessman (2008) amongst others have argued that exploring and analysing the structure (hows) and content (whats) is a largely academic exercise, since attention is inevitably given to both features of narratives. Nonetheless, it is apparent that as an interpretative process there may be more (or less) focus on certain qualities of narratives, such as how they are structured (Mattingley and Garro, 2000). This is dictated by the aims of the research, and the researchers' positioning in the research process (see for example, Riessman, 2008).

The reader is reminded that the narratives in the women's diaries were conceptualised as longer stretches of talk or text, analysed in their sequence, and treated as 'conversational narratives' (Ochs and Capps, 2001). This meant the analysis was not of the more coherent 'big' life stories' or the 'small' stories that take place outside of the research setting (see for example, Bamberg, 1997; Georgakopoulou, 2006; Bamberg, 2011). For this reason performing an interpretation of how the diaries were structured facilitated my familiarisation with, and ability to make sense of the diaries as diverse data (see for example, Willig, 2001; 2013).

## Exploring stories' structures

A structuralist analysis can be used as a way to focus on the organisation of the narrative as a 'whole'. Within Liebich et al.'s (1998:13) model this type of analysis can span from a broader analysis of the 'plots or structures of complete life stories' to a narrower focus on the 'discrete linguistic characteristics' and discourses deployed. I found it helpful to differentiate between the fabula (parts) and szjuhet (whole) of narratives, in accordance with the structuralist and narratologists' approaches to analysis (Labov, 1972; Onega and Garcia, 1997). I discussed in Chapter 2 that 'story' and 'narrative' were treated as conceptually the same, although during this structural analysis treating the fabula/story and szjuhet/narrative served a useful purpose. As Riessman (2008) argued, this stage was valuable during the early stages of the analysis in particular.

### *Labovian analysis*

Analysing the structure of the diaries and the diary entries was subjected to a Labovian analysis (Labov and Waletzky, 1967; Labov, 1972), within which Labov argued there are six fundamental narrative 'elements' that make up a fully-formed narrative. Table 4 provides an account of these six narrative elements.

Table 4. Details of Labovian (1972) approach to narrative analysis

Narrative element

Abstract	Summary of event or action being described in the story. The abstract provides the 'point' (Riessman, 1989: 1745) of a story
Orientation	Information about the scene of events and the setting, time, place, situation and characters
Complicating Action	This moves stories forward and tells the audience 'what actually happened? and 'what happened next?' (Elliott, 2005). Also known as the 'complication' (Aristotle), 'problematic event' (Bruner, 1986) and 'turning point' (Lieblich et al., 1998)
Evaluation	The narrator 'steps back from the action to comment on the meaning and communicate emotions and reflections during the evaluation'. (Riessman, 2008:84)
Resolution	When the plot is resolve this tells the audience how the story ended
Coda	By including a coda the narrator ends the story and returns their perspective to the present time

The structuralist analysis helpfully looked to how the narratives the women told were organised and constructed, depicting how stories were goal-directed in seeking to tell stories in particular ways (Riessman, 2008; Holstein and Gubrium, 2012). I could see from looking at the diaries that the women had completed the elements of the basic story, in Labovian analysis terms. There were stories within which there were actions and experiences, scene-setting and characters, as well as points at which stories unfolded to change the pace and nature (complicating action/turning points) so to invite audiences to witness ‘what happened next?’ In addition, evaluative points were made, which was particularly apparent as afforded by the diary method as promoting more self-reflective storytelling (see for example, Alaszewski, 2006; Bartlett and Milligan, 2015).

Labovian analysis was in this way useful to get a sense of how the story was told, and with what effect they had on me (as the known audience). However, there was such a varied and voluminous amount of data that the focus on structure alone distracted me from the content and meaning-making performed by the women as the first-person story narrators. Consistent with the critiques I discussed in Chapter 2 (Mattingley, 2000; Wikan, 2000; Riessman, 2015), the diaries also were not generally linear accounts. Diaries as involving stories told in real-time were often unended and did necessarily have narrative elements of a Labovian analysis, such as an ‘abstract’ or ‘resolution’. This limited the usefulness of a structural analysis, though provided a valuable layer of the narrative bricolage (Riessman, 1990; 2008).

## Exploring story-themes

Alongside studying the structure of the stories, I found it helpful to generate 'story-themes' (McAdams, 1993). This thematic type of analysis is a popular approach in qualitative research, and has been used within research with women living with chronic illnesses. For example, Kralik et al. (2001) conducted a thematic analysis as part of feminist research exploring the experiences of women in 'mid-life' when exploring accounts of sex and sexualities. The women explored how their 'appearance, desires...sexual expression' formed part of how they made sense of their sexualities, but with illness 'intruding' (Kralik et al., 2001:185) upon emotions and sexual practices. Kralik et al. did not locate the study as a narrative analysis, although the style of representing the results, and inclusion of long quotes showed the markings of a thematic-style of narrative analysis, or 'thematic narrative analysis' (Riessman, 2008).

Riessman (2008:74) suggested a thematic narrative analysis retains the temporal sequencing of each segment of stories and keeps stories 'intact' (ibid), retaining the sequence of the narrator's words and events in narratives. A content-focussed analysis is a valuable 'layer' of the narrative bricolage, although this alone neglected the social context and joint construction of meanings (Mishler, 1986). Thematic analysis therefore did do enough to allow me to interpret other aspects of the 'bigger picture' (ibid) to stories, such as how the construction of the stories was within the researcher-researched relationship, and

social setting of the research. In line with Ochs and Capps (2001) discussion of the conversational narratives, I was also interested in the tellership and tellability of the stories told.

### **Frank's typology of illness narratives**

One means of adding to layered analysis was to apply Frank's (1995) typology of illness stories. This looked at the structure, contents and 'performance' (Mattingley and Garro, 2000) by the storytellers when constructing illness stories. Frank's typology complemented the artful approach I took, with Frank arguing that narratives are forever changing. In this way a metaphor may be applied to narrators as 'patterns in a kaleidoscope: for a moment the different colours are given one specific form, then the tube shifts and another form emerges' (Frank, 1995:76). Many researchers have approached analysis of stories of illness by using Frank's (1995) typology (see for example, Nettleton et al., 2001; Thomas-MacLean, 2004; Whitehead, 2006; Smith and Sparkes, 2012). This has been possible by exploring the extent to which people living with illness, or who experienced a health-related experience, tell stories that are 'restitution', 'quest', or 'chaos' stories. These stories were envisioned by Frank to be a way to consider how people living with illness make sense of the problems of embodiment (control, desire, body-and other-relatedness) that was discussed in Chapter 2 (see pages 57-59).

## Three 'types' of illness stories

### *Restitution stories*

Restitution stories are retrospective though are future-focussed accounts of personal stories of the illness journey over time, from 'before' to 'now'. This type of story is about striving to 'return' to a state of health and wellbeing that is idealised and polarised to being ill or diseased. In this way the restitution story is a medicalised narrative that positions ability and disability as binary concepts and ways of being in the world. To return to 'normal' and able-bodied being is positioned as involving the previously 'ill' protagonist getting better and recovering having fought the fight against illness as the enemy (see for example, Smith and Sparkes, 2007). Structurally, restitution stories are the most aligned with the 'good story' (Labov, 1972) structure, with more coherent beginnings, middles and ends than with other 'types' of illness stories (see for example, Thomas-MacLean, 2004). Narrators telling restitution stories proclaim optimistically and loudly as part of the highly tellable story of recovery that 'I have' or 'I will get better soon' (see for example, Nosek et al., 2012).

### *Quest stories*

The quest story is defined as emplotments of protagonists within stories who discover, learn and find meaning in their experiences, as part of existential accounts of 'suffering' providing opportunities for personal growth (Frank, 1995; Crouser, 1997; Thomas-MacLean, 2004). For example, a quest narrative can shine a positive light on the



uncertainties of illness, providing space for making sense of and accepting the changes illness brings (Smith and Sparkes, 2005). Quest stories are about making the most of illness as a 'challenge' (Frank, 1995:117-119, parenthesis added), or even an 'initiation' (ibid.) in life. An example of a Western cultural script of illness as a quest is the current contemporary rhetoric of positivity (Ehrenreich, 2009; 2010). This complements the restitution story, with the person living with an illness such as Cancer, constructing story emplotments about bravely facing illness head-on, and being 'positive' at all times! Such a narrative is arguably problematic when considering the third type of illness story about suffering also holds meaning for many chronically ill people.

### *Chaos stories*

The third and final type of story is as an 'anti-narrative' that is different to the more optimistically toned restitution and quest stories. Chaos stories bring to the fore experiences of feeling overwhelmed by illness. With little hope of restitution from illness, the chaos narrative is about being 'swept along, without control, by life's fundamental *contingency*' (Frank, 1995:102, italics in original citation). These stories are about suffering and the continued 'struggle' (Frank, 1995:104) to keep going, whilst also having lost hope of getting better. In this way, chaos stories are told when 'consciousness has given up the struggle for sovereignty over its own experience' (Frank, 1995:102), and they may be fragmented and less coherent (Thomas-MacLean, 2004). Due to the lack of control over illness, the emplotments position the ill persons as lacking a 'route

map' (Nettleton et al., 2006:1173) from which to see any foreseeable story end, positive or otherwise.

The chaos story is an example of a story that tellers do not like to tell, and audiences do not like to hear (Frank, 1995). In the IBS literature, for example, women living with IBS perceive the illness to be misunderstood by other people, and stigmatised (see for example, Dancey et al., 2002; Casiday et al., 2008a; Håkanson, 2010). Questions I sought to explore as part of the application of Frank's typology during analysis included to what extent the women constructed the more tellable restitution stories, or the stories with a low tellability (Norrick, 2005), which were 'untellable' outside of the research context? Furthermore, were there any emplotments of quest type stories in the diaries?

## **Note-taking interpretative process**

### *Devising reflexive ways to dwelling 'in' the data*

Some narratives researchers suggest that exploring the form and content of narratives can facilitate researchers immersing themselves 'in' the data (Carless and Douglas, 2013). Frank's typology and Labovian analysis helped with this, although in addition I wrote down my reflections, thoughts, and ideas whilst reading and making sense of the diaries. I filled an entire notebook within a few days when I started doing this, and also annotated printed copies of the anonymised data, stored securely in a locked file holder when not being used. My initial

response to the diaries seemingly gathered a momentum of its own, allowing me to 'become one' with the data, or 'indwell' as Smith and Sparkes (2012:56) described this. The process of indwelling is a 'reflective posture' qualitative researchers can adopt in seeking to become 'immersed' (ibid) with the data (see also Smith et al., 2009; Willig, 2013). As a woman living with IBS and chronic pain my 'embodied engagement' (Smith and Sparkes, 2012) was also integral to the process of indwelling, which I explored in creative and artful ways.

## Poetry as process

Crafting poems and using poetry as a performance-based method can facilitate carrying out an intuitive, embodied and interpretative narrative analysis (see for example, Mauthner and Doucet, 1998; Poindexter, 2002a; Furman, 2006; Smith and Sparkes, 2012). I conceived of the narratives as doing something, in accordance with the social constructionist view of discourses deployed as part of the social act of storytelling (see for example, Potter and Wetherell, 1987; Edwards and Potter, 1992). I am a regular consumer of poetry, and I had the idea of utilising poetry as a device to facilitate interpreting the data (Glesne, 1997; Poindexter, 2002a; Furman, 2006). Indeed, past researchers have drawn upon artful methods such as poetic inquiry (Owton, 2017) as a valuable tool by which it is possible to make sense of personal narratives of meaningful human experiences (Miles and Huberman, 1994; Glesne, 1997; Poindexter, 1998; 2002b; Furman, 2004; Prendergast et al., 2009; Owton, 2017). Poetry-as-method was

helpful in the context of the current in two complementary, but different ways.

## Poetic re-transcriptions

Some of the women's stories in their research diaries were particularly long, sometimes containing few or no paragraph breaks and pauses. This made them feel 'lengthy, unwieldy' (Riessman, 2008) stories that formed part of deeply rich and meaningful, though amorphous, diary data. One aspect of the poetic re-transcription was a way of breaking down the diary entries into a more manageable form.

### *Gee's method*

Gee (1991) proposed that an in-depth structural re-transcription can make sense of even the most impenetrable and disjointed narratives. He gave the example of an analysis of the narratives told by a woman living with schizophrenia. Riessman (2000) suggested that Gee's (1985, 1991) approach to a poetic (re)structuring of the data could help 'slow down' (Riessman, 2008:94) the pace of narrating. She used a music analogy to explain this describe this, which I found helpful in making sense of the construction of poetic stanzas:

...[it] slows down the woman's stream of talk to examine  
how each part fits into the whole, and what each topic

shift contributes to the overall effect (Riessman, 2008:94,  
parenthesis added)

Gee's method was designed for use with analysing oral narratives, but this is a view that is embedded within a structuralist conception of narratives as focused on narratives as written text (Bal, 1992). As a researcher-as-bricoleur this provided me with the space to consider how to apply Gee's ideas to the written narrative data, innovatively integrating different textual forms as part of my interpretations.

Poetic re-transcription entailed segmenting entries into 'stanzas', like within the traditional poetic form (Gee, 1991). Poetic stanzas can be taken as a 'group of lines about a single topic' (Gee, 1991:27). The analysis involved copy and pasting the content of the diaries (what was said), and noting any interruptions or changes in the way diary entries were constructed. Poindexter (1998, 2002b) added that poetic re-transcription entails exploring 'unambiguous phrases, strong statements, eloquent expressions, (and) wording that appealed' to her. She then crafted research poems. Gee devised a socio-linguistic approach to analysing narratives originally, and Poindexter applied Gee's ideas in attending to the stress (emphasis), and pitch of words used by participants. For example, in the following sentence the capitalised words are those that are stressed or emphasised: the CAT SAT on the MAT; whilst changes in pitch constitute the 'falls, rises, rises-and-falls, or falls-and-rises in relation to the normal (base) pitch

level of the sentence' (Gee, 1991:22). The musical analogy Riessman (2008) used conveyed the way the poetic re-transcriptions explored the ebb and flow of storytelling as a verbal communication practice.

### **Process of constructing research poems**

The diary data was in written form, although this did not mean the stories could only be understood in this way. When reading the diaries it was as if I could hear each of the women 'in my head' reading their stories. In this way I was interacting with the narratives as addressed to an audience by the women who were in dialogue with me (their known audience) and readers of the research (their imagined audience). To craft the poems I began by reading aloud the diaries, and recording myself reading these on a voice recorder. This was stored securely afterwards as part of the 'raw' data. I noted when listening to myself reading the diaries aloud that I stressed certain words, and there were changes in the pitch of storytelling too. This act of reading and recording myself made the diaries more tangible, allow me to engage with the data in an embodied way, using my voice and hearing. The imaginative and creative process of crafting the research poems from the recordings utilised my ways of knowing the world, allowing poetry to act as a vehicle to represent my interpretations (Sarbin, 2004).

#### *Exploring 'voice' and tellership*

Listening back to the reading aloud of the poems was fascinating, and I felt energised by the process of developing an artful means of engaging

in an embodied and artful way with the women's stories. I had heard myself reading aloud the women's stories, but questions remained about the tellership and 'telling' of the stories. For instance, I wanted to explore what was meaningful to the women in their stories, and this involved analysing the voice with which the stories were told. Was there more than one voice telling the stories as part of the construction of 'dialogical' narratives? If so, did this in some way connect the women's personal stories to the 'culturally scripted voices', as discussed in Chapter 2 within the context of women's self-silencing who are living with depression? Ochs and Capps (2001) following Bakhtin (1981) had argued towards every story being told through the voices and utterances of others. In this way the act of storytelling was embedded within the context of the research relationship (Gilligan, 1982). I crafted another type of research poem to facilitate interpreting and 'hearing' the voices the women adopted to tell the stories in their diaries (see for example, Brown and Gilligan, 1992; Edwards and Weller, 2012).

### **Constructing I-Poems**

Listening to first person stories to hear which voices are telling the stories forms the basis for the Voice-Centred Relational Method (Mauthner and Doucet, 1998), and Brown and Gilligan's (1992) Listening Guide Method. The multi-layered methods involve researchers conducting multiple readings of the data. Whilst I could have utilised this approach, I have already discussed how the process

of analysis was iterative and creative. Therefore, the approaches outlined by Mauthner and Doucet (1998) and Brown and Gilligan (1992) were valuable, but in combination with the other structuralist, thematic, and performative analyses carried out using different theoretical lenses and methods as part of the narrative bricolage analysis.

The method of crafting I-Poems involved pulling out sentences that include a personal or collective pronoun sentences. Shifts between pronouns such as 'I' to 'you', 'we' or 'they' (Mauthner and Doucet, 1998:132) were extracted from the stories in order to analyse their meaning from the perspective of the 'voice' telling the story. Jack and Dill's (1992) work with women living with depression utilised Brown and Gilligan's (1982) Listening Guide, which is how the arguments were developed that the women participants engaged in the negative and moralistic self-evaluations ('I'm not good enough', for example). Whilst time-consuming, the process of crafting I-Poems allowed me to step back from the data, and consider from what perspective, or in which 'voice', the women were telling their personal stories.

The process itself entailed extracting the first person, or collective pronoun sentences from the diaries into a separate electronic document in the computer. As Hesse-Biber and Leavy (2008) have highlighted, these clauses often follow a pattern by including a subject and a verb. I used different font to highlight verbs that performed



different functions, as well as underlining any shifts in the voice doing the telling. For example, as was seen when the stories were told by switching voice from speaking in first person ('I') to a neutral omniscient 'you'. The task of constructing I-Poems was enjoyable and further embedded me within the research process, providing another way to illustrate my role as jointly constructing the meanings of the stories constructed (see for example, Mauthner and Doucet, 1998).

## Summary of analytical approach

### Leaving room for 'mess' in method

This chapter has offered a 'coherent' (Willig, 2013:171) account of the analytical approach, which is necessary when disseminating and conducting rigorous qualitative research (Elliott et al., 1999). The bricolage analysis has been shown to be multi-layered, and to have involved adopting different theoretical and practical tools to facilitate the narrative analysis. The poetry-as-method for example, brought me (the researcher) into the analysis, showing how stories are always embedded within a social context, and can be interpreted in multiple ways (Flick, 2000; Andrews et al., 2004). The only caveat I would add to this is that, aside from crafting research poems, I retained the structure of the stories, and words the women deployed, in their original form when representing the analysis over the next three chapters. Collectively, the array of analytical devices left space for the 'mess' (Riessman, 2015:1066) in stories as being about human lives, which are by nature disorder and unpredictable.



## Chapter 7: Stories of hoping and embodied suffering

The previous chapter provided an overview of the analytical framework that I have framed as a narrative bricolage. In this chapter I will explore on one 'layer' of the interpretation within which I loosely applied Frank's (1995) typology of illness narratives to help with analysing the women's stories. Not all of the excerpts from the diaries address emplotments of IBS and illness in the stories told. Yet, all the stories can be interpreted as sharing concerns with being emotive stories told most often about events, thoughts, feelings and experiences, that took place recently and unfold in real-time. Throughout the diaries, the women as narrators position themselves in their diaries as the protagonists who either seek to be hopeful or construct stories of embodied suffering. Hopeful stories were at times as part of emplotments within stories about illness-related experiences.

### **Storytelling as catharsis**

The emplotments of illness ranged from being about 'mundane' (Hyers et al., 2006) and ordinary everyday activities and routines to being part of dramatic emplotments of one-off meaningful events that took place in the women's lives. The psychologist Pennebaker (1989) argued decades ago that diaries have the potential to allow people space for expressing their emotions, with the act of keeping diaries and writing about personal experiences as cathartic. The interpretation supported

diary research that highlights the value of diaries as a useful research tool that aids personal reflections and meaning-making (Bartlett and Milligan, 2015; Meth, 2004; Thomas, 2007a; Meth, 2017). This method offered a portal for exploring difficult and sensitive experiences as reconstructed within the diaries (ibid.)

## Hope and restitution stories

To begin this chapter I give an example of storytelling that was retrospective in being an illness journey over time. This account from Maria's diary was one of the few instances of writing about IBS experiences in this way as most of the diary constructions took place in the present or recent past, as real-time storytelling. In this story Maria constructed an illness narrative within her day 6 entry, with Maria's emplotment of IBS as having been more severe and debilitating in the past. IBS was emplotted as better 'now' than 'before', as per the illness restitution story. Further in accordance with the restitution plot was the way Maria emplotted the doctor and Western medicine as having alleviated her illness. The diary entry did not begin with this story though. Instead the entry began as a present tense story about Maria's perceptions of her diary after reading this back during the diary-writing week. This was an instance of when Maria positioned herself as a reflexive subject happy to engage in 'participant reflexivity' (Riach, 2009).

*'Spent more time complaining about stupid stuff?'*

Maria (stanzas 2-3, day 6)

1 I just re-read what I wrote the last few days. With the exception of yesterday's actual good entry, I spent more time complaining about stupid stuff. What the heck do I have to complain about IBS wise? Am I really doing Dee any good by doing this diary?

2 I read all the comments on the online IBS forums. Some of these people have real medical issues which apparently don't seem to be helped by medicine. They have violent attacks and have to stay home from work and school. They end up in the emergency room. They have accidents when traveling and can't eat anything. I've never had it that bad.

By engaging in participant reflexivity Maria positioned herself to as occupying the identities as both a woman living with IBS and as a research participant. She was concerned with how her audience's perceptions of her, in my interpretation of the content and way Maria told this story, asking the question 'Am I really doing Dee any good with this diary?' (stanza 1, day 6). In this way Maria deployed judgmental and denigrating discourses that positioned her as evaluating her diary as not being any 'good'. There was only the 'one good entry', and she had been 'complaining about stupid stuff' (stanza 1, day 6), she

reflected. Dee opened up a dialogue with the diary's audience and implicitly asked me ('Dee'), the researcher and known audience, about how we felt she was doing as a research participant.

This was interesting as at the beginning of her diary on day 1 Maria had also engaged in the participant reflexivity, introducing herself as a person who 'decided' to take part in a research project. On day 6 she had tentatively followed up this point by querying what her audience thought of the stories she had told: were they just 'stupid stuff'? Whilst I would have liked to reach out to Maria and thank her for her generosity of a research participant and not to think badly of her writing, this would not have been my place as the researcher and not her therapist. The way Maria told this story nonetheless permitted room for her being able to maintain the hope that she was a 'good' participant after all, since her questions about her 'performance' were left unanswered.

### **Comparing oneself to others**

Maria made sense of the self-critical reflections in her own way through considering her experiences when compared to others who have IBS after 'reading all the comments in the online forums' (stanza 2, day 6). It is possible to see in the I-Poem I constructed and this is included below, an interpretation of the meaningful shifts in the 'I' and 'they' first-person and plural pronounced clauses, and the verb clauses too, in demonstrating how Maria wanted to position herself compared

to the people she read about in the virtual IBS forums. The account positioned Maria as engaging in Othering, but the effect of the 'us' and 'them' thinking served a different function.

*'I've never had it that bad'*

Maria I-Poem (stanza 2, day 6)

I read all the comments

these people have real medical issues

They have violent attacks

They end up in the emergency room

They have accidents

I've never had it that bad.

Drawing social comparisons (Festinger, 1954), Maria compared herself as not as worse-off as 'these people', which was part of her deployment of discourses of downward social comparisons (Major et al., 1991). She had 'never' (stanza 2, day 6) had it 'that bad' (ibid.), and the examples justified as to why she thought this. For example, 'They have violent attacks' (ibid.), which Maria is assumed to not have. Past research has provided evidence that downward comparisons can be

psychologically beneficial (Buunck et al., 1990; Suls et al., 2002), and bolster esteem as a psychological coping strategy (Suls et al., 1991; Tennen and Affleck, 1997). However, my interpretation was that Maria was making comparisons as part of her line of questioning as to whether she was a 'good' participant, or not. Maria wanted the audience to understand her uncertainties, which had the effect of diminishing the seriousness of her IBS. 'They' after all, had 'real medical issues' (stanza 2, day 6).

### **Being ill 'enough'**

Maria's story explored the topic of negotiating her illness legitimacy in staking her claims as a woman living with what was for her, real and deeply meaningful lived experiences of being a chronically unwell person. Maria was not the only one to have done this in her diary, though I have included her story as a particularly clear example of the process of deliberating how 'good' she was. In this way her narratives morally negotiated her if she could stake her claims as having been successful as an ill person (Frank, 1997:134). This was a self-reflexive and conversational account when Maria considered her identity as a person living with a 'medically unexplained illness' (see for example, Looper and Kirmayer, 2004). As discussed in Chapters 1-2, Maria showed how she too was concerned with showing she could demonstrate she was 'ill enough' to claim her illness status. This extended the view that there are concerns about the illness hierarchy between 'real' identifiable disease and illnesses such as IBS that are



medically unexplained and 'fake' (Nettleton et al., 2004:47; Swoboda, 2008). For Maria, the concern was also in showing how her subjective embodied experiences of illness compared against others she shared an illness identity with. I understand this as a complex way in which the stigma surrounding contested illnesses played out in the scene of Maria's everyday life, showing the way Western medical discourses inform personal meaning-making with illness embodiment (Jones et al., 1984; Asbring and Narvagen, 2002; Glenton, 2003; Taft et al., 2011). For Maria reconciling this on day 6 in her diary entailed distancing herself from the more ill others living with IBS.

### Hoping for wellness

The tone of Maria's storytelling changed here as her statement 'True, years ago...it did stop me'. As this signalled a change in the telling of the story I separated this into the next stanza of the diary entry. This was the beginnings of a construction of an illness narrative.

*'True, years ago ... it did stop me'*

3 True, years ago in my teens it did stop me from doing things. My IBS meant I couldn't eat before going to a movie. I couldn't eat out at a restaurant more than a 15 minute drive from the house and on vacations I used the excuse the kids were tired to eat in the hotel room. I hated traveling by car because it meant not eating all

day and even then I wasn't guaranteed I wouldn't get sick. I tried everything for years, keeping a food diary, eating, not eating, staying away from certain foods, eating more ruffage. Nothing worked. I lived on Imodium and would take it 1st thing in the morning to prevent me from having to go to the bathroom if there was stuff I needed to do and get through the day. Finally I ended up seeing the gastroenterologist and after doing a colonoscopy and endoscope he prescribed Lotronex. What a difference! After finally figuring out the right dosage my life improved 99%! I wish some of these other people could experience the life I have now.

Maria moved from a space where the audience could co-tell (Ochs and Capps, 2001) the story, to end the line of rhetorical questioning and social comparisons. She emplotted herself into the story as remembering times gone by when she experienced pain, discomfort and everyday inconveniences connected to being unwell. This was a story about suffering, but the way she constructed the account shut-down the dialogue with the audience in order to tell a retrospective and well-structured monologue. This adhered to the conventional Western story structure plot with a beginning, middle and end (Labov, 1972; Riessman, 2008; 2015), and I interpreted this as a restitution

story with the story plot that for ‘every suffering there is a remedy’ (Whitehead, 2009:2238).

*‘What a difference!’*

Maria moved from a place of illness to wellness as binary states of being, within which found the medications led her to feeling ‘What a difference!’ (stanza 3, day 6). Maria detailed just how she had struggled, communicating clearly to the audience the care and control required as part of her attempts to feel better, and not experience debilitating symptoms (‘I tried everything for years, keeping a food diary, eating, not eating, staying away from certain foods’, *ibid.*) Consistent with Schneider et al. (2009) amongst others, eating routines were central to Maria’s ways of coping with illness by avoiding and controlling dietary regimes and routines, as well as taking medications to affect digestive processes and bowel habits (‘Imodium’, *ibid.*) (Schneider et al., 2008; Casiday et al., 2009; Håkanson, 2010; Mazzawi et al., 2013). For Maria, as for some of the other women living with IBS in the current research, taking a pragmatic approach to treating illness as a problem (Swoboda, 2008) ensured it was possible to do the ‘stuff I needed to do and get through the day’ (Maria, stanza 3, day 6).

However, despite her proactive approach Maria emplotted her doctor as saving the day: she ‘Finally’ found relief after the tests, and the new medication prescribed to her was the salvation she eagerly anticipated (‘I ended up seeing the gastroenterologist and after doing a

colonoscopy and endoscope he prescribed Lotronex. What a difference! After finally figuring out the right dosage my life improved 99%!'. This subsequently ended her narrative about how she compared herself to others, since she 'wished these people could experience the life I have now!' In other words, for other people living with IBS 'they' too could hope to get better just as Maria claimed in her restitution story!

Smith and Sparkes (2005) carried out research with men living with severe spinal cord injuries and suggested that restitution stories are tales of 'concrete hope'. Narrators construct accounts that are, or are intended to, help maintain hope in a clear and 'concrete' way. The hope is for recovery and being relieved of illness and disability. Yet as Frank (1995) argued there are limits to such a story in the case of chronic illness, even if this makes for a highly tellable story that is warmly received by audiences also wanting evidence that 'I too can recover from illness or disability', should such a narrative be called upon. This is an example of the only story that was told in her diary that could provide her with a happy ending to the stories about her life. The story was about hopes to get better, that for Maria were somewhat realised with her life 'improved' (stanza 3, day 6) markedly after the medical intervention. Yet, the other emplotments of IBS and the broader term of experiencing 'sickness' and being 'tried' told a contrasting story of Maria's IBS experiences 'now', as I will discuss later in this chapter.

## Quest stories of reflexive subjects

To move on to another example of hopeful and optimistic storytelling. This time the stories explored embodied experiences of illness as opportunities for ascertaining ‘transcendental hope’ (Smith and Sparkes, 2008). By facing illness and injury ‘head on’ (Frank, 1995:115) the protagonist is able to open up opportunities to grow and learn about oneself as part of philosophical and existentially meaningful story constructions. Diaries are personal documents that lend themselves well to this type of storytelling given the lack of a physically present co-teller and space for narrating without interruptions (see for example, Alaszewski, 2006a; Bartlett and Milligan, 2015). Nonetheless, as Ochs and Capps (2001) and I have argued, reflective storytelling still leaves space for co-telling and inviting the audience to respond to the stories that are told.

An excerpt from Diana’s diary is offered as example of the quest story plot (Frank 1995), as she emplotted herself as the ill protagonist who navigated the ups and downs of living with chronic bowel illness (see for example, Charmaz, 1991). In Diana’s diary, she adopted a cheery and light-hearted style of storytelling, which was included within the visual and written stories. In spite of being cheerful, Diana nonetheless told her stories in ways that showed there were important life lessons to be learned, and these provided the evaluative points (Labov, 1972), or ‘moral of the story’ (Mattingley, 2000:185).

## Learning and existential meaning-making

*'Being ill for a long time really is a test'*

Diana (stanzas 3-4, day 2)

3 Did odd jobs around the house then became quite productive with uni work. Noone is in the house this weekend – just me (and the cat) being alone in the house.

4 It reminds me of when I was at my worst illness wise and I became stuck in between the four walls of my room – staring at facebook waiting for people to contact me and ask me how I am or if I'd like to go out. Its suprising how people easily forget about you if you're not physically there. Being ill for a long time really is a test of who's a good friend. Out of sight, out of mind is far too familiar.

Personal narratives can be initiated randomly (Ochs and Capps, 2001), and Diana's day 2 entry conveyed this as she was 'reminded' of difficult past experiences 'when at my worst illness wise' (stanza 3, day 2). The repetition of the point about alone in the house ('Noone is in the house this weekend – just me (and the cat) being alone in the house' (stanza 3, day 2) also highlighted how meaningful this was to her. In this entry Diana was writing 'today' and 'this weekend' (stanza 3, day 2). Like with

Maria's story, she then moved into reflecting on the past, within which IBS was emplotted implicitly as a theme of the story about being a young woman living with a restricting bowel illness. She communicated the message to the audience that one of the difficulties of being ill 'for a long time' (stanza 4, day 2) was how friendships were at risk. She could not be 'physically there' (ibid.) and so felt like she was forgotten ('Out of sight, out of mind', ibid.) Switching from personal pronoun to 'you', Diana commented that 'people easily forget about you if you're not physically there' (ibid.). The content and structure of this emotive account of illness was about the pain of feeling alone, 'stuck in between the four walls of the room...staring at Facebook waiting for people to contact me' (ibid.)

*'Out of sight, out of mind'*

Öhman et al. (2003) found the theme of 'being alone in illness' after exploring experiences of people living with chronic illness. Diana also alluded to this in her story. She constructed the story about the embodied experience of loneliness and in doing so conveyed how the feelings of social isolation were an unwanted consequence of living with illness that is chronic, unpredictable, painful and restricting (Dancey and Backhouse, 1993; Bertram et al., 2001; Dancey et al., 2002; Hall et al., 2005; Micallef-Konewko, 2013). This was in spite of the advances in new technologies and her access to social media ('Facebook', stanza 4, day 2) as a way of connecting with others. Diana's emplotment was that she still did not feel connected in spite of this. She 'waited' (ibid.) for others to contact her. I will explore in the

following chapter how this is further informed by the sense of embarrassment and shame that further contributes to illness as emplotted as intrusive within the context of everyday activities (see for example, Dancey et al., 2002). To add to this though, Diana emplotted illness as 'living with sacrifices' (Rønnevig et al, 2009:1680) such as not being able to meet with friends and 'go out' (stanza 4, day 2), which was something not alleviated by the internet and social media.

### **Relationships online as a double-edged sword**

Contemporary digital culture has seen consumption of social media to be 'pervasive and growing rapidly worldwide' (Fardouly et al., 2015:28). Research in the US and Europe has found that young people and those in early adulthood are more likely to consume social media than older people, following national surveys carried out in different countries (see for example, Pew Research Centre, 2015). Yet, research shows an increasing number of adults are joining their younger counterparts, as was found by Sensis (2017) in a national survey that found 8 in 10 Australians (79%) are using social media. Maria, for example, wrote about her consumption of social media when taking part in an online health community ('IBS support group', see earlier in this chapter) that people living with IBS can gain social support and share health information (Cotton and Gupta, 2004; Kim et al., 2013). Yet, Diana and Maria showed the possible limits of social media, consistent with contemporary research exploring possible negative effects of social



media as a double-edged sword in the women's lives (for example, Fardouly et al., 2015; Fardouly and Vartanian, 2016).

*'They are always there'*

Diana's day 2 entry was a brief but meaningful personal story set within the social context of friendships maintained online. For Diana, it was her relationships with her parents 'offline' that she emplotted as being more fulfilling. Her parents were 'always there' (stanza 2, day 5), but her peers 'aren't' (ibid.) I interpreted the story-theme of relationships as they were emplotted into the aforementioned day 5 excerpt from Diana's diary, and the following day 2 entry as contributing to the unfolding construction of a quest story. Diana learned from her illness-related experiences who she could rely upon, and who she could not.

Diana (stanza 2, day 5)

Anyway had a tea then went to the cinema with me dad  
which was nice. Being ill had made me incredibly close  
to my parents because they are always there when  
people my own age aren't and don't understand.

In this story, Diana constructed a real-time account within which she enjoyed having spent time having 'a tea...[and] the cinema with me dad which was nice' (stanza 2, day 5, parenthesis added). This then led

Diana into a self-reflective story about her parents and how they much they meant to her. The previous story from Diana's day 2 entry about her peers letting her down was turned around as part of this more optimistic telling of a story about looking on the 'bright side' of her situation, seeing that 'people my own age' (ibid.) might not be 'there', but her parents are. I interpreted this to be a way in which Diana invited the audience to see how she could tell a story of illness that was positive and hopeful, finding existential meaning from her difficult and isolating experiences of illness embodiment. This shared the markings of the quest story as an emplotment of an 'ill person's belief that something is to be gained from the experience' (Frank, 1995:115). It was a nuanced example about Diana's unique experiences of what life was like for her, as a young woman living in modern Western society and with a chronic bowel illness.

At a personal level it could be interpreted that on a personal level avoided telling stories that positioned her as 'whining and complaining', consistent with women living with chronic illnesses involved in Werner et al's (2004:1041). Whilst putting on a brave face and being an agentic protagonist was admirable and showed resilience, this also could be argued to have been a personal story that aligned itself with a privileging of cheerful optimism within Western societies (Ehrenreich, 2009; 2010). Balancing the more hopeful stories were accounts of embodied suffering that was not resolved with a positive message that could be taken from constructions of quest or restitution stories.

## Chaos stories of suffering

Chaos stories are solely about the struggle of illness and everyday experiences. Protagonists are positioned as enveloped in the 'chaos' of illness. A good example of this are stories about pain, as pain forces consciousness to the present and immediate experience of discomfort and unpleasant bodily sensations (Bendelow, 1993; 2009). Pain is emplotted in chaos stories as suffering that goes on and on, featuring in emplotments that are pessimistic and see the protagonist lost, encased with negative thoughts, feelings emotions and hopelessness (Thomas-MacLean, 2004; Smith and Sparkes, 2007; Nosek et al., 2012). The chaos story evokes feelings of despair as raw unembellished 'anti-narratives' that Frank (1995) argued to lack beginnings, middles and ends. I would add to this that such stories have low tellability in being difficult for narrators to tell, and for audiences to hear, exploring taboo topics and experiences of suffering and pain (Ochs and Capps, 2001; Norrick, 2005; Smith and Sparkes, 2007).

### Getting through the day

*'Same old same old'*

Maria (stanzas 1-2, day 3)

1 Exhausted all day. Fell asleep at 10 pm last night, just to wake up at 2 am sick. Same old same old. In the bathroom for 45 minutes every hour until I was finally able to fall asleep on the couch at 5 am. Of course the

alarm is set for 5:45 am. What a great day this was. Stomach in knots all day. Medicine didnt work so I ended up taking an Imodium at 11 am just so I could get something done at work.

2 I swear, if Annabella (Loan officer) doesn't cut her crap out and stop whining about anything and everything I'm going to go insane. Its like dealing with a spoiled child. She's a mature adult. No you can't have everything you want. She's the only negative thing in the entire department. When Aunty Agony gets going she tries to bring everyone else down too. I spend so much energy trying to counter that I have no energy left for me, and being sick only makes it worse. She's going to push me to the point where I'm going to go off on her. Of course I'll be wrong because it'll be unprofessional but at what point is enough enough? I cant believe she actually thinks she's entitled to more than anyone else. I'm the damn Supervisor and I dont get as much time off as she does. If I actually got paid by the hours I'd make a fortune!

This diary entry is from day 3 in Maria's diary, which I reconstructed as four stanzas, beginning with stanzas 3 1 and 2 detailed above. It is possible to see a very different type of story being told here when compared to the analysis of the day 6 diary entry (see earlier in this

chapter). This was a story that was about a typical day in Maria's life, from which IBS is weaved into the stories told, but not as the main story-theme. She deployed ordinary and everyday discourses and did not dramatize events. This gave the impression of her feeling despondent at being so tired and understandably drained ('Exhausted all day', stanza 1, day 3) after she awoke early and was feeling ill ('wake up sick at 2am', stanza 1, day 3). This was an example of the way illness was euphemistically emplotted as 'sickness', highlighting how storytelling was 'experience-near' (Garro and Mattingley, 2000:160) or 'close to the ground' (ibid.), without necessarily deploying medical discourses that focus on a language of bodily symptoms. What was important to Maria was how the sensations of exhaustion, or sickness, were part of personally meaningful experiences emplotments of illness within the context of her everyday life. In this case, with IBS and illness contributing to the drudgery of her day as having began with tiredness. For this reason, I did not find it surprising that Maria did not exclusively tell an illness story as IBS was but one part of life for her (Garro, 1992).

*'I swear...I'm going to go off on her'*

Maria swiftly changed the pace and style of storytelling soon after writing about her night, shifting into an angry voice to tell the story about work. The sudden change of topic saw a stream-of-consciousness style of narrating, exploring an exchange at work. Frank (1995:115) referred to the chaos story as being about protagonists as they feel 'sucked into the undertow of illness'. I would add to this that

Maria's story suggests it is possible to extend the definition, with Maria telling an 'experience-near' and fragmented account of her attempts to make sense of Annabella's behaviour, that made her angry and frustrated ('I swear, if Annabella ... doesn't cut her crap out' stanza 3, day 6). Further informing the telling of the chaos story was the intensity with which she constructed the account as if her feelings literally 'leaked' out of the page, as per Ochs and Capps' (2001) concept of an 'emotional outburst'. This is not an 'outburst' about losing control, but as part of the feelings brought up by the act of storytelling. Storytellers are 'catapulted into intense emotions associated with the experience' (Ochs and Capps, 2001:92). Maria angrily stated her incredulity at Annabella: 'I swear...I'm going to go insane...No you can't...She's going to push me ... I'm going to go off on her' (stanza 3, day 2).

Despite the threats, Maria did not lose control, or at least she did not write that she did this in the story she told on day 6. Her emplotments were self-reflective, and positioned her as a narrator using the space to tell first-person stories about a difficult working day. I interpreted the stories as having been unsaid at the time, and this added to the emotive, unrehearsed and less articulate nature of the 'chaotic' storytelling. For example, she may have perceived herself as feeling 'pushed' to the point of 'going off' on Annabella, though she did not for moralistic reasons as something that would be 'wrong' and 'unprofessional' even she had had 'enough' (stanza 2, day 6). Yet her

emplotments on day 6 went on to show Maria as reflecting on why she experienced such as dissatisfaction and discontent at work.

Narrative reconstruction can create space for resisting and resituating oneself in the social milieu through providing opportunities to resist dominant subject positions by articulating the contradictory meanings in their experience' (Langellier, 1989:1-2). It is possible that by telling the stories about embodied experiences of suffering, Maria found diary-writing cathartic. She used the diary space to reconstruct a version of events where she emplotted herself as less passive, and silently threatening to assert herself since 'enough is enough' (stanza 2, day 3). Furthermore, the diary provided space to continue into a more reflective story, which was another turning point in the diary entry.

### **Fatigue and femininities**

Maria moved to asking rhetorical questions, slowing down the pace of narrating from the angry account of how work had gone that day. This brings in the story-theme of fatigue, as defined as a sensation that is more than tiredness and cannot be 'relieved by rest or sleep' (Lackner et al., 2013:2). Fatigue is not related to activity and does not 'correspond to one's level of exertion' (ibid.) In addition to being about fatigue as connected with IBS embodiment (Gralnuk et al., 2000; Labus et al., 2007; Lackner et al., 2013), I interpreted Maria's story to connect to Western cultural scripts of femininities. Maria was not the only person to explore feelings of fatigue and exhaustion, although the

following story was selected as this is another example of a chaos story that has now become a coherent and articulate account of embodied suffering.

*'I spend so much energy'*

Maria (stanzas 1-2, day 3)

3 How come I spend so much time and energy making everyone else happy? I spend hours doing the monthly schedule and make sure everyone else has enough Saturdays off, they get their 1/2 days and how do I do that? I end up working 4 Saturdays in a row, I never take my 1/2 days and I work open to close on Fridays when I make sure no one else has to do that. Maybe if I wasn't so nice I wouldn't feel so taken advantage of.

4 Great, Imodium just wore off. It's going to be another long night apparently.

The question Maria posed about why she uses 'so much time and energy' (stanza 3, day 6) on others' happiness is a particularly emotive and sad positioning of Maria as a protagonist. Öhman et al. (2003:528) argued that people living with chronic illness explored how they accommodated uncertainties and liminality as part of illness embodiment in their research. This involved a state of being 'hovering



between suffering and enduring', which in Maria's wrote was part of her work-related stories. IBS further effected her feelings exhaustion and being drained of her 'energy', with euphemistic discourses deployed of fatigue as embodied and omnipresent (Shorter, 2008: 3000). Fatigue was an embodiment of illness that enveloped her emotions, feelings and actions throughout the various domains of her everyday life (Kleinman, 1988; Frank, 1995; Bowditch, 2006; Moss and Dyck, 2008; Swoboda, 2008). This was a story told from the perspective of a woman who feels exhausted by her actions of 'making everyone else happy' (stanza 3, day 6), at the cost of her own joy and contentment.

*'Maybe if I wasn't so nice'*

Maria asked herself, why she was putting her colleagues' needs before my own ('I spend hours doing the monthly schedule and make sure everyone else has enough Saturdays off ... how do I do that?' stanza 3, day 3). I interpreted this as Maria's exhaustion at her unpaid emotional labour (Hochschild, 1979; Bartky, 1990), which had left her feeling spent and exhausted. Jack (1991) argued this is a way in which women are left with emotional distress when living in Western societies that teach girls and women to put others' needs before their own, in accordance with Western societal gender norms (Gilligan, 1982; Brown and Gilligan, 1992; Jack and Ali, 2010). Western gender socialisation has been argued by Brown and Gilligan (1982) to encourage the moral development of girls as relational beings, who then go on to listen to

damaging 'culturally scripted voices' (Gilligan, 2010) that encourage women to silence their needs and voices.

Maria could be interpreted as having reflected on how she did this at work, with the work schedules and keeping quiet when disrupted by Annabella's behaviour, though I make this point with some hesitation. It would be ethically questionable to impose my analysis as a feminist researcher (see for example, Miller et al., 2012). Yet, in exploring an interpretation of the data I was persistently troubled with the message to Maria's story that was felt caught up in a pattern of self-silencing. She did however end the story in a way that challenged this positioning, querying to herself and the audience: 'Maybe if I wasn't so nice I wouldn't feel so taken advantage of' (stanza 3, day 3).

*'Why am I so weak?'*

I want to explore another story that I interpreted to be a chaos narrative about an experience of suffering, though this was a story about a one-off event that took place after Alice visited her friend. The diary entry on day 3 of Alice's diary retained the qualities of being visceral, emotive and about an experience that was difficult. Yet, Alice's style of storytelling throughout her diary was coherent and clear.

Alice (stanza 5, day 3)

Rosamund drops me off at the tram stop. It's 10:15pm and no one else is on the platform. It feels lonely. Two young men appear wearing tracksuits. I feel nervous. They stare at me and one comes + stands close, still starry staring.

I have my phone + What's App Rosamund. She quickly drives back and comes to the platform. By this time the two men have lost interest and moved further up the platform.

It was the first time in a while I have felt scared I was totally alone and vulnerable. They could have mugged me, anything.

I go to a different carriage I think and question myself. Why did I feel scared? Why am I weak?

This story was told in a way that was evocative and suspenseful, with Alice emplotting herself as feeling disturbed by the two men who loitered near her when she travelling late at night. This story stood out in her diary as Alice moved from writing a cheerful narrative of her evening with Rosamund to the event-based account of finding herself feeling 'alone' with no one else' around' (stanza 5, day 3). She had

messaged using the mobile phone messaging application WhatsApp to come to help her as she 'felt nervous' (ibid.), although by the time Rosamund arrived, she emplotted the two men as having 'lost interest' (ibid.) and left her alone. This was a story about struggling with her feelings of having been a passive and 'vulnerable' (ibid.) protagonist, who felt 'totally alone and vulnerable' (ibid.) on the eerie platform.

The risk discourse Alice deployed encouraged the audience to see Alice's fears justified. Alice left untold why she experienced these anxieties, though I interpreted this to be a story about Alice as a woman fearing male violence. She euphemistically deployed discourse that 'anything' could have happened, which I took as leaving unsaid her reference to rape or sexual violence. Considering the story in a wider cultural context provides a way to understand the story, though I would far from agree with Alice's reflections on her 'weakness' ('Why did I feel scared? Why am I weak?' stanza 5, day 3) for feeling intimidated. I would have liked to be able to reach out to Alice who so harshly judging herself, though as a researcher not a therapist this would not have been appropriate. Furthermore, and even if this was ethically appropriate behaviour, the nature of diary methods prevented me responding to Alice's distress in reconstructing the events in her diary.

## Women fearing male violence in day-to-day life

The United Nations (2008) argued that on a global scale, women are more likely to be victims of sexual and physical assault. This shows just how endemic male violence is within women's everyday lives, and I would argue that this is connected to the pervasive rape myths (see for example, Brownmiller, 1975).

Rape myths are attitudes and false beliefs about rape that are widely and persistently held, and that serve to deny and justify male sexual aggression against women. (Lonsway and Fitzgerald (1994:133)

Rape myths act by controlling women's everyday movements through public spaces and so provides a way to understand Alice's story as a gendered account, contextualised within a culture where women are encouraged to feel 'vulnerable' for being outside and alone at night in a public space. Whilst it cannot be denied that safety is an issue for women (and anyone) in public spaces, this contributes to the polarising of public and private spaces that is critiqued by feminists (see for example, Ribbens and Edwards, 1998). The USA National Crime Victimization Survey (Bureau of National Statistics, 2015), for example, has demonstrated that male perpetrators of violence against women are far more likely to be known to victims (see for example, Burrows, 2013). Women are more likely to be assaulted or raped by someone

they know rather than a (male) stranger who attacks them on the street (see for example, United Nations, 2008; Edwards, 2011).

Alice constructed this story in a way that denied her courage in resisting the rape myths and cultural scripts that see women as at risk of 'anything' happening, as shown by her actions going out at night. Yet Alice's story provided a useful instance of how Western women are conflicted by feelings of empowerment that arrive from feminist activist attempts to refocus attention on perpetrators. Redfern and Aune (2013:79) justifiably argue that women and girls' fear of male perpetrators of violence is a 'feminist issue'. Yet Alice's story suggested feminism has some way to go in continuing to challenge the pervasive narrative that exists in a culture where male violence and female victim-blaming is endemic. In this way Alice's story is an important example of the way everyday gendered experiences of 'suffering' are politicised stories that act as commentaries upon contemporary cultures. Western scripts of femaleness and femininities could be seen here to continue to circulate messages that women are 'weak' continue to circulate societies, and inform women's ways of making sense of their experiences.

## Summary

This chapter has focussed upon the story theme of illness narratives, with Frank's typology as a guiding framework, and exploring the

culturally preferred hopeful and optimistic stories, as well as stories about suffering. I have sought to provide an array of excerpts from the women's diaries that are unique, and in this way depict the diversity of the women who took part. The stories drew upon Frank's (1995) restitution, quest and chaos narratives framework, though I have demonstrated that such stories can be seen as reaching beyond the story-theme of illness and IBS. Illness embodiment was instead emplotted as part of the women's everyday lives as enmeshed and part of stories they had to tell.

In this chapter I have also began the conversation about diary methods as enabling the audience to witness the women's storytelling, which was at times contradictory and provided accounts that reflected the tensions and 'messiness' of everyday lives. In the following two chapters further examples will be explored as part of interpretations of other stories in the women's diaries that look to another 'layer' or level of the narrative analyses.





## Chapter 8: Stories and gendered perspectives on everyday illness embodiment

This chapter explores a different lens on the personal stories, considering how they connect to cultural scripts of femininities and gender. There will also be a deeper exploration of stories about embodied experiences of illness in this chapter and the next (Chapter 9). Some parts of this chapter were of illness, and others were not, which continues to depict how the women's meaning-making was informed by their unique and women's socially situated knowledge and experience of the world (Haraway, 1988). Further to this, and following on from some analyses in Chapter 7 of Maria's and Alice's chaos stories, some stories were told in gendered way, with the women making of their experiences by drawing upon cultural scripts of femaleness and female bodies as different to men. I will discuss shortly for example, how some of the women used the metaphor of pain-like-contractions, which arrives from the term 'uterine contractions' that occur during child-birth that some women involved in past research describe as intense and painful (see for example, Gibbins and Thomson, 2001). In this way, even though feminist theory 'aims to minimise biological differences' (Grosz, 1994:17) between men's and women's bodies, the stories provided accounts of women's experiences of illness as shaped by ideas of femaleness and shared

experiences of changing bodies as cisgender women (Young, 1983; 2005).

## Stories of intrusive illness

To begin with a story about an experience of IBS that was constructed by Helen about intense and unpredictable IBS-related pain. Like some of the other women in their diaries, Helen wrote her diary with small and well-articulated paragraphs. This highly structured and prose-like form lent itself well to constructing a poetic re-transcription based on Gee's method, and so I made few changes in re-presenting the diary in this thesis, and during analysis. The excerpt from Helen's diary is the entry from day 7 in full, with the same punctuation and line breaks, except for the space between the end of stanzas 1-2, which is marked with an asterisk (\*). I added this as my interpretation was that the point at which her dinner was interrupted by her 'urge to go' (stanza 2, day 7) marked a turning point (Labov, 1972) in the account of the dinner party event.

*'Feeling like this was a nightmare'*

Helen day 6 (stanzas 1-5: the whole's day entry)

1 Spent the day preparing for a dinner party with friends. I always enjoy preparing the food and getting the house ready to entertain.

Our friends arrived about 7, started the evening well with some nibble and wine. \*

2 Just before I was about to serve up the first course I had the urge to go to the toilet. I sat for about 5 minutes. Nothing happened but the urges to go were really painful.

I was aware I was away too long but it was almost like having a contraction.

I managed to get back to the meal but I was very uncomfortable.

3 Within half an hour the feeling was back and I had to leave the table again. This time I was almost in tears, the pain was so bad I was feeling sick as well.

Still nothing, so finally I went back again to dinner.

By this stage apart from feeling sore I was getting very embarrassed. Trying to get a meal together feeling like this was a nightmare.

4 By the end of the main course I was back to the bathroom again.

I was straining, having a hot sweat and feeling sick.

The pain was bad, finally a small amount escaped. By this time the dinner I was looking forward to, I couldn't wait to be over so I could go to bed.

5 I think its time to visit my doctor again to talk about managing my problem.

I interpreted this as a coherent chaos story about embodied suffering, as Helen emplotted herself into the story as being 'swept along' by illness, at the will of her body (Frank, 1992). The narrative construction on day 7 (stanzas 1-5) demonstrated how pain was an embodiment of illness and involving suffering and troublesome social consequences (see for example, Baumeister, 1991:235, Waskul and van der Riet, 2002; Bendelow, 2009). Helen's account of the dinner party provided an account of how this is subjective experienced that can be the embodiment of suffering, which transcends a mind-body binary (Bendelow and Williams, 1995a, 1995b; Williams and Bendelow, 1998; Honkasalo, 1998; 2001).

As with Maria's diary entry on day 3 (see Chapter 7), the audience is encouraged to attend to the experiential aspects of the events that unfolded. Helen avoided deploying medical discourses of 'symptoms' and instead utilised discursive devices to show the passing of time in the narrative, and emotive sentences, which served to build suspense and create drama ('Spent the day preparing for a dinner party...I always

enjoy preparing the food’, stanza 1, day 7; Just before I was about to serve...I had the urge to go’ stanza 2, day 7; ‘Within half hour the feeling was back’, stanza 3, day 7). Helen also euphemistically deployed discourses to explore her bodily experiences, without drawing upon medical narratives (for example, ‘Within half an hour the feeling was back and I had to leave the table...the pain was so bad...Still nothing, so finally I went back to dinner’, stanza 3, day 7). Consequently, the effect of Helen’s suspenseful and dramatic storytelling made it possible for the audience to experience the hurried trips back-and-forth from the toilet to the table, along with Helen.

*‘I was away too long’*

This compelling illness narrative was crafted with great care and attention and detail, providing the sequencing of events in a way that made it highly tellable to the audience. It was a chaos story about illness embodiment as suffering pain and inconvenience, as well as embarrassment (‘I was getting very embarrassed’, stanza 3, day 7), which would likely have a less receptive audience than the readers of Helen’s diary if she discussed this in an everyday social setting. Talk of IBS and bowels in everyday social situations would have had low tellability because at a cultural level it is not socially acceptable in Western societies to talk of bowels and poo with others (Toner and Akban, 2000; Lea, 2001; Haslam, 2015; Donezal, 2015). I interpreted Helen to have silenced herself from telling others, according to the story she constructed, in order to maintain a cheerful demeanour and show how focussed she was on making the dinner party a success.

However, consistent with ideas about women's self-silencing in theory by Jack and colleagues (Jack and Dill, 1992; Jack and Ali, 2010) this came at a cost. She positioned herself as a protagonist who could not do what she sought to do, in spite of her efforts to be the silent heroine of her story who tried to ignore her shame and guilt at being 'away too long'. She was left drained, wishing the time away ('I couldn't wait to be over so I could go to bed'. stanza 4, day 7).

As Scheff (2015) has argued, shame and guilt are moralistic emotions that do not require an audience, and I suspect even if Helen had disclosed how she felt to her guests, she would still be upset at 'failing' to be a 'perfect' dinner host. Subsequently I was unsurprised to see how Helen emplotted herself as going to great lengths to fulfil her duties successfully as the dinner host. Yet, as she felt progressively more ill she could not keep up this role easily, having to keep going back to the toilet when she got an 'urge to go' (stanza 2, day 7). She therefore surmised that she was not doing well as the host because she judged herself as 'away too long' (stanza 2, day 7) from her guests. The omission of whether she told her guests added to my interpretation of Helen's account as being about her many efforts to keep 'passing' (Goffman, 1963) as if everything was 'normal'. She sought to carry on the activities as if she were able-bodied and 'healthy' rather than experiencing the bodily sensations that accompany living with unpredictable bowel illness. This was possible because she had an invisible illness.

Helen's account was of IBS disrupting her party brought up issues around the importance of normalcy, and appearing well, with passing-as-normal constituting a story-theme across the women's diaries. Goffman (1963) in writing a theory of stigma argued that identities may be discredited or discreditable. IBS as an invisible illness is the latter classification, and so stigma is something only experienced if people choose, or involuntarily show themselves to be unwell to others (see for example, Micallef-Konewko, 2013). Helen's story showed the physical experience may have been unseen, but concealing her pain from others clearly (and understandably) took a toll on her during the dinner party. She chose not to share how she was feeling, which may be because IBS and bowel illness are stigmatised making bowel-talk and illness-disclosure difficult, according to past research (see for example, Joachim and Acorn, 2000; Taft et al., 2011). Furthermore, talk of bowels is not a topic for the dinner table (Lea, 2001). Perhaps she avoided disclosing her illness identity because she was ashamed, and says herself her frequent departures to the toilet left her feeling 'sore...and very embarrassed' (stanza 3, day 7).

## Discourses of pain-like-contractions

Another part of Helen's story also 'felt' salient to me when reading and making sense of her day 7 diary entry. Helen deployed a gendered metaphor in the process of comparing the 'urges' as so painful, and 'almost like having a contraction' (stanza 2, day 7). This is medical discourse that emplotted IBS as creating the lower abdominal

cramping, and that created a desire for Helen to push-out what was inside her body: the bodily waste leftover from digestion, rather than giving birth to a baby. Helen euphemistically described her relief when ‘finally a small amount escaped’ (stanza 4, day 7), which I assumed to be about the passing of gas or faeces, though she left this part of the story untold.

Consistent with the diagnostic measures for IBS, Helen’s pain was relieved by her passing wind or faeces, which reinforces the medical framing of the illness ‘symptoms’. The storytelling offered much more than a literal and simplistic description of symptoms however, with Helen grounding the story of her pain-like-contractions from a (cisgender) woman’s standpoint. Whilst Helen may have told this story drawing upon her personal experiences of childbirth and the pain of IBS, she was not the only to deploy discourses in this way. The example below is from Eliza’s diary, although a number of the women utilised birthing, pregnancy, and pain-like-contractions metaphors in their diaries. I chose Eliza’s diary as an example as this a particularly evocative and vivid series of narrative constructions when compared with the other types of stories Eliza told in her diary.

### **Pushing out the pain**

Eliza deployed discourses that emplotted IBS as involving pain-like-contractions, like Helen on day 7. In the retrospective story, Eliza constructed an account of an experience of IBS on holiday. She did this



in the same way as Helen in providing a linear account a series of events, which also explored the experience of pain when involved in social activities. Eliza's story similarly emplotted IBS as having disrupted planned events, and left her feeling 'very embarrassed + ashamed' (stanza 5, day 3) at the time.

*'After a lot of agony on holiday'*

Eliza day 3 (excerpts from stanzas 4-5)

4 After travelling around in a camper van for 5- weeks, I seemed to have gained confidence in going to the toilet for a poo, where I can! This has helped relax me enormously, but not after a lot of agony on holiday. I feel I should share this experience.

5 I had vomiting + diarrhoea for three days, followed by TEN days of constipation I didn't go to the toilet in those TEN DAYS!! On the tenth day I was in agony on the floor of the van + had to get my friend to drive me all over to get a doctor...This took hours, and I was having contractions every 5 mins. I couldn't physically sit on my bum to had to balance on my hip + prop myself up with my legs + hands. Finally got to the doctors who x-ray'd me. (£100+!!) Had to have an enema – got a "do it yourself" kit. I asked my friend to take me to our other friends house so I felt comfortable

doing the procedure. I didn't feel comfortable but at this point of agony I was beyond caring! 1 hour of the most intense, humiliating, painful + disgusting thin I have been through (and I have had major surgery, and other equally nasty encounters in hospitals many times). It really was too awful to describe. I felt like I was giving birth (more for the fact of the induced contractions the enema gave me). 10 mins after I had emerged from the loo, I felt fine! Although very embarrassed + ashamed.

As part of this story about IBS on holiday, Eliza deployed gendered discourses to articulate the pain she felt. This was part of emplotments of IBS-related experiences, but also of the treatment for her severe constipation: an enema. This is a medical tool involving inserting a warm substance or liquid into the anus to prompt defecation (Higgins, 2006), which was prescribed to Eliza to administer herself ('a 'do-it-yourself kit' (Eliza, day 3). This she experienced as being 'like giving birth' (stanza 5, day 3), which further extended the 'agony' she emplotted herself into the story as having already experienced when travelling in the camper van ('I was in agony on the floor of the van... I couldn't physically sit on my ~~bum~~ to had to balance on my hip + prop myself up with my legs + hands', stanza 4, day 3). In these ways Eliza conveyed an image akin to a woman on the verge of giving birth, who experienced the uterine contractions and whose consciousness lay

in the corporeal experience of birthing. It is interesting the way Eliza deployed this metaphor to allow the audience to visualise her sat poised in mid-air, trying to get comfortable, perhaps grimacing with the intense discomfort of the constipation. This continued up until the point at which she is relieved of her pain, but not after having emplotted the enema as being experienced as 'like childbirth', as she sought to expel the waste products from her body.

### **Performing narratives of illness**

Eliza chose to construct this retrospective, rather than real-time, account of experience on holiday. This showed how stories are always told to an audience as an act of communication within a social realm (Potter and Wetherell, 1987; Edwards and Potter, 1992). Eliza's stories were about her life as told (Mattingley and Garro, 2000) and positioned her as a reflexive subject who was aware her holiday story would be warmly received by the real and imagined audience of the research. This was in stark contrast to Maria's narrative from day 6 (see Chapter 7) where positioned herself as questioning if she was 'good enough' to be a research participant or not, compared to others in the 'forums. Eliza positioned herself as an 'expert' in being an IBS patient, able to deploy the medical jargon having much experience of being treated by Western medicine in the past ('I have had major surgery, and other equally nasty encounters in hospitals many times' stanza 5, day 3). Eliza drew upon her cultural resources as a woman who was young (in her 30's), and who was a postgraduate student with a background in

biological science. This may be why she seamlessly switched between colloquial and euphemistic discourses, and medical and scientific discourses ('I couldn't physically sit on my...bum to had to balance on my hip + prop myself up...got to the doctors who x-ray'd me', stanza 5, day 3).

In the narrative construction Eliza's story seemed to take on a momentum of its own, with deeply emotive storytelling that made this another example of the teller experiencing an 'emotional outburst' (Ochs and Capps, 2001). In this compelling and engaging story, Eliza deployed temporal discourses and grammar ('TEN DAYS!!', stanza 4, day 4) to construct an engaging and emotive narrative. This served to invite the audience events to follow events as they occurred over time (for example, 'in a camper van for 5- weeks', stanza 4, day 3; 'had vomiting + diarrhoea for three days, followed by TEN days of constipation', stanza 5, day 3). The I-Poem that I constructed is included below for the reader's benefit. This showed how the person pronoun clauses further informed the power of the narrative constructions and storyteller's 'performance' (Mattingley, 1994; Mattingley & Garro, 2000).

Eliza I-Poem (excerpts from stanza 5, day 6)

I was in agony

I was having contractions

I couldn't physically sit

I asked my friend to take me ... so I felt comfortable

I didn't feel comfortable

I was beyond caring!

the most intense, humiliating, painful + disgusting thin I  
have been through

I felt like I was giving birth

I had emerged from the loo,

I felt fine! Although very embarrassed + ashamed

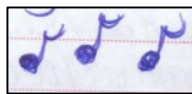
Slowing down the pace of the narration and considering the way Eliza constructed this story showed how she was not only re-living her distress ('I was in agony...I didn't feel comfortable...I felt like I was giving birth' and so on). Additionally, Eliza showed signs of being able to make light of the experience as Eliza's narrative performance added to the dramatic effect of the use of punctuation, repetitions of words, and superlatives. I found the vision of her struggle to sit down funny, or farcical, whilst also recognising the seriousness of this situation. This could perhaps be seen as an in-joke shared between Eliza and myself given how Eliza knew I was an insider researcher who could likely relate. If this were the case then Eliza would have guessed correctly, having known from bitter experience struggling to sit comfortably

because of bowel issue related pain. Diana's diary was similar to Eliza's in telling stories that were at once serious, and also slightly funny and humorous.

*'If only they knew'*

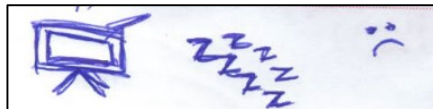
Diana day 2 (stanzas 5-6)

5 As I have no plans I've distracted myself with 'me' things – picked up my guitar, done some overdue reading and listened to some music.



la la la la

Will most likely spend the evening in front of the tele watching X Factor wondering why I haven't got a boyfriend...hahaha.



BORED.

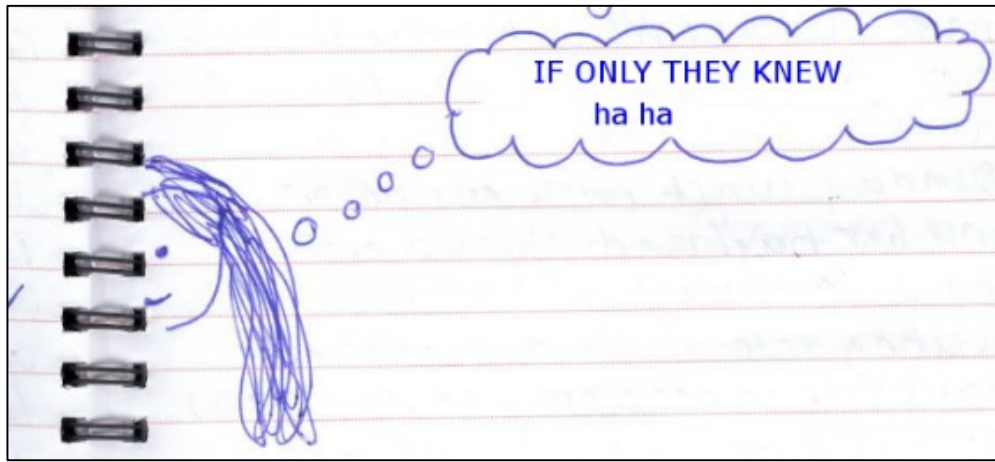
6 hmmm...what do guys actually think of girls with bowel problems?

People often say I'm so pretty,

bla bla bla...and I'm waiting

to tell them the

gross bit



This story from Diana's diary is unlike Eliza's day 3 holiday story as it set in the present day as she wrote in a conversational style about her evening ahead ('I've not plans...Will most likely spend the evening in front of the tele watching X Factor' stanza 5, day 2). Rather than reflecting on past events, the story unfolds in real-time, and Diana emplotted herself as amusing and 'distracting' (ibid) herself with what she described as "me' things' (ibid). This is very much a story about Diana, where she constructed her identity in the story as someone who likes music, and drawing, as the doodles and drawings across her diary suggest. However she is upset, according to the doodle of the unhappy face (☹) implied, because she is 'wondering why I don't have a boyfriend' (stanza 5, day 2) and is also feeling 'BORED' (ibid.) There is a shift in the voice of the story after this, which I separated into the next poetic stanza for interpretative purposes. Diana marked this with the spaces between the paragraphs, and in moving from real-time storytelling to reflecting. She asked the rhetorical question and then includes the sentence that read like poetry, with each line leaning into the next, just as Diana 'waits' to tell the anonymous 'people' what the *truth* is, the 'gross bit' (stanza 6, day 2).

At the time of the research Diana was a young woman who was interested in exploring romantic relationships, and I interpreted this story to be an interesting construction of what it meant for her to be a young woman living in a culture where able-bodiedness is privileged. Diana positioned herself in this story as a woman who identifies as heterosexual (or bisexual), emplotting her curiosity at male responses to her as a woman living with IBS ('what do guys actually think of girls with bowel problems', stanza 6, day 2). She rhetorically answered herself as part of two utterances that dialogically blend two voices, one commenting that others 'say I'm so pretty', whilst the other made the insider joke that revolved around her decision whether to disclose or conceal her bowel illness. In this story at least she emplotted herself as keeping her illness status to herself ('IF ONLY THEY KNEW' *ibid.*) Yet the dialogical voices heard in this storytelling, and the drawing of half of a face smiling to herself was, in my interpretation, intended to illustrate to the audience how Diana felt torn. She might smile alone with the empty compliments about being 'pretty', which is just 'bla bla bla' (*ibid.*) to her. Diana emplotted herself as being able to put on a smile, made possible by IBS being an illness hidden from others. Whilst ironic in its tone, the story was written in a way that I interpreted as self-conscious, with Diana aware of how 'untellable' her story was.

Consistent with Billig's (2005) argument, humour and laughter shared between the storyteller and audience as interactional partners made talk of taboo topics possible for Diana. She deployed humour in the story addressed to the audience in her picture, and also when



reflecting on the meaningful topics of what others ‘think’ of her, including ‘what boys think of girls with bowel problems’ (stanza 6, day 2). The deployment of humour and regular non-verbal utterances (‘ha ha’) acted as a storytelling strategy for Diana here in this story and at other times in her diary, just as it was shown to be integrated into Eliza’s earlier holiday story. I would argue that this is made it possible for Diana, and also Eliza and some of the other women, to find ways to tell stories of embodied experiences of suffering. This may be considered more amenable to audiences in Western cultures given the privileging of heroic tales of being hopeful, ‘getting better’ and *always* staying positive.

## Stories about feeling ‘stressed’

In the final part of this chapter I provide one example of a story about the embodied experience of ‘stress’. Eliza, Helen and Diana told stories that showed the experience of suffering as an embodiment of pain, and emotions such as shame. Other stories that some of the women constructed in their diaries were not about IBS, but rather about embodied experiences of stress, which did not always include IBS embodiments. Instead, addressing the research questions about gendered narratives told by the women, I provide an example from Georgiana’s diary. Georgiana wrote about IBS, but the majority of her diary was written in real-time about the recent past or near future. She adopted a stream-of-consciousness style of writing her electronic diary, with many paragraph breaks that lent themselves well to poetic re-

transcription. The following story is about the experience of stress, which is something articulated in different ways by a number of the women in their diaries. In much of Georgiana's diary she constructed stories about her day as busy, showing how for her as with all of the women, IBS was only one part of her everyday life.

*'I sometimes feel like I'm on a conveyor belt'*

Georgiana (day 3, stanzas 5-6, and day 4, stanzas 1-2)

Day 3

5 Going to get ready and go out for supper Rose. Am absolutely shattered and could really do without it, although I know I'll be fine once I get there. Going to have a shower to wake myself up and then Tom and the children will drop me off so I can have a drink and walk home.

6 Lovely evening with Rose. She's been promoted so we have a bottle of cava to celebrate. I momentarily feel envious and know that coming to Spain put a stop to my career progression (I'm lucky to have a job at all) but it passes in a moment as I know I have a blessed life here.

#### Day 4

1 Very tired this morning but very pleased that I drank lots of water last night so not suffering too much. Thankfully the morning is a breeze compared to yesterday so I get too work without feeling too stressed. It's amazing how quick you get used to change. Everything should be a breeze now that Tom is here every other week but it doesn't feel like that and I still find myself getting stressed about ridiculous things like the house being a mess and the ironing piling up and even though I know it's ridiculous I can't seem to stop myself.

2 I sometimes feel like I'm on a conveyer belt and I can't keep up or get off but I'm the first one to complain when we have nothing organised or nothing to look forward to and I know that in a couple of weeks when things have quietened down I'll be the one looking for things to do.

It is possible to see in this example of stories told by Georgiana her easy and free-flowing storytelling style. I interpreted the entries to have been written hurriedly at the end of Georgiana's busy and long days, within which she often emplotted herself as 'tired' (stanza 1, day 4), and seemingly rushing from one activity to the next. The way

Georgiana narrated being on a conveyor belt stood out to me when reading this diary entry. Like Schneider and Fletcher's (2008:141) her thoughts, feelings, emotions were connected as part of a spiralling 'cascade of impact, leaving Georgiana feeling 'stressed' and anxious. Whilst the participants in Schneider and Fletcher's research wrote about their experiences in a Cartesian way, separating the mind and body, and physical, emotional, social and psychological experiences, Georgiana's account did not do this. Like with Maria's entry in Chapter 7, Georgiana's anxieties were conveyed by the way she told her stories, deploying literal figurative discourses to find a language to articulate feelings of tiredness, fatigue, and trying to 'keep up' (stanza 2, day 4) with the relentless activities of everyday life.

This was not a story about IBS. It was about thoughts, feelings, and emotions. Bendelow (2009:44) argued stress can manifest as 'sickness, madness, pain' and other unpleasant embodied sensations. Perhaps this theory may resonate for Georgiana, although this was not the point of the stories she told on days 3-4. Rather, her stories provided an account of what it means to be living with the continual and embodied experiences of fatigue, pain and suffering as embodiment, rather than as part the mind-body dichotomy (Scheper-Hughers and Lock, 1987).

## Moving between hopes and suffering

I want to highlight another interesting aspect of my interpretation of the stories in Georgiana's diary on day 3-4. This conveyed a tension between Georgiana's perspectives on her life, and herself. Breaking the stories up to into the first-person pronoun I Poems is helpful in illustrating this for the reader's benefit.

*'I have a blessed life...I can't keep up'*

Georgiana I-Poem (day 3, stanzas 5-6, day 4, stanza 1)

I know I'll be fine once I get there.

I can have a drink and walk home.

She's been promoted so we ... celebrate

I momentarily feel envious

I'm lucky to have a job

I know I have a blessed life

pleased that I drank lots of water

I get too work

I still find myself getting stressed

I know it's ridiculous

I can't seem to stop

I sometimes feel like I'm on a conveyer belt

I can't keep up

I'm the first one to complain when we have nothing  
organised

I know that

I'll be the one looking for things to do.

In my interpretation of Georgiana's contradictory emplotment of her self-reflections about feeling 'stressed', tired and overwhelmed, and also positive and happy about her life as it was at the time she wrote in her diary. It is possible to get a sense of the ebb and flow of the way Georgiana constructed these stories, and emplotted herself within these. She is pessimistic and tired, not wanting to go out, but then adds as part of this conversational and rhetorical narrative that: 'I know I'll be fine once I get there' (stanza 5, day 3). This move between two opposite states is also emplotted into the story on day 3 when Georgiana about having felt 'momentarily envious' (stanza 6, day 3) of her friend's job opportunities, but then quickly relinquishing this statement ('I'm lucky to have a job...I have a blessed life', *ibid.*).. This

also happened on day 4 (stanzas 1-2) as she moved between feeling 'stressed' and perceiving this as 'ridiculous', but then deciphered that she might experience life 'on a conveyor belt', though she would be 'bored' if it were any other way.

Murray (2000) and Good and Good (1994) argued that with every narrative analysis there are multiple readings. Stories are dialogical and it is possible to hear many utterances in the voices telling the stories (see for example, Bakhtin, 1975; Riessman, 2008). Aside from the layered approaching to unpacking multi-layered analyses, Georgiana's diary provides an example of how she self-consciously justified her thoughts and beliefs. She emplotted herself as feeling many thing, and so her stories contradicted one another, taking away from the impact of each point she had made about feeling 'envious' or 'lucky', for example. Murray (2000) and Good and Good (1994) argue that, as a result:

Each story casts doubt on the others, or provides a potential alternative interpretation of the illness and of other stories about it. (Murray, 2000:39)

In my interpretation, one reading of Georgiana's stories 'cast doubt' on one another, though not in the sense that they created *doubts* in the extent to which audiences could believe the stories as truths. The aims of the current research were not to understand stories 'captured' as

lives as lived, but rather than as constructed within the research setting for the purpose of research participation.

Craib (2004:71) has argued that personal narratives are always contradictory (Craib, 2004:71), and may be understood by considering 'faith' as an abstract property of narrativity. 'Bad faith' stories are existential accounts that in some way deny some aspect of a nuanced and personally meaningful experience. For example, I would agree with Craib (2004) that storytelling can be conflicting, indecisive, and have confused messages that are more or less 'authentic' in their ability to convey what it means to be human. Perhaps this is a way in which it is possible to interpret Georgiana's diary as conveying her juxtaposed feelings of hopes and of struggles, and of searching for ways to make sense of her contradictory experiences? Her stories therefore could not be strictly aligned with the typology of (illness) stories discussed in Chapter. The stories of everyday life as unfolding conversational narrative had elements of both quest and chaos narratives. My sense is that, aside from analysing the details of the stories, Georgiana's diary provides an example of how the diaries were an adept way in which it is possible to explore accounts of the complexities of human existence, which necessarily involves embodied experiences suffering.



## Summary

The stories discussed in this chapter and the previous chapter are interpreted as having emplotted IBS and illness as something the women found as familiar, but as still causing ‘continual disruptions’ (Honkasalo, 2001; Werner et al., 2004). This went against previous research that suggests chronic illness involve biographical disruptions immediately after illness onset (Bury, 1982). Instead to make sense of IBS and illness, and of suffering as a part of everyday, the women emplotted themselves within stories of embodied experiences of ‘passing’, in line with Western cultural scripts that see able-bodies as viewed more positive than ill or disabled embodiment (see for example, Shildrick, 2015). Gender has been shown to be part of these conversations about illness embodiment, particularly within the context of stories of pain-like-contractions as a way to explore IBS from a cisgender female standpoint. In the next chapter I will provide a more detailed interpretation of stories about shame and embarrassment as connected to bodies, illness embodiment, and female subjectivities.



## Chapter 9: Stories of body shame and unsightly female embodiment

This chapter will look more deeply at the interpretations of the women's stories of IBS as gendered and encased in feelings of self-consciousness about their bodies. This provided some argumentations towards ideas by Bartky (1982; 1990), Jeffreys (2005), and Donezal (2015) that shame manifests in gendered ways for women who experience body shame as defined as 'shame that arises as a result of the body' (Donezal, 2015:7). Body shame is about perceptions of the women's ability to control their bodies and is about 'body and bodily management ... appearance, bodily functions or comportment' (ibid). Scheff (2001; 2015) argued that the common-sense understanding of shame is as a negative emotion involving 'a feeling of intense disgrace' (Scheff, 2015:112), and this contributes to feelings and experiences where shame is experienced being culturally tabooed and 'unspeakable' (ibid) to others.

This chapter will explore interpretations of stories of everyday experiences of shame and embarrassment surrounding living with a chronic bowel illness. Furthermore, connections will be drawn between the ways the women's personal stories of gendered IBS embodiment are aligned or opposed to wider cultural scripts of illness and hegemonic femininities, as per Western societal cultural norms and ideals. Such stories knit together the personal and individual

perceptions of body image in order to show how body images are conceived ongoingly, and as materially and socially symbolic (see for example, Grogan, 2016). In this way the women's perceptions of their bodies are 'derived to a large extent from the perceptions, sensations and movements of the organic body...[therefore]... body image is in a continuous process of production and transformation' (Grosz, 1994:74-75, parenthesis added). This final chapter thus offers an interpretation of another layer to the analysis that addresses the research questions regarding gender, illness and cultural scripts of femininities and 'ideal' female bodies.

## Stories of embarrassing bodies

### Abject embodiment

There were many examples of IBS as emplotted into the stories as linked to feelings of shame. I have discussed some examples of this in the previous chapters, such as when interpreting Eliza's holiday story (Chapter 8). To provide another example from Helen's diary, within which her emplotments were of IBS in relation to her objectified and shameful 'bowel' (ibid.)

*'My worst nightmare '*

Helen (day 1, stanzas 11-14)

11 They have a lovely home down here and we have our own bathroom! My worst nightmare is sharing an apartment when we travel with friends. I love the fun of it but having one bathroom that always seems to be off the living area is just awful.

12 I have a very explosive bowel. A lot of the time when I feel the urge to go down to the toilet all that happens is a terrible, loud explosive noise. Edgar thinks I should rent myself out for sound effects to a movie company!

We manage to laugh about it but the reality of it is so embarrassing.

13 If I am at the mall I will go home rather than sit in a cubicle with people coming and going trying hard not to be heard.

14 So, as you can imagine toilet facilities are a very important thing for me when planning a stay with friends or travelling.

Helen constructed these stories that took place within the scenes of her everyday activities and personal relationships, and the public setting of 'the mall' (stanza 13, day 1). Yet Helen also made space for

reflection and implicitly addressing the audience to tell her story about her 'loud' and 'explosive' bowel, which she emplotted as part of her she could not control. This provided another example of Helen's means of 'passing' as 'normal' to other people, as discussed in relation to her dinner party story (see Chapter 8). Helen's diary entry on day 1 (stanza 11) began as a real-time conversational narrative about 'today', although in this entry Helen moved into a reflective story. She invited the audience into the scene of storytelling in order to explain exactly why her friends' home is 'lovely'. Namely, because Helen and Edgar (we) 'have our own bathroom!' (stanza 11, day 1). For the reader's benefit the I-Poem shows how Helen moved between first person pronoun clauses and pluralistic pronouns, either for her friends ('They') or for her and Edgar ('we'). This is significant as it shows how Helen went about emplotting herself and people she cared about in the stories that showed her experiences of IBS embodiment were ever-present in her mind.

*'Very explosive bowel'*

Helen I-Poem (stanzas 11 – 14, day 1)

They have a lovely home

we have our own bathroom!

My worst nightmare

I love the fun of it but

I have a very explosive bowel

when I feel the urge to go

Edgar thinks...rent myself out...to a movie company!

We manage to laugh

If I am at the mall I will go home

you can imagine toilet facilities...very important thing

Slowing down the narrative through constructing a poetic transcription facilitated my interpretation of just how important this was to Helen, to whom toilet spaces were clearly very important to her, as she says herself in the context of 'planning' holidays ('as you can imagine toilet facilities are a very important thing for me when planning a stay with friends or travelling', stanza 14, day 1). Helen is the protagonist of the story who openly positions herself as a storyteller happy to let the audience in on her *secrets*, which I interpreted as something she told very few people (if anyone).

## **Toilet spaces**

Helen's story is about how living with a bowel illness infringes upon movements through and ways of occupying certain spaces in a social sphere. White (2016) argued that for people living with IBS the toilet

space takes on seminal importance. The current research would suggest this also to be shown to be the case given how toilets and bathrooms were a story-theme throughout Helen, Eliza, and Diana's diaries. Eliza's holiday story for example, tapped into the issues of when the public and private binary is disrupted as bodily boundaries blur with the involuntary loss of control of one's bowels, or necessity to evacuate the bowels because of constipation. The 'Around the Toilet' project (Slater et al., 2015) more broadly explored toilets and disabilities, and similarly emphasised how toilets are far from 'mundane spaces'. The ability to access a toilet where Helen would not be heard, for example, mattered deeply to her. This was markedly emphasised in Helen's story as she commented that 'My worst nightmare' would be experiencing the fear and anxiety of being heard, which for Helen (as with Eliza in Chapter 8) had meaningful social ramifications if they were to be 'heard'. Privacy when going to the toilet was a 'very important thing' (stanza 13, day 1) , which was her euphemistic way to discuss IBS symptoms as getting 'the urge to go', as Helen did elsewhere in her diary. Helen adhered to the cultural dichotomising of the public and private space, and the way in which bodily processes and embodiment are woven into norms surrounding when, and where, it is appropriate to display body products.

Douglas (1970) argued that bodily waste and other expulsions and leakages from the body are not literally 'dirty', though within Western cultures any habits and products connected with bodies are considered 'dirty' and provoke 'disgust' if seen by other people (see for example,



Cregan, 2008; Ogden, 2013). In this way it is considered socially unacceptable to defecate (or poo), or pass wind (fart) around other people (see for example, Lea, 2001). In this way control of one's own body is paramount when considering the social etiquettes and norms that personal body behaviours are informed by. Waskul and van der Riet (2002) argue that to lose control of the body thus leads to experiencing an 'abject embodiment', which they explored in their research with people living with cancer who were based on a palliative care unit. As I discussed in chapter 2, bodies are embodied and are also connected and take on a 'paramount importance to the self' (Waskul and van der Riet, 2002:509), and self- and body-images. For this reason living with a bowel illness could be argued to have involved living an abject embodiment, according to some of the women when constructing stories about their lives as women living with IBS. Ensuring access to the toilet space in *private* provided a way for Helen, and some of the women, to emplot themselves into stories of illness as actively self-managing their illnesses. Yet, these passing strategies were not always possible to accomplish, such as Helen emplotted her intense fear at sharing an apartment where people were living in close proximity.

### **Humour and bowel-talk**

Making the point further about the shame of living with a bowel illness, Helen constructed the additional story about her 'loud explosive bowel' (stanza 12, day 7). Humour can lighten the tone when faced with

serious situations and in this way is integral to to the social sphere (Billig, 2005). I interpreted this to be the reason behind Helen sharing the joke with Edgar so they can 'laugh about' (stanza 12, day 1) her *noisy* bowel. Yet she privileged the audience on the 'reality of it' (ibid.) for her as something 'embarrassing' (ibid.) and shameful. This shows the complex ways in which humour is intertwined for Helen, with experiencing her body and embodiment as abject (Kristeva, 1982) or as a form of 'abject embodiment'.

Lea (2001) argued that deployment of euphemisms and crude language, or toilet-humour (Haslam, 2015), makes talk of bowels (or bowel talk) as a taboo topic in Western cultures, more socially unacceptable. Subsequently there is a message imbued within Western cultural scripts about human bodies as needing to be controlled (see for example, Turner, 1984; Waskul and Vannini, 2006). Yet, Helen's story and Eliza's story from Chapter 8 showed how stories about that are shameful and important are at once something that can be joked about, whilst at the same time being untellable, or 'too awful to describe' as Eliza worded this in in her diary (see Chapter 8). Helen showed laughter to be part of her way of making sense of the situation when Edgar heard her bowel noises and teased her. I interpreted her 'disclosure' to tell another story that contradicted the jokes they shared, with Helen positioning herself as a first-person protagonist and storyteller who was merely trying to 'pass' as someone who could try to lighten the tone when faced with her chronic and uncontrollable bowel.

## Stories of body battles and body images

The stories so far have focussed on the shame of bowel illness and ‘embarrassing’ bowels and bodies. I want to move on this final section of the analysis chapters to explore another aspect of IBS as involving living with an abject and gendered embodiment, according to the stories some of the women had to tell in their diaries. The story themes of body size and shame, and body image is central to the following stories where the women emplotted themselves as engaged in battles with their bodies’ appearances and behaviours.

*‘When it’s bad I feel like an enormous whale person’*

Adele (day 1, stanza 3-4)

3 I’ve always really battled with how I feel about my body and my weight and the last few days I’ve really felt this and the impact my IBS has on it. When I’m symptom free, I feel light and happy but when it’s bad I feel like an enormous whale person.

4 I’ve just started sort-of super-casually seeing this guy...and we had a really nice time at the weekend; he came round spontaneously on Saturday night. I felt lucky that I was able to be that spontaneous as my tummy (this is generally how I refer to my IBS/gut in my head!) behaving and I was feeling good... but generally

it stops me from being spontaneous and/or means that I have to be really careful to plan when to take various medications. It's so boring.

Adele's story emplotted her as able to make jokes about her IBS, comparing herself to a 'whale person' (stanza 3, day 1) – though this is a serious story about illness embodiment and suffering. Adele was writing about her 'battle' (stanza 3, day 1) with how she felt about her body. These stories were reflective stories about the meaningful ways Adele sought to make sense of societal pressures to meet feminine ideals. Furthermore, Adele emplotted herself as feeling unable to be the person she wanted to be because her IBS 'stops me from being spontaneous' (stanza 4, day 1). Adele invites the audience into her world by adding the aside that to her IBS and her body are 'my tummy' which 'is is generally how I refer to my IBS/gut in my head!') (stanza 4, day 1). In this way Adele deployed discourses that see a Cartesian split, but in this case to construct the stories of her fight between 'me' and IBS/her 'gut' as 'my tummy'. In this way my tummy is objectified as an autonomous entity, but also personified as something that belongs to her (*my tummy*).

In her story constructions Adele's way of positioning 'me and my tummy' is similar to the way participants in Håkanson et al's (2009) and Håkanson's (2010) research objectified their abdomens when exploring illness-related experiences. Adele deployed negative and derogatory

discourses to frame her body as 'unreliable' (Håkanson et al, 2009; Håkanson, 2010) and uncontrollable, and in this way she was positioned herself as passive in the embodied experiences of suffering, as per the chaos type of narrative.

Adele's story and some of the other women's were told as part of stories of appearances, bodies and body images, within which illness was sometimes emplotted and sometimes not. I have provided Adele's diary as an example, though there were many examples that tapped into the story-theme in the diaries of Adele, Georgiana and Helen. What these stories shared were the women's emplotments of their vigilance towards their bodies, and their bodies moved, behaved, and looked. I interpreted Adele's diary on day 1 was particularly apt in capturing the sense of dissatisfaction she experienced relative to her body image and appearance. Furthermore this entry illustrated my interpretation that Adele was objectifying her body in a way that is argued to be a cultural phenomenon in Western societies.

### **Monitoring and misbehaving bodies**

Objectification Theory (Fredrickson and Roberts, 1996) proposed that women engage in everyday bodily monitoring and surveillance. McKinley and Hyde (1966), Bordo (1993) and Wolf, (1990), for example, have argued that women and girls are encouraged from a young age as part of gender socialisation to recognise to be feminine means valuing and making effort to look in a certain way. Past research

has shown that women living in Western cultures perceive their bodies negatively, judging themselves against their ability to meet the 'slim' and thin, or 'toned' body ideals (Orbach, 1986; Bordo, 1993; Ogden, 2010; Grogan, 2016). Adele's stories affirmed such an argument, with her personal story drawing upon the Western cultural script of idealised femininities as necessitating meeting body ideals and engaging in body monitoring. Her diary was also one of a number of the women's that showed how illness embodiment is connected with the women's ways of making sense of their bodies and body images.

Though Adele aligned herself with the cultural and gender norms of meeting slim thin ideals, the 'battle' she had suggested she tried to resist the societal pressures and be happy with her body. However, for Adele according to the stories she told in her diary, she was instead preoccupied with moving between that juxtaposed and binary states of feeling 'light and happy' (stanza 3, day 1), or heavy and taking up too much space in the world 'like an enormous whale person' (ibid.). Her life involved living with liminalities and uncertainties, which provides another argument towards the limitations of binary thinking when considering the embodied experiences of women living with chronic illnesses such as IBS (Moss and Dyck, 2003). I want to provide another example from Adele's diary to illustrate another example from Adele's diary that explored the story-themes of body image, but also of abject embodiment.

*'Sexy as a slug!'*

Adele (day 6, stanzas 1-2)

1 Jonas is coming tonight, I'm actually just waiting for him to arrive. Medication has worked really well today so I'm feeling really good about myself. He's coming up for a gig and then staying the night.

2 I can get really anxious about my IBS when it comes to sex – if I'm having a bad day, the last thing I want to do is be naked in front of someone else and I feel about as sexy as a slug! But when it's good, I can feel really comfortable about my body. Not much else to say about today.

Day 6's diary entry but a short but deeply meaningful story, set in real-time about the recent past, 'today' (stanza 2, day 6). Adele emplotted herself once again, as juxtaposed between two ways of being and this was connected with her appearance concerns and body image. IBS embodiment is more the focus of this story, with illness emplotted as having social and relational consequences for her, as discussed within the context of Adele awaiting Jonas' arrival (stanza 1, day 6). There is humour in the way this story is told ('I feel about as sexy as a slug!' stanza 2, day 6), and this provided a way to make this story of suffering more 'tellable' given the taboo surrounding talk of bowels and bowel illness (Lea, 2001' Taft et al., 2011. Adele deployed another animal

metaphor, conveying an image of herself to the audience that when she is unwell she feels 'sexy as a slug', like a shapeless, slimey, and unsightly creature. This provocative discourse about when Adele is not 'really comfortable about my body' (stanza 2, day 6) further reinforced the message from day 1's story. Namely, that she felt 'light and happy' or heavy, big and like a 'whale person' when her IBS occurred.

Adele's story privileged the audience with a frank and open account of how illness played out in her life. She narrated this first-person story about intimacy, sex and body image from a standpoint of being a young (aged 20-30s) heterosexual Western woman. This is also the positioning Diana adopted in her diary, according to her story when she explored her reflections over what 'boys' think of 'girls with bowel problems' ('IF ONLY THEY KNEW!!' see Chapter 8, p196-199). The impact of illness on sexual relationships and libido is something researchers have claimed to be problematic for women living with chronic bowel illnesses (see for example, Dancey et al, 2002; Speigal et al., 2004). Adele's experiential story added to this body of work by providing a nuanced and relatable account of what Swoboda (2008) framed as the illness embodiment problem of 'desire', drawing upon Frank's (1995) work. Adele's story was literally about desire in being about her sexual needs and relationships, which she emplotted as being tempered by feeling ill and living with an undesirable and abject embodiment. IBS was an 'unpleasant companion' (Rønnevig et al., 2009:1679), there in the background to the scenes of Adele's everyday life and relationships.



I have discussed Adele as a young woman's concerns over her body and her appearance, though to provide another example from Georgiana's diary. Georgiana is older than Adele and also emplotted herself as concerned with her appearance when she felt ill and 'bloated' (stanza 1, day 2).

### Hugeness of the bloated stomach

*'Nothing that highlights my 'pregnant' tummy'*

Georgiana (stanzas 1-2, day 2)

1 Woke up early again. Very annoying as I could do with the extra hour's sleep. Tummy still bloated, lots of wind and uncomfortable feeling. This leads me to start thinking about what I am going to wear today – something not too tight and nothing that highlights my “pregnant” tummy. Everything quiet in the house so stay in bed thinking about everything that I have to do today, including my diary.

2 Decided on jeans and a loose top so no need to worry about bloated stomach. I realise that this is something I do most days without even thinking about it ie I choose my clothes based on how bloated my stomach is or isn't. In fact my whole wardrobe is designed to disguise my stomach. My body frame is quite slim but my

stomach sticks out like a balloon and I'm always conscious of it.

This story is at once about illness embodiment and body image and appearance concerns. Georgiana aligns herself with the Western cultural script about the ideal slim and thin body in this personal story, as Adele also did. Rather than deploying animal metaphors, Georgiana deployed the pregnancy metaphor within the context of her point about her stomach looking 'pregnant' (stanza 1, day 2) because she is 'bloated' and has 'lots of wind' (ibid.) To emphasise this point Georgiana also deploys the metaphor of her stomach 'sticking out like a balloon' (stanza 2, day 2). The effect of these emplotments therefore provided evocative ways Georgiana conveyed to the audience how she monitored her body closely and, like Adele, felt that IBS made her body change in shape and size. The ways the women emplotted the bloated tummies was as unsightly and unattractive parts of their bodies, which they were 'always conscious of' (Georgiana, stanza 2, day 2). In this way their bodies' appearances preoccupied their waking thoughts as they surveilled whether their bodies would look 'today'. The symptom of bloating may be a physical experience, but it has social, emotional and cultural meaning for women living with bowel illnesses. When contextualised within a Western cultural setting it is possible to see how these personal stories are shaped by the scripts of idealised female bodies (Toner and Akban, 2000).

Georgiana emplotted in her story herself as engaging in the 'passing' strategy to cover up the bloated, balloon-like tummy by choosing her 'whole wardrobe' (stanza 1, day 2). She reflected that 'this is something I do most days without even thinking about it ie I choose my clothes based on how bloated my stomach is or isn't' (stanza 2, day 2). Georgiana's story saw her 'disguising' not only her stomach, but she also concealed her body-shame (Donezal, 2015) and her invisible illness.

The 19<sup>th</sup> Century English fairytale of Goldilocks and the Three Bears was about the little girl Goldilocks, who knocks on the door of a house that she finds empty. This house belongs to three bears, which Goldilocks enters and then proceeds to try each of the three bears – a big Daddy bear, a medium sized Mummy bear, and a small baby bear – porridge and try out their beds. This historical children's story reminded me of the way Georgiana wrote about her attempts to find an outfit that was 'just right', like Goldilocks in her pursuits of the right heat and amount of porridge and the perfectly sized and shaped bed. Georgiana crafted her story in a way that allowed the audience to imagine her that day when she wrote in her diary, and other 'most days' sifting through her wardrobe trying to find the perfect outfit. When Georgiana felt ill, this meant choosing an outfit that hid her tummy's shape and size.

I interpreted what Georgiana left unsaid in this story to be meaningful when considered alongside her narrative about her approach to

choosing clothes that were 'just right'. She did not say how often she felt unwell and selected clothes to disguise her tummy, or why her bloated stomach was a problem for her. This was just as Adele did not reflect upon why her 'misbehaving tummy' was shameful for her.

## Summary

Past IBS research has consistently shown body images issues and bloating symptoms as problematic for women living with IBS and illness as 'gendered' (Björkman et al., 2013) issues (Toner and Akban, 2000; Bengtsson, 2006; Voci and Cramer, 2009). Whilst there was diversity and differences in the extent to which bodies and body images were explored by the women in the current research, this chapter has highlighted how illness embodiment and gendered stories about body images issues were meaningful to the women when telling stories of their everyday lives. This chapter has explored in detail some examples of stories about body shame and abject embodiment as story-themes within the diaries completed by the women involved in the current research. The various stories of 'body battles' have shown the complex ways women make sense of their bodies as ill and objectified bodies. Furthermore, it has been possible to see how women's 'leaky' (Shildrick, 1994) and constantly changing bodies are experienced as part of female embodiment in ways that intersect with embodied experiences of illness as abject and perhaps even, grotesque (Douglas, 1970).

## Chapter 10: Telling the ‘untellable’ stories

Ephemeral plants have a short life-cycle. They can be weeds that takeover land that is disturbed by activities such as farming. They can flower and decorate the floors of forests and woodland paths. In the stories that the women constructed, illness was emplotted into the stories as the weedy ephemeral plants that grow and die, invading and intruding upon fertile land just as illness was invasive, intrusive, and cyclical with periods of resurging or remitting bowel issues (Dancey et al., 2002). In this way illness was emplotted synonymous with Charmaz’s (1991) notion of chronic illness as constituting ‘good days’ and ‘bad days’. Consistent with Kralik et al’s (2004; 2006) research exploring the experiences of women living with illnesses such as chronic pain and depression, the women in the diary emplotted IBS as a lurking presence; a ‘constant companion’ (Kralik et al., 2004:262; Kralik et al., 2006) in daily life; and something ‘Same old same old’, in Maria’s words (see Chapter 7).

The nuanced, personally meaningful and unique stories constructed provided a lens upon the everyday minutia of one week in the life of women leading busy lives, and living with chronic bowel illness. This was possible because of the merits of the largely unstructured diary format lending itself to opportunities for a stream-of-consciousness and self-reflexive style of storytelling. The focus on ‘conversational narratives’ as between the ‘big’ life stories obtained from interview research, and ‘small’ stories generated in conversational analysis, thus provides new directions from which researchers can approach studying

everyday experiences (Ochs and Capps, 2001). I would argue that the research also highlighted this to be advantageous when seeking to engage in ethically involved and feminist research, putting participants in control of their actions and endeavours within research studies.

The narratives constructed were unique and socially situated stories, which makes drawing conclusions about the story data 'challenging' (Sargeant and Gross, 2005:150). For instance, there was no hypothesis tested. There were nonetheless shared 'story-themes' in the diaries that can be discussed.

## Pervasive cultural narratives of perfection

Ogden (2013) conducted research interviewing and surveying children living with the bowel illnesses Ulcerative Colitis and Crohn's Disease (or Inflammatory Bowel Disease, IBD). Ogden noted how the participants accounted for how this as not 'stop[ping] us 'trying' to be 'normal' - though they spoke of normalcy as elusive (Ogden, 2013:80). This positioned illness embodiment as polarized with normalcy, which was also the way in which the women living with IBS in the current research constructed stories. The current research further reinforced the message that living with IBS is perceived as stigmatised and viewed negatively by other people (see for example, Dancey and Backhouse, 1993; Taft et al., 2011). The women's stories were not about the medical experiences, as within past IBS research, set in the healthcare setting, but set in the scenes of the women's everyday lives. In this way

the research generated valuable new knowledge about women's stories of illness and IBS. This was interpreted as couched in accounts of ongoing efforts to 'pass as normal' (Goffman, 1963) to avoid judgment and stigma.

## **Beauty and the Bowel**

Passing and finding ways to avoid the stigma of concealable and invisible illness has been explored extensively within the context of research with people living with HIV/AIDS (Persson and Richards, 2008), chronic pain and headaches (Lonardi, 2007) and people who identify as LGBT+ (see for example, Herek et al., 1996). The current research showed how 'passing as normal' was of relevance within the stories the participants told in their diaries. The research has explored how the women emplotted their bodies as Othered - as 'tummies' and 'the bowel' that were objectified entities that were out-of-control, abject and disruptive. What was especially problematic for the women in the current research was the bloating, loud 'noises' (see Chapter 8), and rush to get to the toilet as having social and gendered implications because of bowels that were uncontrollable. Consistent with arguments by Grogan (2016) and Widdows (in press), the women's stories explored their struggles to meet unachievable body-ideals of slenderness and control. This also meant 'failing' to look 'normal', and 'be perfect', which was taken for granted as something they 'should' be concerned with. In this way, consistent with past research that has been informed by feminist theory, bodily dissatisfaction and negative body images created feelings of body shame (Donezal, 2015). Perhaps

the stories could be said to have been 'dirty tales' (Defenbaugh, 2011) of tabooed illness from the standpoint of being a Western woman.

Ogden (2013) argued that part of the difficulties of living with a bowel illness such as IBD arrives from the messages within contemporary Western societies about bodies and beauty:

Our obsession with bodies within the Western world is apparent when we consume any medium of communication. 'Perfect' bodies...are brandished on advertising boards, within magazines, newspapers, films and television screens and emulated within everyday life by modification of bodies through make-up, dieting, exercising...to obtain as close to the 'ideal' bodily forms as possible. (Ogden, 2013:81)

Ogden argued for the role culture and 'any medium of communication' as playing their part in perpetuating scripts of idealized bodies and perfect bodies. I would argue that the women living with IBS were subjected to these messages, and so felt no more able to resist societal pressures to try to achieve the perfect body 'brandished on advertising boards, within magazines, newspapers' (Ogden, 2013:81) than anyone else. This shows how pervasive cultural scripts of perfection are. Yet as Shildrick (1996; 1997) proposed, femininities and female embodiment can be seen as an ongoing 'collapse of the human itself as a bounded being' (Shildrick, 1997; 2002). In other words, as discussed in the early chapters of this thesis, women's bodies are constantly changing and



this is part of their material realities (Grosz, 1994; Ogden, 2013). The women's stories thus were written in a way that emplotted them as having made sense of their experience by situating themselves both as Western women, and as 'ill people' constructing accounts that aligned their personal and gendered experiences of IBS (Björkman et al., 2013) with feminine embodiment.

### *Monstrous IBS Bodies*

I would add to this that the challenges of embodiment were embedded within contemporary Western cultures that not only privilege 'perfect' looking and behaving bodies, but also embodied selves that are 'fully presen[t]...self-sufficient and rational' (Shildrick, 2002:5). Shildrick (2002) contested the notion of a Western modern subject by critiquing the polarizing of the normal and monstrous, which could be seen in the stories the women told about needing to 'pass as normal'. Illness as chronic and unpredictable is anything but 'rational'. Pain as an embodied experience was emplotted as detracting from 'self-sufficiency' given the nature of embodied experiences of suffering. In this way ideals of a unified and bounded or 'leaky' (Shildrick, 2004) body are false, since all bodies are 'liminal' - never the 'monster' or the perfect, contained, 'normal' body (Shildrick, 2002). Shildrick (2002:1) argued that cultural fascination with 'the monstrous' as Othered within cultural narratives of normalcy are 'a deeply destructive force'. This is connected with contemporary experiences of 'vulnerability, [as] an existential state...[that is] a negative attribute, a failure of self-protection...like the notion of the monstrous largely projected on to

the other and held at bay lest it undermine the security of closure and self-sufficiency' (Shildrick, 2002:1, parenthesis added). Such a theoretical argument implies a way to conceive of just how problematic the polarizing of the normal and the 'monstrous' are, as seen within the women's stories of the personal and cultural positioning of the women's IBS Bodies.

There is a dearth of literature that brings together research exploring the intersections between illness and feminism in disability studies, expanding on the ideas of other feminist-disability scholars interested in chronic illness (Donaldson, 2002; Thomas, 2007b; Driedger and Owens, 2008; Donaldson, 2011; Jung, 2011b). Knowledge about women's accounts of their experiences of chronic illnesses such as IBS in psychology and mainstream health research rarely explore culturally constructed meanings, excluding the sub-disciplines of critical health psychology and community psychology (Stainton-Rogers, 1996; Murray, 1999; Kagan et al., 2011; Horrocks and Johnson, 2012). The valuable messages from the current research will be usefully shared amongst health professionals and clinicians, psychological and health researchers, and disability studies scholars through publishing in journals such as the *Journal of Advanced Nursing*, *Disability and Society*, and the *British Journal of General Practice*. This will ensure the valuable new knowledge about the women's difficulties making sense of the 'monstrous IBS Body' is disseminated more widely than within academia.

## Creative and relational feminist methods

There remains a cultural perception of diaries as a confessional tool where diaries reflect and explore experiences of 'private spheres' (Harvey, 2011), as informed by the 'false' dichotomizing of the public and private setting. In this way utilizing diary methods is not perfect, and constitutes a limitation of the research as excluding some women with perceptions of the 'private' diary, or to whom articulating thoughts, feelings, and experiences into words is difficult. What I surmise is that the mixed-media diary methods were one feature of the current research design that were a powerful way of initiating a dialogue about difficult embodied experiences of suffering in ways less utilised in past.

This leads me to questions of interest within feminist research, such as whether it was indeed possible taking part in the research was emancipatory, or cathartic. Was the experience a positive and empowering one, as other diary researchers tentatively claim (Meth, 2004; Thomas, 2007a)? Wilkinson and Kitzinger (1996) and Miller et al. (2012) suggest it is naïve to presume research has a positive effect on participant's lives, or that it is possible to empower marginalized groups within feminist research. I would agree. However, as Sargeant and Gross (2005:150) argued after conducting narrative research with adults living with IBD, the narrative methodology prompted a dialogue that say 'the life-story interview as a [form of] social action'. I have concluded from the current research that it is not possible to make any assumptions of the research being a positive experience. However, by

devising a methodologically innovative means of analysis via the bricolage concept, this contributed to freeing me as a researcher-as-bricoleur from 'exhaustive preliminary specifications' (Kinn et al., 2012:1287) that were 'unlike linear, step-by-step processes' (ibids). This provided space for play and imagination as part of the analytical process, and thus instigates new conversations within an overly medicalised IBS literature. In this way the research achieved its aims to be experiential and human, adding to the literature that seeks to avoid quantifying human experiences (Schneider and Fletcher, 2008).

As Kinsella (2006) argued creative methods have more power than this as they unpack 'tensions' (Kinsella, 2006:39) and 'resist' (ibid.) dominant discourses in professional practice. In this case, qualitative researchers can challenge the hegemony of the interview as the most prolific means of data collection. Challenging orthodoxies beyond the research and academy, feminist researchers can also utilise creative method to open new conversations about power, ethics, and research involving marginalized groups, such as women living with contested and invisible illnesses. Nothing is taken for granted when approaching research in this way, and this helps to reinforce the case for seeing theory and method as mutually reciprocal, and grounded in women's ways of knowing and understanding the world.

### **Poetry-as-method**

In producing research that adopts feminist epistemologies it is necessary to tackle the 'false' disjuncture between theory and method

and researcher and researched (Maynard and Purvis, 1994; Ribbens and Edwards, 1998). Utilising poetry-as-method and other forms of arts-based inquiries thus invites others to engage in an imaginative and playful means of generating new knowledge (Poindexter, 2002; Kinsella, 2006; Prendergast et al., 2009; Prendergast, 2010; Gergen and Gergen, 2011; Gold, 2013; Taiwo, 2011; Kara, 2015; Owton, 2017). It also arguably provides a platform for resisting taken for granted ways of 'doing' research. The multi-layered analysis with the poetry-as-method (Poindexter, 2002) facilitated an interactive and relational analysis that ensured my embodied engagement (Smith and Sparkes, 2012). It also made the research story as written in this thesis an account that I hope reads more like a 'conversation' (Witkin, 2007:478) between the researcher (myself), the researched, and consumers of the research. In this way I would invite other qualitative and feminist researchers to bring themselves firmly into the research context by utilising imaginative and playful methods that see beyond disciplinary silos and methodolatry (Chamberlain, 2000).

### **Creative disseminating**

I would argue that these arguments about challenging orthodoxies and taken-for-granted ways of doing research extend to the process of dissemination. In this way the approach to knowledge transfer can open up or shut down 'conversation' (Witkin, 2007:478) between the researcher and audience of research information that is disseminated. Bartlett (2012) argued that cartoons are 'a ubiquitous form of visual communication...often overlooked in methodological debates about

dissemination'. Within the research and therapeutic context, cartoons have been shown to be received positively when communicating information about health-related matters, such as how to self-manage IBS (Kennedy et al., 2014). I would agree that cartoons are a powerful form of communication, and they have the added benefit of being implicitly about to be funny or ironic - just as the diaries were at times funny, sometimes in a subtle and ironic way (Bartlett, 2012). Diana's diary was testament to the power of cartoons, and it is an appropriate means of dissemination to carry the message of storytelling through visual mediums by using cartoons. When considering methods of dissemination qualitative researchers can benefit from leaving space for dialogue with the audience by adopting creative tools during all stages of the research process.

For the reader's benefit, two of the cartoons are included that show some of the beautiful artwork that will be incorporated as part of research dissemination. There were many narrative constructions, and so the cartoons will only pick up a few of the story-themes explored within the women's emplotments in their diaries. The cartoons have been produced by illustrator Holly Cruise (<http://hollyzone.co.uk/>).



Figure 6. Cartoon (1) to be used during dissemination of the research findings



Figure 6. Cartoon (1) to be used during dissemination of the research findings

In brief, cartoon (1) explores the embodied experience of one type of bodily sensation (diarrhea, or the frequent need to go to the loo). This was an experience that a number of the women emplotted into stories about their everyday lives, such as Helen's 'dinner party' (Chapter 8).

Cartoon (2) explores emplotments by the women about their everyday lives, within which pain and suffering was at times emplotted into stories of embodied experiences of IBS. This cartoon was inspired by Georgiana's story about her emplotments of feeling 'stressed' and 'on a conveyor belt' one day (see Chapter 8).

## Post-script and reflections

This leads me to consider my experiences of the research process in more detail, answering questions about reflexivity as part of feminist research practice (Miller et al., 2002). I have avoided (and continue to deny) my voice a prominent place in the thesis. It was of greater concern and relevance to the research aims to put the stories of the women living with IBS in the foreground of the research 'story' that is presented. Whilst the PhD submission satisfied the requirements of doctorate examination, it did however highlight just how central my experiences were to the final research product. Far from being objective and distanced, everything about the research project was about 'me', a woman living with IBS in contemporary Western cultures.



My quiet struggle ran alongside completing the PhD, and I have come to see as having been my way of attempting to 'pass' as a 'normal' and able-bodied woman.

Like the other women, the performance of normality was part of my way of making sense of female illness embodiment. Other researchers have conducted auto-ethnographic research around experiences of bowel illness (Defenbaugh, 2008). For me this was too exposing, and distracting from the messages guiding the research process. Yet, the thesis in the form that was submitted at PhD submissions was mixed up with my suffering with headaches, anxieties and pains. In the thesis I have mostly retained in the original form prior to the viva, which conveys some ways that my embodied engagement played out as part of complex entangled wording at times, as well as typographical and formatting errors that have now been amended. I have come to see that this is important in articulating to the reader how the thesis is itself an embodiment and a metaphor for just how challenging it is to keep up the performance of 'normality' as a woman living with a chronic illness.

## Silent heroines, no more

Which stories are your stories? What am I if not for your stories?

Our illness, a dirty secret,  
disguised under layers of grimacing smiles,  
and performing wellness well.

Which stories are your stories? Which are mine?

I feel your pain in my bones, in my bowels,  
in my private howls of anguished, silenced suffering.

Stories told, stories heard,  
are mine, and mine are yours.

I share your shame, I share your guilt,  
of lost friends, life interrupted by gloomy uncertainties.

I have been transformed by your unspeakable taboo tales.

Told by women who no longer deny themselves space  
in a world of encroaching inequalities.

You are silent heroines  
saying silence - no more.

But what stories will others hear of our stories?

Will they hear the the breaks in our voices,  
as we choke on memories of foreshadowed choices.

*This poem was written and inspired by the women participants.*

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## Appendices



# Appendix A

## Details of ethical protocols

This is a copy of the ethical protocols that were planned during the early phases of the research. What is detailed below was included on the application that satisfied the requirements of the Manchester Metropolitan University Research Degrees Ethics' Committee.

### *Process consent:*

The BPS (2010) suggests that researchers are responsible for gaining the informed consent of the people involved in research and provide “ample opportunity” for learning and “understand[ing] the nature, purpose and anticipated consequences” of their research participation. Consent is required on an ongoing basis as the ethical dilemmas posed to participants change during the research. For this reason the term ‘process consent’ (King & Horrocks, 2012) may be a more suitable concept to describe the ongoing *process* of negotiation consent (Eynon et al., 2008). In spite of best efforts, gaining consent is a challenging task for even seasoned researchers. There is always the potential for people to misunderstand information or not ask questions should anything explained by unclear (see for example, Eynon et al, 2008). To minimise the possibility of misunderstandings preventing the women with IBS involved in the study being able to provide process consent the researcher will be in regular contact with the women taking part. The researcher will be contactable over the phone or email from the first point of contact should women have any questions, seek advice or decide to withdraw from the study. Information about what women involved in either phase 1 or phase 2 have to do is provided in different formats (during discussion and in research documents) using jargon-free and concise language that will promote quick and easy understanding of the terms of research participation.

### *Right to withdraw:*

An exemplary of gaining process consent is to provide information to participants about their right to withdraw from research whilst negotiating participation and after data collection. Researchers are ethically obligated to do this whilst making clear that withdrawal from research is possible without impunity (see for example, Willig, 2001). The researcher will communicate this to women taking through explaining on the phone during and after completing diaries (in phase 1) or interviews being held (in phase 2); as well as in the documents distribution. In addition, the caveat with which withdrawal is possible will be explained, which is that the researcher is informed about decisions to withdraw prior to a date (that will provided on the information sheet/ consent forms) as at this point the relevant study phase' analysis will be complete.

#### *Debriefing:*

According to the BPS (2009), the debriefing process provides another chance to read information about the research and gives the researcher an opportunity to check how things have gone for participants. The debriefing process also includes the ethical protocols in place. A 'robust' (BPS, 2013) debriefing processes is especially important within 'internet-mediated' research as the researcher is physically distanced and has fewer visual cues to go on whilst checking in with participants during and after data collection. During both phases the women with IBS will provided with debriefing sheets and the content will be discussed over the phone or at the end of phase 2 interviews. As part of this process the researcher can signpost any women that request more information about resources and 'sources of support', and be reminded of the ethical terms and conditions. By developing a good rapport and maintaining regular contact on phone or email, the researcher will streamline the debriefing process during the phase 2 online, video interviews.

#### *Protecting participants from harm and psychological distress:*

There are a number of ways that the women with IBS taking part may experience discomfort or psychological harm due to their involvement in research. Ken Plummer (2001:210-11) describes how narrative research is a risky endeavour in the hands of an inexperienced



researcher given the delicate nature of the research topic. It is likely the researcher will need to manage the emotional response expressed by women involved in the research when telling the stories about aspects of their lives that they consider meaningful. In addition, women involved in the study (and the researcher too) must make sense of the conundrum of who 'owns' the highly personal 'data' and the emotional impact of the researcher's intrusion (and subsequent extraction) from women's lives once they have been 'coerced' (Plummer, 2001:65) into telling personal narratives (Joselsson, 1996; Kelly et al, 1995).

Should anyone have an adverse reaction to being interviewed or completing their diary, for example women may get very upset, the researcher will handle this sensitively and empathically. It will be emphasised that women only have to talk (or write) about whatever is comfortable and withdrawal is always an option. By maintaining regular dialogue and talking through issues over the phone or in person this will help to work through any adverse effects of being involved in the research. A few suggested 'sources of support' are captured in the debriefing sheet in addition to this.

#### *Psychological distress to researcher:*

It is possible the researcher experiences distress. This may be particularly relevant as an 'insider' who is able to identify with women with IBS. Ways of managing this include the researcher talking to their PhD supervisors within supervision, which is a safe and confidential space for sharing experiences of the research. In addition, the researcher will maintain a 'reflexive diary' (King & Horrocks, 2012:129) so it is possible to actively and critically reflect over their experience of conducting the research. Willig (2001) advocates this type of practise within qualitative researcher as a way of engaging in of 'personal reflexivity' (Willig, 2001:19). This is a valuable way of making sense of the research process and feeds into the analytical process. Narrative researchers emphasise that such note-taking and reflections allows for contextualising the data, which takes the form of co-constructed stories (for example, Flick, 2000).

### *Privacy, anonymity and confidentiality*

Privacy is a basic human right for everyone, including people involved in research. As is stated by the BPS (2010), it is therefore another ethical responsibility of researchers to take measures to treat participants' personal information and data with 'respect' through implementing safety and confidentiality protocols. This includes the secure storage of all data and anonymisation of identifiable information (such as names and addresses) to maintain confidentiality and prevent people discussed being identified, respectively. Maintaining privacy extends beyond this and also includes the researcher fully explaining how data will be used and stored, how and until when. Unless participants consent to the terms illustrated by the researcher and consent to this in writing their data cannot be used in the research (BPS, 2009). These checks on whether women are happy to have their data 're-presented' (Reavey & Johnson, 2008) will be another important part of the ongoing negotiations of process consent beginning from the first interaction with potential research participants.

### *Who 'owns' the data*

Leading on from exploring the ethical issues surrounding participants' privacy, anonymity and confidentiality are questions about who 'owns' the data. It has been argued that researchers should openly acknowledge their conflict of interests with regards to this ethical issue since whilst negotiating how data will be used (and potentially disseminated to a broader audience) with participants (see for example, King & Horrocks, 2012). Narrative researchers may find this especially challenging since their data constitutes stories people construct about their lives. When considered from this angle, Ken Plummer's (2001) assertion that participants would be justified in claiming ownership over their personal stories. What will happen during and after the research to the data and any products of the research (the diary 'document' and any research papers published) will form part of the ongoing dialogue between the researcher and women taking part.

### *Tensions caused by positioning as an 'insider' research*

Feminist researchers address the imbalance of power between researcher and participant in a number of ways, including by situating themselves within the research. As the researcher in this project has chosen to position themselves as an 'insider' (with personal experience of IBS) this raises the important question of how to maintain a respectful, professional distance and simultaneously develop good rapport. The need to be "friendly but not too friendly" (Oakley, 1981:33) remains a 'thorny issue' (Runswick-Cole, 2011) for qualitative researchers seeking to be authentic, although it is arguably necessary when working ethically. In spite of this delicate balancing act, the researcher's decision to construct an insider positionality is necessary so to avoid Othering women and making them feeling deceived and exploited (King & Horrocks, 2012).

### *Storage of data:*

- During recruitment and data collection, the researcher will send and receive emails from their secure MMU email account. The emails will remain stored on here (on secure email servers) for the duration of the project.
- All data will be stored using a file name that does not include any identifiable material, such as names or dates.
- Personally identifiable material obtained during data collection (such as names and contact details) will be stored separately to the raw data. This will be stored for 5 years. The anonymised versions of data will not include any personally identifiable information<sup>2</sup>.
- The researcher will allocate each woman with IBS with a randomly generated code once they have signed a consent form and agreed to take part. Following data collection a pseudonym will be used to anonymise the data (phase 1-written diaries and transcripts of video diaries, phase 2-interview transcripts). The individual codes and pseudonyms will be captured on copies of the consent forms and will not be shared to maintain participants' anonymity and confidentiality.

- Record-keeping entails data being stored on password protected computers. Back-up copies will be saved in encrypted folders or memory sticks for safe-keeping.
- Any raw data - the original version of data generated by the research – will be anonymised so any identifiable information, such as the personal details of the participant and anyone discussed, can be seen. All data is then subjected to a process of being anonymised to maintain anonymity and confidentiality.
- Data will be saved in an encrypted folder using a program called AxCrypt.
- The electronic files containing the signed written consent forms will be stored separately to the raw data in secure encrypted folders.
- Raw data will be anonymised to maintain anonymity and confidentiality of women that take part and anyone referenced in the diaries or during interviews.
- Signed written consent forms will be scanned into the computer using the secure MMU university scanning facilities and destroy the original versions. The scanned copies of the consent forms will be stored in secure and encrypted computer folders for 5 years. Women with IBS will be informed that scanned copies of consent forms will be stored for this length of time at different stages of the research.
- Only processed (i.e. anonymised) data will be printed during analysis. This will be stored in a secure locked cabinet either at MMU or in the researcher's home office when not being used by the researcher.
- All data will be stored on encrypted folders on the computer or using secure memory sticks. Hard copies of data (for example, paper diaries produced during phase 1) will be stored in locked cabinets. For added security raw data will be stored separately to the processed data within secure computer files.

The protocols outlined below apply to the paper diary data:

- Pages of the diaries will be scanned into the computer using the MMU secure scanning facilities. Anonymised versions of the diary data will be made and scanned into the computer. This data will be stored for 5 years, which will be communicated by the researcher to women taking part at different stages of the research.
- (Original) paper diaries will be stored in a locked cabinet until the end of the project when they will be returned to the author if an up-to-date address is available.
- The researcher will return paper diaries will be returned to women with IBS at the end of the project unless an up-to-date address cannot be obtained. Any additional hard copies of data will be destroyed as soon as is possible (in line with the Data Protection (1998) using confidential waste disposal.



# Appendix B

## Research Information Sheet

### **Women's Stories of Irritable Bowel Syndrome (IBS) Project**



#### Phase 1 (Diary study) Information Sheet

Thank you for requesting further information about the Women's Stories of IBS Project! My name is Devina Lister and I am conducting a piece of research exploring women's experiences of being ill with IBS within the context of daily life and personal relationships. Please read carefully through the following information sheet. You are welcome to contact me by phone or email if you have any further questions or if anything is unclear. If you would like to discuss the research with others whilst deciding whether to be involved then please feel free to do so. Detailed on this information sheet over the next two pages are (Section A) the research purpose and aims, (Section B) what you will be asked to do if you choose to take part, (Section C) ethical issues to consider before agreeing to be involved in the research.

#### Section A) Research purpose and aims

It is important for you to understand the reasons why this piece of research is being carried out. Firstly, this project is as part of my PhD at Manchester Metropolitan University (MMU). Secondly, I am a woman with IBS and one of my research interests is the everyday lives of women living with chronic illnesses. I believe women like you are in the best position to talk or write about your experiences of everyday life, your relationships and your health and illness.

You are being invited to take part in a diary study. The Women's Stories of IBS Project has two studies (or phases) overall and the results of the diary study (phase 1) will be used to inform what I ask another group of women with IBS who take part in (an interview study (phase 2). This research aims are:

- *To explore the everyday experiences of illness for women with IBS*
- *To explore the part women's personal relationships play in their accounts of illness*
- *To explore how different research methods can contribute to the way women with IBS talk and write about their everyday experiences*

There has not been much research involving women with IBS talking or writing about their everyday lives, in their own words. This research will add to the pool of knowledge by providing valuable insights into what it means to be a woman like you with IBS, and how this may (or may not) play a part in everyday life and your relationships. The research will also provide insights into how different research methods contribute to how women with IBS talk and write about their experiences. This is important as we now have entered a digital age. There are more digital technologies than ever before that provide us with many ways in which we can communicate with one another as part of everyday life.

#### Section B) What you will be asked to do

If you agree to be involved in the research I will ask you to complete a diary. You can choose one of the following methods of keeping a diary. Please think about which one of the following diary methods you might choose:

- *Writing a one-week diary using a pen and paper*
- *Writing a one-week electronic diary onto a word processor on your computer*
- *Recording a one-week video diary using a webcam and computer*

There is no right or wrong choice of diary methods. These options are provided so you can choose whichever method you prefer or are most comfortable with or find more convenient. We can talk about these options if you decide to be involved in the research. Here is a bit more information about each method.

- *Writing a one-week diary using a pen and paper*



The paper diary option involves writing a diary using a pen and notebook. I will send the notebook by post along with more instructions on what to do and a stamped addressed envelope for returning your diary. If you choose this method I will ask you to please write your diary for seven consecutive days, with a minimum of one diary entry written per day.

- *Writing a one-week electronic diary onto a word processor on your computer*

The electronic diary option involves typing your diary onto your computer using a word processor. I will send you a memory stick and some instructions by post, along with a stamped addressed envelope for saving and returning your electronic diary. As before, I will invite you to do a diary for seven consecutive days, writing at least one entry per day.

- *Recording a one-week video diary using a webcam and computer*

The video diary option is available to you if you can access for seven consecutive days to a Windows (versions 7 or 8) or Apple Mac (OS versions) computer, which has a working microphone, speakers, webcam and USB port. Your Windows or Mac computer usually has a program called 'Windows Movie Maker' (for Windows computers) or 'iMovie' (for Mac users) pre-installed, which is a relatively easy to use program that can be used to record your video diary (one entry minimum per day). Alternatively, the program can be downloaded (for free) from the internet. I cannot lend you this equipment, unfortunately. As with all the diary methods have any questions or run into any technical issues (although please be aware I am not an I.T. expert).

### Section C) Ethical issues and the research

This final section explains my commitment to protect your identity and securely store your 'data'. The term 'data' is being used in reference to your personal information (your name and other sensitive information) and the diary itself. This project has received ethical approval from the MMU Ethics Committee, which

means the university has formally approved the project as being conducted in an ethical way.

*What will happen to your data?*

I will be anonymising your personal 'data'. This means that I will change names to pseudonyms. If you would like to have your real name included in the research this is an option - let me know if this is the case and we can talk about this more. All other personal information (such as addresses or dates) will be changed or removed.

*How will your data be stored?*

The original and anonymised versions of your diary data will be stored securely on a computer for 5 years. This excludes the paper diaries - your diary will be returned (by post) once I have scanned and made copies of the pages in your diary. If you decide to do an electronic or video diary then the data will be stored using secure (encrypted) password protected computer files and memory sticks.

*How will your data be used?*

The anonymous versions of your diaries will be included in the research analysis. Extracts from your diary entries may be included in the PhD research report as a way of providing examples that support the analysis. This will be read by my PhD supervisors and PhD examiners. I may publish articles or give presentations about the findings of the research although please be reassured I will continue to observe our agreement to protect your identity, keep your data confidential and maintain your anonymity.

*Written consent to take part*

If you decide to be involved in the research, I will ask you to please agree to so verbally on phone or email and also be signing a written consent. This is a one page formal document, which asks you if you understand the terms and

conditions of the research and agree to taking part. I will need you to sign, date and return this to me before you proceed with completing your diary. Once I have this I will scan and make a copy of the signed consent form and store this securely on a password-protected computer for 5 years before destroying the original.

*What to do if you want to withdraw from the research*

Finally, you have a right to withdraw from the research (if you agree to be involved) without giving me a reason why. You can do this even if you have signed the consent form and sent it back to me, or if you have completed your diary. Please let me know as soon as possible by phone or email if you decide to withdraw. It will only be possible to do so up until [REDACTED] as by this stage the analysis will have been started.

Thank you for reading!

That is about it for now. I hope everything is clear and that you understand more about the research. Please do not hesitate to get in touch if you would like to talk more about anything or if you have questions. I look forward to hearing from you.

My contact details are (Devina Lister)

Mobile number: [REDACTED]

Email: [REDACTED]





# Appendix C



## Consent forms

There were three templates of the research consent forms produced, which were for the three chosen diary formats, as follows:



### Written diaries (1)

Women's Stories of Irritable Bowel Syndrome (IBS) Project	
Consent form	
Thank you for volunteering to take part in this research. Your involvement is appreciated. Please could you complete the written consent form by ticking the relevant box next to each question. This needs to be signed and returned to me.	
I agree to complete a diary in order to volunteer to take part in the Women's Stories of IBS Project.	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that my signed consent form will be scanned into the computer and agree that this can be stored securely for 5 years.	<input type="checkbox"/> <input type="checkbox"/>
I agree that Devina Lister has explained the research purpose and aims to me and that I have had opportunity to ask questions about the research.	<input type="checkbox"/> <input type="checkbox"/>
I understand that pages from my diary will be scanned into the computer, with names replaced with pseudonyms and any personal informed changed or removed. I have been told that only the written anonymised data in my diary will be used and that visual data that forms part of diary entries (drawings, photos, etc.) will not be included in the analysis.	<input type="checkbox"/> <input type="checkbox"/>
I understand and agree that extracts from my anonymised diary can be used in the research report, which others may read. I understand that there may be publications and presentations of the research in future.	<input type="checkbox"/> <input type="checkbox"/>
I understand that I can change my mind about being involved in the research without giving a reason why. I understand and agree to notify Devina Lister if I decide to withdraw from the research and should do this before <span style="background-color: black; color: black;">[REDACTED]</span> when the analysis will have been started.	<input type="checkbox"/> <input type="checkbox"/>
Would you like your real name used in the research?	<input type="checkbox"/> <input type="checkbox"/>
Please complete the following to confirm you give your consent to be involved in this research:	
Name 	<i><b>please you're your name here</b></i>
Date 	<i><b>please put the date here</b></i>
Thank you. Please could return your signed form to me using the envelope.	
<hr/>	
For the researcher to complete: WRITTEN CONSENT FORM FOR WRITTEN PAPER DIARIES	
Signed .....	
Date .....	

## Electronic diaries (2)

Women's Stories of Irritable Bowel Syndrome (IBS) Project		
Consent form		
Thank you for volunteering to take part in this research. Your involvement is appreciated. Please could you complete the written consent form by ticking the relevant box next to each question. This needs to be signed and returned to me.		
I agree to complete a diary in order to volunteer to take part in the Women's Stories of IBS Project.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that my signed consent form will be scanned into the computer and agree that this can be stored securely for 5 years.	<input type="checkbox"/>	<input type="checkbox"/>
I agree that Devina Lister has explained the research purpose and aims to me and that I have had opportunity to ask questions about the research.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that pages from my diary will be scanned into the computer, with names replaced with pseudonyms and any personal informed changed or removed. I have been told that only these anonymised versions of my diary will be used in the research.	<input type="checkbox"/>	<input type="checkbox"/>
I understand and agree that extracts from my anonymised diary can be used in the research report, which others may read. I understand that there may be publications and presentations of the research in future.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that I can change my mind about being involved in the research without giving a reason why. I understand and agree to notify Devina Lister if I decide to withdraw from the research and should do this before [REDACTED] when the analysis will have been started.	<input type="checkbox"/>	<input type="checkbox"/>
Would you like your real name used in the research?	<input type="checkbox"/>	<input type="checkbox"/>
Please complete the following to confirm you give your consent to be involved in this research:		
Name		<i><b>please you're your name here</b></i>
Date		<i><b>please put the date here</b></i>
Thank you. Please could return your signed form to me using the envelope.		
<hr/> <p>For the researcher to complete:      <i>WRITTEN CONSENT FORM FOR WRITTEN ELECTRONIC DIARIES</i></p> <p>Signed .....</p> <p>Date .....</p>		

## Paper diaries, with visual and textual data (3)

Women's Stories of Irritable Bowel Syndrome (IBS) Project		
Consent form		
Thank you for volunteering to take part in this research. Your involvement is appreciated. Please could you complete the written consent form by ticking the relevant box next to each question. This needs to be signed and returned to me.		
I agree to complete a diary in order to volunteer to take part in the Women's Stories of IBS Project.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that my signed consent form will be scanned into the computer and agree that this can be stored securely for 5 years.	<input type="checkbox"/>	<input type="checkbox"/>
I agree that Devina Lister has explained the research purpose and aims to me and that I have had opportunity to ask questions about the research.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that pages from my diary will be scanned into the computer, with names replaced with pseudonyms and any personal informed changed or removed. I have been told that only the written anonymised data in my diary will be used and that visual data that forms part of diary entries (drawings, photos, etc.) will not be included in the analysis.	<input type="checkbox"/>	<input type="checkbox"/>
I understand and agree that extracts from my anonymised diary can be used in the research report, which others may read. I understand that there may be publications and presentations of the research in future.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that I can change my mind about being involved in the research without giving a reason why. I understand and agree to notify Devina Lister if I decide to withdraw from the research and should do this before [REDACTED] when the analysis will have been started.	<input type="checkbox"/>	<input type="checkbox"/>
Would you like your real name used in the research?	<input type="checkbox"/>	<input type="checkbox"/>
Please complete the following to confirm you give your consent to be involved in this research:		
Name		<i><b>please you're your name here</b></i>
Date		<i><b>please put the date here</b></i>
Thank you. Please could return your signed form to me using the envelope.		
<hr/> <p><i>For the researcher to complete:</i>      <b>WRITTEN CONSENT FORM FOR WRITTEN ELECTRONIC DIARIES</b></p> <p>Signed .....</p> <p>Date .....</p>		





# Appendix D

## Debriefing sheet

2016 was the planned release date

Dear ...

Thank you so much for taking part in this research, which is being carried out as part of my PhD. This debriefing sheet will briefly outline what impact your participation in the research could have, some resources and sources of support and a reminder about the ethical issues of relevance to you.

Your involvement in this research may enhance current understanding about the everyday lives and personal relationships of women with IBS. Your willingness to take part will enable innovative research to be produced that explores how women with IBS tell their stories of illness in different ways. This knowledge can be used to inform the design of future research.

The research aims are:

- *To explore the everyday experiences of illness for women with IBS*
- *To explore the part women's personal relationships play in their accounts of illness*
- *To explore how different research methods can contribute to the way women with IBS talk and write about their everyday experiences*

I really hope that you enjoyed taking part. Here are a few suggested resources that may be useful to you if you would like to access sources of support and read about others' experiences of IBS.

- The UK based charity The IBS Network (<http://www.theibsnetwork.org/>) has an excellent website with lots of useful information and a helpline.
- Online support forums provide a space for 'talking' to other people with IBS and sharing information about self-management of IBS. For example, it is easy to join 'The IBS Group' support forum (<http://www.ibsgroup.org/forums/>) and there are many Facebook groups.
- Your local health professional can provide support and guidance.
- I am not a trained health professional but you are very welcome to talk to me over the phone, video call or email.
- As a side-note, I would recommend reading about other women's experiences of living with IBS in texts such as 'Sophie's Story' by Sophie Lee or her blog 'IBS Tales' <http://www.ibstales.com/>

Finally, I'd like to reassure you that your data will be stored securely and personal information of any kind will remain confidential and anonymous. If you change your mind about being involved in the research you have until [REDACTED] to do so, just send me an email or call to let me know of your decision and I will take your diary data out of the research and securely destroy it.

If you have any further questions at all please do get in touch by email. I will let you know the findings of the research in 2016, unless you would prefer not to receive this information.

Once again, a sincere thank you for your time and commitment whilst involved in this research.

*Thank  
you*

Devina Lister (tel) [REDACTED]

# Appendix E

## Written diary instructions

### What to include in your diary:

*'Please write one diary entry per day (minimum) for 7 days in the notebook provided.'*



(Your diary)

This is your diary, so please write about whatever is relevant and meaningful to you when thinking about your day-to-day life.

You can do more than one diary entry per day if you want to.

Please use a pen (any colour) but not a pencil. You can use the correction fluid I have sent you to delete and edit what you write before sending back your diary if you want to.

The length of each diary entry is up to you. You could try to write at least one page per diary entry, or just write as much as you can in the time you have available.

It would really help me if you could please type the date or the day of the week at the beginning of each diary entry. If you would not mind doing so please could you also introduce people you talk about when you first mention them: (for example) *Georgie, my grandpa.*

Please feel free to be as open as possible and please, you do not have to worry about spelling and grammar. I am so interested in looking at the meanings you attach to your experiences.

If you want to talk more about what to include in your diary please do feel free to contact me. I'll call during the week to check things are going ok.

I hope you don't mind but I was planning to send you a daily reminder asking you to please do each entry. This will just be a short text or email reminder.

**What to do once you've finished your diary:**

*Once you have completed your diary, please send it back to me in the stamped addressed envelope.*

I will return your diary to you once I have scanned and made copies of the pages, which will have any personal information removed or changed.

If you change your mind about being involved in this research, please do let me know as soon as you can. I can take your diary out of the research up until 15<sup>th</sup> November 2015 as after this date I will have started the research data analysis. Any questions please do not hesitate to get in touch!

## Appendix F

### Post about the research shared in the online IBS support group

Facebook post (1)

'(As many of you know) I'm doing a PhD about the everyday lives and relationships of women with irritable bowel syndrome. If you, or a woman you know, may be willing to talk, write or type about their life *and are willing to be* involved in IBS please do get in touch!

You can email me (in confidence) [at] [REDACTED] for a very informal chat. The country where women are based does not matter.

Be ever so grateful if you could please spread the word and share via your fb and offline networks. Thanks!'

(1 Sept 2014)

Facebook post (2).

'Hi all, just another request for any women with IBS to please let me know if they might be interested in being involved in my research exploring the everyday lives and relationships of women like you. You can contact me for a really informal chat about it by phone (tel. [REDACTED]), via Fb message or email [REDACTED]

If you've done so (and thank you ever so much if you have!) please could you share via your networks offline and online. Thanks!

(12 Sept 2014)