

# Digesting Stigma:

Exploring the Illness Experience of New Zealanders with Irritable Bowel Syndrome.  
(‘It’s just shitty’)

By

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## Abstract

This thesis is an anthropological exploration of Irritable Bowel Syndrome (IBS), and the first ethnographic study of people with IBS in New Zealand. It explores the illness experience of people with IBS and whether stigma plays a role within this experience. IBS is a gastrointestinal illness that affects 10-20% of New Zealand's population. However, its aetiology is unknown, there is no cure, and the biomedical approach that informs its diagnosis and treatment is often incongruous with its lived experience. I posit that the illness experience of my participants and what is stigmatising for them must be understood not only in relation to its physical manifestations but also in relation to the biomedical and neoliberal influences that inform social expectations of the body and social participation. Further, participants experience their IBS simultaneously resisting and participating within these influences to make sense of and manage their illness in a way that aligns with their lived experiences.

All work within this thesis is my own except where otherwise stated.

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# Chapter One

## Introduction

Responses to the online survey began to fly in. This was the beginning of my research and it was starting on a positive note. I was not expecting this. As the surveys were completed I read each one with intrigue, thinking about the commonalities across their responses and the many directions this research could take. People were eager to talk about their illness, sharing their experiences of Irritable Bowel Syndrome (henceforth IBS) and how it impacted their lives. In the first two days of responses my research began to feel like it was coming to life; I had been give direction and participants were leading me with their experiences and narratives. Some of the responses that helped me develop my research included:

*Are you comfortable telling others about your IBS?<sup>1</sup>*

No. I don't like talking about it as I find the symptoms (diarrhoea, bloating, flatulence etc.) embarrassing to discuss. I am often surprised by how nosey people are - virtual strangers press me for the details and it's really awkward. This is often in relation to my food choices. For example, if someone notices that I am not eating a slice of birthday cake, they will ask why and then say, "what will happen if you eat it?". I provide vague answers (such as, "I get sick") and try to change the subject.

Survey respondent A

It's taken me a long time to be comfortable enough to talk about it as I used to not tell anyone. I was also aware of others thinking I was making it up, the stomach pain that is. Because if you don't look sick some people think you're fine. I'd like to make it a more talked about issue for people, especially for youth. There wasn't much information out there when I was diagnosed.

Survey respondent B

*Has IBS affected your life? If so, how?*

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<sup>1</sup> This question and the one below are from the anonymous online survey that began my research. The written responses below each question are from individual respondents. See page 25 for a discussion of the survey and page 101 for the survey.

Yes. Having an upset stomach sucks. Not being able to wear a certain outfit because your belly is as big as a whale, trying to fart casually in public because the pain is so bad and you pray it isn't loud, living in fear of, is it a fart or a poop? Not being able to go to any old restaurant, not being able to eat aioli!!! Not being able to go out and have fun because you are in so much pain, feeling depressed because you ate the wrong thing. Having your mum constantly sending you articles about how it could actually be something else, having your mum talk to you about fecal transplants... It has put a strain on my relationship with my mum because I know she wants to help but it is just frustrating.

Survey respondent C

These responses exemplify the frustrating, intrusive and complicated nature of IBS. Individuals experience the challenges of this chronic illness in differing ways, yet they share a frustration with how society, individuals, and institutions understand, interact with, and make judgements and assumptions about their illness. IBS not only impacts an individual physically but also mentally and socially (Bertram et al. 2001). It was these types of narratives that sparked my interest in IBS. The self and the body are in tension every day for people with IBS. Additional aspects of stigma associated with this illness arise in a rapidly changing society influenced by biomedical and neoliberal values which shape social expectations of the body and social interaction.

In this thesis, I explore the illness experience of people with IBS in New Zealand and any role stigma plays within these experiences. It is the first ethnographic study of people with IBS in New Zealand (which to date has been focused in gastroenterology and medical sciences (see, for example, Talley, Howell, and Poulton 2001; Barbezat et al. 2002)), and the first anthropological study solely focused on IBS internationally. It examines the narratives of five people and 44 survey respondents with IBS in New Zealand. I argue that the illness experience of IBS and that which is stigmatising for my participants must be understood not only in relation to its physical manifestations but also in relation to the biomedical and neoliberal values that inform social expectations of the body and social interaction. By exploring the narratives of people with IBS it became clear that the physicality of the illness though an important component, was not the only aspect that informed illness experience and stigma. Participants illustrated the ideological, institutional, and social aspects of life within New

Zealand that collectively informed their experience of IBS. My participants often identified ways in which they simultaneously resisted, perpetuated, and participated in the expectations and norms that developed from biomedicine, neoliberalism, and historical and cultural understandings of the body, illness and social interaction. The stigma that my participants experienced in relation to their illness permeated many aspects of their lives causing a sense of deviance.

IBS is a gastrointestinal illness that affects 10-20% of New Zealand's population (Health Navigator New Zealand 2016). The aetiology is unknown, there is no cure, and the biomedical discourse that surrounds IBS is incongruous with its lived experience. People who experience IBS often feel isolated from society due to its disruptive symptoms and the stigma associated with uncontrollable bowel habits and its unknown aetiology (Jones et al. 2009, 368; Dancey et al. 2002, 383). When beginning to think about the research questions for this thesis I was focused on researching the stigma and shame involved in the experience of IBS and how the mind-gut connection<sup>2</sup> was perceived by those who had this illness. However, I wanted to keep my research questions broad in case these were not topics that my participants chose to talk about or were my own assumptions about the syndrome. My initial research questions were; how do Irritable Bowel Syndrome sufferers experience their illness at a personal, social and cultural level within New Zealand? What can an anthropological approach contribute to understandings of these experiences?<sup>3</sup> Frustration was a key component in all narratives and permeated every level of the respondents' illness experiences. This included frustration with the assumptions and misunderstandings about IBS; frustration with their own body; frustration with family, friends, and physicians; frustration with social expectations and pleasantries; and frustration with biomedical institutions and the process of diagnosis and treatment. It became clear that this frustration was partially perpetuated by the social stigma that surrounds an illness associated with uncontrollable bodily functions, and being chronically ill with no known aetiology, thus being deviant to social expectations. With these themes coming to light across many of the survey responses, my research focus shifted toward examining what informs the illness experience, as well as what is stigmatising for people with IBS.

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<sup>2</sup> The mind-gut connection, also known as the brain-gut connection, encompasses a new interest within biomedicine that seeks to understand how the gut could be affecting the brain, with the gut now being considered a second brain. In examining how the brain and gut interact we can further understand how functional gastrointestinal disorders like IBS work (Jones et al. 2006).

<sup>3</sup> Although additional questions arose during the research in response to participants experiences these remained considerations within my research.



I investigate the experience of IBS and focus on the personal, social, ideological, and institutional factors at play; responding to Scheper-Hughes and Lock's (1987, 30) call for anthropological research to break down the Cartesian dichotomies of biomedicine and investigate the emotional, social and political sources of illness and healing. I consider how the turbulent history of IBS within biomedicine and the uncertainty of its diagnosis has instigated stigma at the most primary level of understanding IBS. If those experiencing IBS symptoms also experience uncertainty from physicians, family, friends and even themselves at the initial concerns over symptoms, then it may be that stigma and delegitimation are among the initial experiences when seeking help. It is important to understand not only the illness itself but what the symptoms, diagnosis and treatments mean for day to day life.

This thesis contributes to the research within medical anthropology that focuses on the experience of chronic illness. Research on the stigma associated with IBS and experienced by those who have this illness has previously been conducted within areas of psychology, gastroenterology, and quality of life research (see, for example, Dancey et al. 2002; Jones et al. 2009; Toner and Akman 2000; Taft et al. 2011). Such research is only partially focused on the lived experience of those with IBS, as stigma can only be measured through their experience of it. Data is often collected through questionnaires and participants' responses are analysed using statistical analysis, with little of their lived experience being present in findings, discussions, and conclusions. An exception to this is some research within *The Journal of Family Practice*, where interview methods have been used and participant narratives are occasionally used within data presentation (see, for example, Bertram et al. 2001; Casiday et al. 2009). Though IBS has not been specifically researched in medical anthropology it is named throughout medical anthropological and sociological research that focuses on chronic illness, medically unexplained symptoms, diagnosis, and stigma (see, for example, Nettleton 2006; Jutel 2010; Buchbinder 2011; Olson and Abeysinghe 2014).

## **Situating the research**

As people who have IBS experience their illness through their bodies, social interaction, and social expectations, it is important to understand not only the social reactions such as stigma to an illness but also what informs how the illness is experienced in relation to the institutions and

ideologies that are dominant within New Zealand society: in this case biomedicine and neoliberalism. The gut has often been overshadowed in biomedicine, and disciplines that study biomedicine, by supposedly more crucial organs such as the brain, heart and lungs (Enders 2015, 9). However, a recent surge in research on the gut and its link to the mind has instigated greater understanding of just how important the gut is to human life and function (Enders 2015; Vanner et al. 2016). Medical anthropology has played a role in these recent investigations due to its interest in ‘the interaction between the body and its social and cultural setting’ raising questions of the broader aspects of the gut such as personal experience (Fortin, Gomez, and Gauthier 2013, 72). Understanding the mind-gut connection in IBS is crucial to understanding how the illness is experienced. Though little is known about the illness psychological treatment of IBS when medical treatment has failed can be effective (Gerson et al. 2006, 2845). This supports the knowledge that IBS is a mind-body condition in which all aspects of illness must be considered rather than just physical symptoms (Gerson et al. 2006, 2845). In understanding IBS, we also need to understand how the gut affects mind and body and in turn how the mind and body then interacts within society differently due to illness. It is important to understand not only illness itself, but what the symptoms, diagnosis, and treatments mean for day to day life. I explore the personal experience of IBS drawing understandings less from a biomedical lens and focusing on the social and institutional factors at play. I examine biomedicine through the experiences and perceptions of my participants.

Medical anthropology lies on the intersection of the social and natural science and is concerned with biological and sociocultural phenomena particularly in relation to health and disease (Helman 2007, 7). In this thesis, I draw on and contribute to the literature that focuses on lived illness experience, the body and illness (see, for example, Good 1994; Charmaz 1995, 2002; Garro 1992; Dumit 2006; Jackson 2005; Lock 1993; Scheper-Hughes and Lock 1987), biomedicine and neoliberalism (see, for example, Trnka and Trundle 2014; Nettleton 2013), and stigma (see, for example, Yang et al. 2007; Ablon 2002, 1981).

I adopt an interpretive, experience-near approach that emphasises the analysis of people’s narratives about their illnesses, and aim to provide an ethnography of IBS in which my participants illness experience is recounted through their narratives, in order to understand more closely the individual experience of such an illness. The term experience-near was developed by Kohut, a psychoanalyst, and later adopted and described by Geertz (1983, 57) as a concept that ‘someone – a patient, a subject, in our case an informant – might himself

naturally and effortlessly use to define what he or his fellows see, feel, think, imagine, and so on, and which he would readily understand when similarly applied by others’.

In his 1988 book, *The Illness Narratives*, Kleinman expanded this concept to emphasise the importance of understanding and examining how people make sense of illness experiences through narratives. He also pointed out that the stories people tell about illness provide insight into how they experience illness. An interpretive approach places the relationship between culture and illness at the forefront of analysis in anthropology and focuses on embodied experience as the basis and problematic of illness representations (Good 1994, 55). The interpretive approach emphasises the importance of producing experience-near accounts which make the body present in illness (Good 1994, 55). By paying close attention to narratives we can produce these experience-near accounts, and this allows an explanation of the relationship between sickness and conflicts in the social world, illustrating where these conflicts occur and how symptoms are experienced as troubling due to their impact on social relationships (Brown and Closser 2016, chap. 1). Many scholars have discussed the importance of illness narratives particularly in understanding the experience of chronic illnesses (see, for example, Garro 1992; Charmaz 2002; Good 1994; Kleinman 1988). Narratives are not just stories about what has, is or could happen but are also representations of how people ‘attempt to negotiate or construct both individual selfhood and social relations’ during their illness experience (Brown and Closser 2016, chap. 1).

As well as approaching the research from an experience-near and interpretive perspective, I also utilise an approach to medical anthropology that studies biomedicine as a system of knowledge and social practice (Brown and Closser 2016, chap. 1). By studying biomedicine, the medical anthropologist is able to uncover the epistemology of scientific and medical knowledge as well as how these forms of knowledge gain power as authoritative knowledge rather than beliefs (Brown and Closser 2016, chap. 1). An example of this approach can be found in Scheper-Hughes and Lock’s (1987) article, *The Mindful Body*, that examines a crucial component of biomedicine; that the mind and body are separate entities. Scheper-Hughes and Lock (1987, 10) argue that the hegemonic power of biomedicine and its fundamental concept of mind/body dualism has diminished the ability to understand and express the myriad of interactions that happen between the mind, body, and society.<sup>4</sup> Trundle, Singh, and Bröer

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<sup>4</sup> This is discussed further in Chapter Five.

(2014) provide an excellent examination of when biomedical knowledge is questioned and contested in their chapter, *Fighting to Be Heard*. The chapter explores the experience of people who encounter conflict during the phases of diagnosis within biomedicine and offers a critique of medical and scientific authority (Trundle, Singh, and Bröer 2014, 179). These examinations and critiques of biomedicine highlight the alternative way in which illness, mind, body and society interact and can be understood, breaking free from the binds of a hegemonic biomedical model and exploring the lived experience of illness. Many other anthropological and sociological scholars have studied biomedicine through chronic illnesses highlighting the gaps in medical and scientific knowledge which people with chronic illnesses and medically unexplained symptoms fall through resulting in frustration, delegitimisation and stigmatisation (see, for example, Jackson 2005; Glenton 2003; Nettleton 2006; Dumit 2006). By studying biomedicine and how people interact with and within it, we can shed light on how it influences illness experience.

In combining an interpretive approach, and an approach that analyses biomedicine as a system of knowledge and social practice, I examine how my participants experience their illness within a society dominated by a biomedical model, and where stigma arises due to interaction within this biomedical model and social expectations and understandings of the body. My participants' narratives allow me to study how biomedicine has informed their illness experience whilst also being incongruous with it. In much the same way, I also explore how neoliberal values have informed my participants' experience of IBS in conjunction with biomedicine. Biomedicine and neoliberalism will be discussed later in this chapter and will highlight the social expectations of the body, social interaction, and societal participation they create. By studying the people who experience IBS using these approaches my participants shed light on how IBS is experienced in New Zealand and where stigma arises within this experience.

### **Body and illness**

Scheper-Hughes and Lock (1987, 7-8) suggest that the body can be viewed and understood from three different perspectives. Firstly, as the 'individual body' phenomenologically experienced, which assumes that everybody must have some sense of the embodied self as being apart from other individual bodies; secondly, as a 'social body' that refers to the body as a natural symbol with which to think about nature, society, and culture; thirdly, as a 'body

politic' which refers to the regulation, surveillance, and control of bodies both collectively and individually in reproduction, sexuality, work, leisure, sickness and other forms of human difference. In understanding and viewing the body in these three separate yet overlapping ways we can analyse how certain kinds of bodies are socially produced and how individual bodies are experienced within different societies. Scheper-Hughes and Lock (1987, 7) further state that the 'body in health offers a model of organic wholeness' while the 'body in sickness offers a model of social disharmony' highlighting that the body can be studied to understand society and society can be studied to understand the body. I refer to these three bodies throughout this thesis to analyse individual experience of the body as well as the interaction between the body, society, biomedical institutions and neoliberal forms of regulation, and like Scheper-Hughes and Lock, I illustrate that bodies carry social meaning.

Lock (1993, 134) calls into question the truth claims of medical and epidemiological sciences in her article, *Cultivating the Body*, and examines how the body has been theorised by various anthropologist that situate the body as a product of particular social, cultural and historical contexts. In doing so she aims to move toward an improved dialogue with scientific knowledge while also remaining alert to universal truths, entrenched power bases, and intransigent relativisms. Lock (1993, 135) states that anthropological research has illustrated how the body is inscribed with social categories, noting that these inscriptions are 'prescriptions about bodily fluids, cosmetics, clothing, hair styles, depilation, and ornamentation' which act as signifiers of local social and moral worlds. In completing a review of the anthropological literature theorising the body, Lock (1993, 134; 148) states that we should resist all pressures to produce tidy answers about the body, remain eclectic in our approach, being content with the body as a fluid, elusive, and uncontrollable, and instead highlighting its infinite complexity. Lock (1993, 136) challenges the biomedical objectification of the body, stating that people both have and are bodies and that subjectivity cannot be ignored when thinking about the body.

Much of the literature on chronic illness is focused on the physiological aspects of chronic illness management however anthropologists have been making important contributions in expanding this literature to understand the social and cultural dimensions (Hunt and Arar 2001, 347-348). Research developed from an anthropological perspective is now being used in clinical literature and teaching with resulting benefits to conceptualising and developing effective treatment regimes and to decrease the delegitimisation of illness.

Within the biomedical model the body is primarily considered a physical object that can be subject to illness and can be treated through scientifically tested medical applications (Womack 2010, 12). This approach considers ill health to be a process whereby objects (the body and organs) can be understood and treated within defined categories of diagnosis and associated treatments. Clearly this does not account for the fact that ill health is influenced by individual experience and social and cultural factors. Good (1994, 116) suggests that we take an alternative anthropological approach when trying to understand the body and illness, stating that:

For the person who is sick, as for the clinician, the disease is experienced as present in the body. But for the sufferer, the body is not simply a physical object or physiological state but an essential part of the self. The body is subject, the very grounds of subjectivity or experience in the world, and the body as 'physical object' cannot be neatly distinguished from 'states of consciousness.' Consciousness itself is inseparable from the conscious body. The diseased body is therefore not simply the object of cognition and knowledge, of representation in mental states and the works of medical science. It is at the same time a disordered agent of experience.

This highlights the disconnection between experiencing and observing an illness. For those who experience illness their understanding of its aspects and effects are drastically different from those who are told about an illness and its symptoms precisely due to the latter's inability to experience the illness in the same way as the former. Good (1994, 117) notes that for some conditions the objectivist rendering of the body by biomedicine has provided benefits but in many cases and particularly in relation to chronic illness it has created a distorted form of medical practice, which abstracts 'the world of physical objects and physiological processes from social and meaningful phenomena'.

I investigate the experiences of people with IBS using Good's (1994) framework of understanding illness, however, it is also important to keep in mind how biomedicine and those who interact with it generally understand the body and illness. Jackson (2000, 145) notes that medical professionals, particularly those involved in public health medicine, do not engage enough or usefully with that which anthropology might offer. She states that if anthropology is the study of humans and how we interact with each other and our environment, and medicine involves the meanings of health and ill health as well as science, then medical professionals should be aware of how societies are structured and how different groups of people understand

and address illness and disabilities (Jackson 2000, 145). Biomedicine offers a partial analysis of illness and aims to gather facts and regularities of nature that can be considered universally affecting all humans in the same way (Lewis 1993, 191). These definitions illustrate how a combination of an anthropological and biomedical approach could work together to benefit our understanding and knowledge around how ill health is experienced in different contexts. It might also shed light on illnesses that do not conform with and/or challenge a biomedical approach.

IBS is one such illness, it moves in and out of a biomedical framework and will benefit from an anthropological analysis alongside a biomedical one. Good (1994, 117) illustrates how chronic pain, a common symptom of IBS, challenges the foundation of biomedicine – ‘that objective knowledge of the human body and of disease are possible apart from subjective experience.’ Chronic pain cannot be understood by separating physical objects (the body) and mental states, therefore a biomedical approach to understanding this condition essentially renders it unintelligible and may lead to problems in diagnosis and treatment (Good 1994, 117). Biomedicine traditionally tends to view the body’s many organs as unrelated objects and this creates difficulty when illness involves multiple organs within the body and is affected by environmental and social factors (Womack 2010, 12). The body is a complex organism in which all parts interact, and it is also part of the larger organism which we call society (Womack 2010, 12). Douglas (1970, xxxvi) argues that the body is the most accessible reflection of a social system. The social body establishes how the individual physical body is understood and scrutinised and in turn sustains a particular view of society (Douglas 1970, 74).

### **Biomedicine and neoliberalism**

In their editorial note, *Is the 21<sup>st</sup> century the age of biomedicalisation?*, Moyer and Nguyen (2017, v) highlight how biomedicine, as a now global medical model, has changed the way human bodies are understood, categorised, and treated noting that this is clearly visible in struggles over health care access, medical treatment, legal rights, and medical authority. My participants have sought diagnosis and treatment within this biomedical system, which is now the dominant medical model in New Zealand (Deed 2007, 28). Though their core engagement has been with biomedical practice in seeking treatment for their IBS symptoms, when there has been little success they have turned to alternative therapies often creating a personalised mixture of multiple treatments from a variety of medical, alternative medicine, psychological,

social and spiritual systems and practices. Biomedicine is legitimised as the dominant health model both politically and socially, and dates from the Enlightenment, a European intellectual movement during the late 17<sup>th</sup> and 18<sup>th</sup> centuries (Macdonald and Park 2005, 91).

Nettleton (2013, 226) posits that a defining feature of health care in post-industrial nations is the grip of neoliberalism and its emphasis on choice, responsibility, individualism, commercialism, and competition. Rose (1996, 150-151) highlights that countries such as Australia, Britain, and New Zealand have transitioned from welfare states to neoliberal societies, removing the responsibility of the government for the well-being of its citizens, and instead placing increased responsibility on individuals to maintain their own social, economic, and somatic well-being (Rose 2001, 6). Rose (2013, 249) highlights that this responsibilisation can have negative effects for individuals often placing unwanted roles and social obligations upon them, setting expectations which must be met to be part of society.

Neoliberalism started as an economic policy in which a free market valorises individual contribution with little institutional oversight (Navarro 2007, 9). Although it is at its core an economic policy, ideology will always impact the body, medical systems, health, and social expectations (Helman 2007, 96). Within an economic policy such as neoliberalism the body is understood as part of a system in which bodies produce labor and production. Thus, in a neoliberal context, the body is expected to be able to produce as efficiently as possible and be as healthy possible to provide optimal and continued profit (Ayo 2012, 101). The promotion of a healthy lifestyle now pervades Western neoliberal societies and encourages social values such as prudence, hard work, responsibility and asceticism (Ayo 2012, 101). Inhorn and Birendaum-Carmeli (2010, 94) highlight how the neoliberal values of individual rights, choice, and freedom invests the individual with increased responsibility for their health and illness and develops an expectation for the individual to care for themselves and always work toward a better quality of life. Trnka and Trundle (2014, 136) explore and discuss the ‘modes of responsibility that extend, challenge, or co-exist with neoliberal ideals’ and broaden understandings of how neoliberal responsible subjects are situated within multiple structures of dependencies, reciprocities, and obligations. They therefore highlight that within neoliberalism, there is not only individual responsibility, but also responsibilities for others (Trnka and Trundle 2014, 150). In doing this they highlight how neoliberal values of individual responsibility co-exist with other forms of responsibility that people navigate in society.



Though the idea that we need to be responsible for our own well-being seems important, it also provides a trap in which people are obliged to take on this role of sole responsibility and so become subject to new expectations of ensuring that their bodies are healthy and that they can manage the consequences of choices about health care (Rose 2013, 349). This creates understandings of the body which then inform society's view of how a body should function to meet social obligations and expectations. People are constantly challenged with problems of how to maintain a healthy body when daily life requires more and more demanding workloads and social pressure to produce. To be of value to others we feel like we must function as expected and it becomes increasingly hard to ask for help from others when it is needed due to these societal pressures.

## Stigma

Brown and Closser (2016, chap. 1) note that stigma is a central theme in ethnographic descriptions of people who appear different or deviant and who are often subjected to negative judgments, assumptions, and discrimination from others. Goffman's (1963) work in, *Stigma and Social Identity*, was the defining point for understanding how stigma is developed in society and in particular how it categorises people in relation to medical social science.<sup>5</sup> Goffman (1963, 3) defined stigma as 'an attribute that is deeply discrediting' to an individual and that the stigmatised is 'reduced from a whole and usual person to a tainted, discounted one'. Medical anthropologists have since developed the understanding of stigma in relation to medical conditions highlighting where stigma arises as follows:

... the nature of an illness, its history, and attributed characteristics; sources of the creation and perpetuation of stigma; the nature of the populations who are perceived to carry the illness; the

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<sup>5</sup> The term stigma originated in Ancient Greek society. For the Greeks stigma referred to 'bodily signs designed to expose something unusual or bad about the moral status of the signifier' (Goffman 1963, 1). Goffman (1963, 1) notes that these bodily signs were often branded into the body as a way to advertise that the person was blemished, polluted, and to be avoided particularly in public places. In Christian times the meaning of stigma evolved being attributed two new aspects: firstly, it was referred to as a sign on the body indicating the touch of 'holy grace' (stigmata); secondly, stigma referred to the bodily sign of physical disorder developed from medical knowledge (Goffman 1963, 1). How the term is used today has developed to refer also to the disgrace of disorder, and deviance, rather than solely the bodily evidence (Goffman 1963, 2). Goffman further notes that changes have occurred in the kinds of disgrace that arouse stigma and concern. Here I suggest that the biomedical model and neoliberal policy that permeates New Zealand society have shaped what is considered disgraceful in terms of my participants' illness experience along with the social expectations placed on the body today. Thus, replying to Goffman's (1963, 2) statement that 'students, however, have made little effort to describe the structural preconditions of stigma'.

kinds of treatments and practitioners sought for the condition; and how individuals with stigmatised medical conditions cope with societal insults that endanger their personal identity, social life, and economic opportunities (Ablon 2002, S2).

This quote illustrates the many ways in which a medical condition can be stigmatising and emphasises that stigmatisation is not solely in relation to a physical mark but also in relation to how a particular illness is managed and understood.<sup>6</sup> Ablon (2002, S4) states that stigma can be created and perpetuated through negative attitudes, assumptions, judgments and statements by family, friends, physicians and other medical practitioners as well as via the 'larger social context of public opinion and values'.

Kleinman and Hall-Clifford (2009, 418) outline how the concept of stigma has undergone important shifts in both definition and characterisation since Goffman's work in the 1960's. They argue that 'the study of stigma has focused too heavily on psychological approaches and has neglected to sufficiently incorporate understandings of stigma and stigmatised individuals as embedded in local moral contexts' (Kleinman and Hall-Clifford 2009, 418). This thesis answers the call that they make for an anthropological contribution to the study of stigma that seeks to understand 'the unique social and cultural processes that create stigma in the lived worlds of the stigmatised' (Kleinman and Hall-Clifford 2009, 418). They state that this should be the first step towards combating stigma, and argue that in examining how values enacted in people's lives affect stigma, we can develop more effective ways to instill anti-stigma interventions (Kleinman and Hall-Clifford 2009, 418).

The uncontrollability of bodily functions such as bowel movements, and a close relationship with excrement, are central components of IBS which make those who have IBS subject to stigma. In Douglas's (1966) book, *Purity and Danger*, she discusses the power of pollution beliefs within society through the concept of hygiene. Her discussion of how bodily functions such as bowel movements are often seen as taboo or dirty, providing some form of social status relegation for anyone associated with a lack of control of this function is particularly relevant to this thesis (Douglas 1966, 122-125). As Douglas (1966, 2) notes, dirt is disorder and matter out of place, yet what is dirt only exists in the eye of the beholder. Van der Geest (2007a, 381)

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<sup>6</sup> For further discussions of the nature of stigma and medical conditions see, Jackson 2005; Yang et al. 2007; Kleinman and Hall-Clifford 2009.

states that the concept of dirt allows people to create order in their lives, and its classification illustrates how such order is constituted as well as where moral boundaries lie in relation to it. Excrement for many cultures is seen as dirty and polluting particularly when considered out of place, and the act of excretion is seen as private and taboo even though it is a part of daily life for all humans. Van der Geest (2007a, 381-382) also notes broadly that people who are associated with dirt are often subject to disgust from others and that excretions from the body constitute the most strongly felt 'matter out of place'. Van der Geest (2007b, 75) suggests that the lack of interest in studying defecation as a way to understand cultures stems from anthropologists' own culture as they themselves seem restrained by codes of morality stopping them from speaking and writing openly about 'such dirty and childish matters as human defecation'. Admittedly I myself even avoided writing too much about this important aspect of IBS to begin with though my conversations around bowel movements and faeces with participants were common, relatively comfortable, and dotted with laughter. Loudon (1975, 2) notes that there is no human society in which excreta and the act of excretion is not subject to social arrangements in which boundaries and expectations are developed. In highlighting the boundaries and expectations around excrement that are engrained in society we can understand how an illness such as IBS can become subject to stigmatisation when it is seen to cross these boundaries and expectations.

Jackson's (2005, 332) work on stigma, liminality, and chronic pain provides a useful framework for understanding how the body and illness can provoke stigmatising reactions in others, and how people experiencing illness can be seen as threatening social order. She focuses on the stigma that results from chronic pain due to it being an unexplained medical problem with varied treatment. IBS is similar and often also involves levels of chronic pain within the symptoms experienced. The causes of IBS are unknown and treatments are aimed at managing symptoms rather than resolving them. These are aspects of IBS that have developed stigma from family, friends, medical staff and individuals themselves (Taft et al. 2011). The uncertainties and symptoms of IBS have the potential to develop stigma but what role does societal constructions and expectations play in creating stigma? This will be explored throughout this thesis.

The concepts within the literatures discussed in the above section interact in various ways within my participants' narratives and experiences of IBS as evident throughout this thesis.

## Irritable Bowel Syndrome (IBS)

IBS is a common gastrointestinal disorder affecting an average of 10-20% of New Zealander's (Health Navigator New Zealand 2016), and 11.2% of humans worldwide (Lacy et al. 2016, 1394). The prevalence of IBS is higher in women than men and younger people are more likely to be affected than people over 50 years (Lacy et al. 2016, 1394).<sup>7</sup> There is no identified cure, and treatments are based around managing symptoms.<sup>8</sup> IBS consists of several medically unexplained symptoms and is a poorly understood syndrome in which biomedicine has not been able to definitively identify cause, cure or physical markers (Jones et al. 2009, 367-368). As IBS is a syndrome, when using the term illness within this thesis, I will be referring to the experience of a collection of signs and symptoms that combine to characterise a specific health affliction and fall under a diagnostic label.

Medical experts have previously debated whether IBS should be treated with medications, psychotherapy or dietary changes. Some experts even doubted whether IBS was 'real' suggesting that it was 'in the patients' minds' (Womack 2010, 71). Lacy et al. (2016, 1393) provides a standard biomedical definition of IBS as a functional bowel disorder resulting in recurrent abdominal pain associated with defecation or a change in bowel habits. Diagnosis requires the elimination of other illnesses that can be identified through biological markers such as inflammatory bowel disease, celiac disease, Crohn's disease, and lactose and fructose intolerance; and based on clinical history, a physical examination, laboratory tests and if required a colonoscopy and/or other appropriate tests (Lacy et al. 2016, 1395). In many cases this aspect of IBS often leaves those who have been diagnosed in a constant search for answers with feelings of frustration and helplessness (Bertram et al. 2001, 534; Casiday et al. 2009, 40).

IBS is diverse in its reach and is affected by cultural and socioeconomic factors that also likely impact diagnosis (World Gastroenterology Organisation 2015).<sup>9</sup> It is characterised by symptoms of bloating, abdominal pain and cramping, altered bowel function such as

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<sup>7</sup> These statistics have been gathered from the IBS population who have sought medical diagnosis and it is stated that many more people could have IBS who do not seek medical advice (Toner and Akman 2000, 11). Toner and Akman (2000, 11) also state that gender differences in health-seeking behavior could account for the gender ratio.

<sup>8</sup> Possible treatments for IBS will be discussed further in Chapter Four.

<sup>9</sup> For example, the term 'discomfort' was recently removed from the diagnostic criteria (Rome VI Criteria) for IBS as not all languages have a translatable word for the term and it has different meanings in different cultures (Lacy et al. 2016, 1394).

constipation, diarrhoea and gas, and nausea (Longstreth et al. 2006). Other symptoms that have been linked with the syndrome are indigestion, migraine headaches, fibromyalgia, chronic pain, painful sexual intercourse, psychiatric distress, and sleep disturbance (Lacy et al. 2016, 1396-1397). Medical descriptions of IBS commonly state that the symptoms can change greatly both for the individual person and from person to person and can resemble other diseases; often noting that IBS is a chronic condition and that symptoms can fluctuate between mild and severe and sometimes disappear for periods of time (Mayer 2008, 1692). Symptoms can develop from or be exacerbated by ‘prior gastroenteritis, food intolerances, chronic stress and surgery’ (Lacy et al. 2016, 1397). The exact cause of IBS remains unknown and diagnosis tends to be an uncertain process of liminal stages where one moves between the sick/healthy role on a continuum searching to legitimise the pain experience and discomfort via interactions with medical staff and technologies (Bertram et al. 2001, 521). Once a diagnosis of IBS is finalised treatments offered are aimed at the management of symptoms.

Societies and cultures all develop ‘norms’ encompassing what is expected of the body and its functions particularly regarding disease and illness (Levin and Browner 2005, 747). Those with IBS can experience significant anxiety and embarrassment due to the social undesirability linked with altered bowel habits as well as the unpredictable nature of symptoms (Bertram et al. 2001, 524). Basic daily activities such as travel, social interaction and eating can be difficult due to the levels of pain, need for access to a bathroom, and an often very restrictive diet. Given these considerations, IBS is commonly associated with some level of increased social isolation and lack of life opportunities (Bertram et al. 2001, 521). In the past gastrointestinal disorders such as IBS have been commonly understood through a biomedical lens where only biological factors are investigated and where the biopsychosocial and cultural factors are not considered (Fortin, Gomez, and Gauthier 2013, 71). However, recent research has identified that IBS as a gastrointestinal disorder is best conceptualised using a biopsychosocial framework where biological, psychological, and social factors and their interactions are considered when trying to understand illness (Drossman 1999, 3). Many studies focus on the biomedical expert interpretations and representations of IBS and leave out the experiences and voices of those with IBS who interact with these biomedical attempts to address their illness.

## Thesis outline

Most participants chose to talk about their experience of IBS in a chronological order often recounting experiences through stages of pre-diagnosis, diagnosis, treatment, and managing and understanding their bodies. Though participants were somewhat guided by research questions, their responses and narratives in between these questions also commonly took on this structure where the narrative aimed to make chronological sense of their illness experience. As we do not have direct access to the experience of others, studying the narratives of participants allows us to study forms of experience represented and recounted through events which ‘are presented as having a meaningful and coherent order’ (Good 1994, 139). Participants spoke of their IBS as existing over a long period of time and framed by processes of illness development, legitimisation and illness management. Through these considerations, I lay out my thesis based on the chronological order in which most participants spoke about their IBS, reflecting how they make sense of their illness experience and form narratives to communicate their illness.

In the following chapter I introduce the key participants of this research and discuss the methodology and methods used during fieldwork, and my positionality within the research. By beginning this chapter with the introduction of my participants I place their experience at the forefront of this thesis, and develop their individual experiences of the initial stages of their illness here as they did in interviews. I provide an overview of the survey and ethnographic interviews that were used as research methods during fieldwork and the relevance of these for my topic. I also reflect on my positionality as a researcher, as someone who also experiences IBS, and my experience of doing ethnography.

In chapter three, titled *Seeking diagnosis*, I explore the experiences of my participants during the diagnostic processes of their IBS. I discuss how a biomedical model is incongruous with the illness experience of participants yet simultaneously informs this experience by shaping their engagement with the diagnostic process, who they encounter in this process and their efforts to achieve diagnosis to prove and legitimise their experience to others. I note that the process of communicating their illness experience and symptoms in the search for a diagnosis to fit these, involved both perceived and actual stigma within the relationships that informed

their diagnosis. Participants often felt relieved in gaining a diagnosis however this was short lived as the challenges of treatment loomed.

Chapter four, *Managing treatments*, illustrates how participants navigated the multiple treatments they trialed to develop individual management regimes. In this chapter I explore why the biomedical framework alone fails in assisting the treatment of IBS necessitating my participants need to engage with multiple health sectors and treatments which were sometimes in conflict with their own values and others' views of responsible health management. Participants reported feeling that their ability to responsibly take care of themselves and their health was questioned, illustrating the influence of neoliberal values of responsabilisation in their illness experience.

Chapter five, *Body and self in tension*, examines the tension participants experienced between the self and the body due to their IBS. I argue that social expectations of the body and social interaction affect the illness experience of my participants by informing the self of how a healthy body should function in society, and resulting in tension when the body does not meet these expectations. My participants felt that their illness changed the self and their body, and when the body was viewed as inadequate and faulty this resulted in perceived stigma and increased social isolation.

Chapter six, *Stigma of IBS*, is directly focused on the perception and experience of stigma that participants have encountered throughout their illness experience and how they cope with this stigma. I argue that the perceived and actual stigma my participants felt was guided by the social and biomedical expectations of a healthy and polite body, as well as neoliberal values engrained in New Zealand society which place importance on responsibility and productivity. My participants developed ways of concealing their IBS and/or coping with and confronting stigma to reduce its negative impact on their illness experience.

The conclusion summarises the core arguments of this thesis, showing how the illness experience of my participants and what is stigmatising for them benefits from an understanding of IBS not only in relation to its physical manifestations but also in relation to the biomedical and neoliberal influences that inform social expectations of the body and social interaction and participation. Further stating that participants experience their IBS simultaneously resisting and

participating within these influences to make sense of and manage their illness in a way that aligns with their lived experiences while also reducing the stigma associated with it.



## Chapter Two

### Participants, methodology, and methods

It is always nice to talk to people who share your experience and who properly understand. Plus, you go to things like that [illness support groups] and you meet other people and they are like, “have you tried this cool thing? Have you heard about this?”. It’s a really good way to further your resources and it’s just nice to meet people. Even getting to talk to you about IBS is really cool.

Catherine<sup>10</sup>, interview participant

Catherine, has had IBS since her last year at high school in 2015. It developed after a severe bout of *dientamoeba fragilis*<sup>11</sup> which she describes as ‘a form of amoebiasis<sup>12</sup>, like having giardia<sup>13</sup> or gastro.’ After successful treatment for this she developed symptoms characteristic of IBS, yet it took a further nine months to be medically diagnosed. The above quote by Catherine illustrates the importance of talking about illness with others who experience it. She recognises the benefits of discussing an illness like IBS with others and touches on the isolating nature of IBS by emphasising the relief in meeting others with the same illness.

In this chapter I introduce my key participants Catherine, Emma, Hanna, Hazel and Lewis. By introducing my participants before engaging with methods I place them and their voices at the forefront of my research. This was a central consideration throughout my research and in writing this thesis. Following these introductions, I discuss the methodology that informed the structure of this research project, the use of an anonymous online survey and semi-structured ethnographic interviews to conduct my research, and my positionality as a researcher who also

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<sup>10</sup> This is a pseudonym. All participants were given the option to choose a pseudonym to protect their identity. Three participants chose their own pseudonyms and two wanted their real names to be part of the research. I have removed any individually identifying details about my participants however I do note that all participants were based in Wellington during research. Catherine, Hazel, and Lewis all chose to use pseudonyms, while Emma and Hanna chose to use their first names. These are my interview participants.

<sup>11</sup> *Dientamoeba fragilis* is a parasite that can infest the digestive system and has been found to cause gastrointestinal disease (Nagata et al. 2012, 204).

<sup>12</sup> Amoebiasis is a gastrointestinal disease developed by the transmission of fecal matter into the oral route, usually via eating or drinking contaminated food or water. It can cause diarrhoea, fatigue, weight loss, fever and damage to the liver (World Health Organisation 2018).

<sup>13</sup> Giardia is a gastrointestinal disease that is food and water born. It is caused by a parasite in the gut of infected humans and animals. Symptoms consist of diarrhoea, cramping, vomiting, weight loss, fever, and fatigue (Ministry of Health, Manatū Hauora 2017).

experiences IBS. This research draws on 10 interviews with five key participants<sup>14</sup> and 44 responses to an anonymous online survey.

## **Knowing others with IBS**

There are multiple ways in which IBS can develop, yet we know little about these and individual stories about the first engagement with IBS and its symptoms differ widely. As mentioned above Catherine places her development of IBS after a bout of gastrointestinal disease however she also said, ‘I think I already had a few tendencies, like I didn’t eat apples because they just weirdly gave me stomach aches and some foods just do not agree with me’. Catherine is currently studying psychology and is fascinated with the human body. Growing up she was a very active person involved in many extracurricular activities including ballet and music. However, her gastrointestinal illness and IBS disrupted her normal activity.

Emma, a second-year university student and actor, met me for our first interview outside the library. She had just come from a dance rehearsal and was feeling good after a bit of exercise. Emma’s passion is acting, she performs in stage plays and has appeared in a New Zealand film. Her aim is to work in the film industry after completing her degree. Emma also loves to cook and when she has time and the right equipment she enjoys making food that is good for her body. During our second interview Emma noted that she did not have an oven at the time which limited her options when making food, but had managed to master the stir-fry options. Since moving away from the family home for university, Emma has been able to adapt the management of her IBS more effectively. She was diagnosed with IBS in 2014, but had always felt something was not right with her body, and constantly struggled with ‘feeling sort of crap and really bad for about six years’ prior to her diagnosis. She acknowledges that it was good to put a name to her symptoms, yet having a condition that was incurable and manifested so disruptively to her life and ambitions ‘still sucks’. Emma often spoke about managing her daily routine and engagement in social interaction around her symptoms in an aim to reduce the impact of IBS on moments when she felt good, and was confident to leave the comfort and security that home provided.

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<sup>14</sup> Two interviews were completed with each key participant resulting in a total of 10 recorded interviews

Hanna, also a second-year university student, was diagnosed with IBS a year or more after her symptoms arose. She said, 'I remember when I was 10 or 11 I started having stomach pains, I just remember always having a sore stomach and it would be to the point where I didn't want to go to school'. Hanna then recounted multiple inconclusive physician visits and further disruption to her school and social interaction before being officially diagnosed at that age of 12. What led her to seek a medical diagnosis were her symptoms and feelings of 'just not being normal, not feeling like yourself and then it got to a point where it just kind of influenced my everyday life'. Over several years, Hanna has learnt to listen to her body, understand her IBS, and develop ways of managing its various symptoms that work for her. She acknowledges that she has made progress with this management but is still challenged by the chronic and unpredictable nature of symptoms. Hanna and I met for our first interview outside a café. After getting our hot drinks in takeaway cups we walked to our interview room in the library. Hanna is studying psychology and is interested in the study of well-being. Throughout her life, she has struggled with multiple health problems. Learning to manage these has inspired her to help others going through both physical and mental health issues and has sparked her interest in how these two aspects interact.

Hazel, another participant also has a deep interest in how physical and mental health interact. She noted that what she ate and how she managed her body affected her mental health and that she has a desire to learn more about this connection. Hazel currently works for an insurance company. She is also a dancer and performs in competitions throughout the year. Food is a big part of Hazel's identity and how she connects with others. She told me that she expresses her love and care for family and friends through cooking and eating together. Her diagnosis of IBS has provided some challenges to this aspect of her life but after several years she has learnt ways in which to manage them. During our initial interview, Hazel recounted her first instance of IBS during her first year at university:

I was submitting my first essays for the year and of course I left it to the last minute. That's still how I roll. And I just remember being really stressed out and then I submitted my essay and I went to work and I was actually in so much pain. My stomach was just in a horrific amount of pain. I just ended up lying in the back room of the store in agony in the fetal position. And then again there are a few instances of just not being able to get out of bed because the cramps were like that squeezing in your stomach. And so eventually it got to a point where I went to see the doctor.

Like Hanna, Hazel's diagnosis took numerous doctors' visits and was delayed three years after her first experience of symptoms due to a myriad of alternative diagnoses including acid reflux and hormonal development. When she was finally diagnosed with IBS she cried because she was 'just so grateful that somebody had actually listened to me and had been able to describe accurately what it was that I was feeling and then set me on a path to actually make it better or more manageable'.

Lewis, my final participant to be introduced, is an artist who for many years taught art at high school and currently teaches adult art classes. He has a passion for creativity and the sea. Lewis has always lived by the sea and feels that it is healing in many ways. He swims every day though not always in the sea and likes to keep active. Lewis developed his IBS in a similar way to Catherine. His symptoms developed after a 'bout giardia,' which made his symptoms difficult to identify as something other than a reoccurrence of giardia. Lewis recalled his diagnoses of IBS occurring sometime between 1996 and 1997:

I had not long since recovered from a bout of giardia that was quite unpleasant in terms of bowel movements and so I had become sort of accustomed to the unpleasant, regular, and very explosive bowel movements for some time. But it had been sorted with a very strong antibiotic, yet it took some time for that to settle down. I don't know the exact distance between those and the clearance of giardia or when I went to get help. The giardia was definitely before I was diagnosed [with IBS]. I was diagnosed by a doctor who just simply said the symptoms which I have point to be very clearly, Irritable Bowel Syndrome. She didn't do many tests as such, fecal tests or anything from memory, she may have. I think she may have checked to make sure any levels of giardia had gone. And therefore, made that other diagnosis.

For Lewis IBS has been a constant factor in his life for over 20 years and there is some regularity and predictability to his symptoms, however there are still moments when he is caught out by them. During our conversations, he often reflected on how IBS had become a part of his everyday life, and how the disruptive symptoms had effected his life over time in different ways.

## **Constructing the field**

It is commonly understood that an anthropologist's training and personal experience often informs their fieldwork choices and writing (Gallinat 2010, 25). This research developed out of engagement with medical anthropology at university, and a personal curiosity and desire for clarity about an ambiguous illness, IBS. An interest in medical anthropology and more broadly cultural anthropology began in my second year at university. A fascination about how health and illness is understood and experienced within society increased as I completed my honours degree. The introduction of medical anthropology into my academic pursuits has shaped the focus of this research, yet I needed to have a specific focus if I was to complete research on how illness is understood and experienced.

For many years, I have experienced symptoms that fall within the diagnostic criteria for IBS and over the past two years I had self-diagnosed myself with IBS and have subsequently been medically diagnosed with it. My life has been crisscrossed with those who live with and experience this chronic illness. However, it is an aspect of our lives that we do not directly acknowledge with others as the nature of IBS generates avoidance and secrecy. Why is it that we do not discuss such an illness or in many cases even acknowledge it? Those who have IBS often feel isolated and forbidden from highlighting it as an illness afflicting them (Bertram et al. 2001, 523-524). This question and statement are what drove me to construct my research around IBS.

I felt somewhat challenged as a researcher in the beginning of this project as I did not have a geographically bounded field site. However, after reading more about methods and approaches to the field I came to realise that the field site could not only be defined by a physical geographical boundary but could instead encompass an interrogative boundary. An interrogative boundary being a field site in which the 'questions that impel the ethnographer, overarch geographic considerations' and link separate places, people and experiences together into a single ethnographic field of enquiry (Madden 2010, 53). Madden (2010, 53) suggests that we should define ethnographic fields as part social, part geographical, and part mental construct, rather than being focused on the geographical boundaries. I think of my field site as defined by an interrogative boundary within New Zealand that is focused on understanding the

experiences of people with IBS. Therefore, my field site is bounded by an illness shared by people living in New Zealand who have chosen to take part in this research.

Cognisant that my research was focused on a topic that is personal and which many people are uncomfortable discussing, research methods were aimed at creating an opportunity in which people could be involved anonymously and discretely as well as in person. With this in mind, I completed the process to gain ethical approval outlining the use of an anonymous online survey and semi-structured interviews to complete the research.<sup>15</sup>

## Survey

The decision to use a survey as a research method stemmed from the considerations that some participants may wish to be anonymous and it would allow those that do not wish to speak directly to someone about their IBS the chance to share their experiences and thoughts about their illness. It was also a potentially effective way of gaining key participants and the responses collected through the survey could add to what was discussed in any in-depth interviews, creating a larger field of evidence for the themes drawn from the interviews. The survey also helped to facilitate my aim for fieldwork to be participant driven. People could choose to do the survey and then could choose to contact me if they wanted to complete a series of interviews and/or discuss my research further. I thought that this method might counter any negative assumptions that potential participants may associate with medically involved research. It has been highlighted by several anthropologists that those with chronic illness and those who have felt contested and delegitimised in medical experiences are often cautious of future interaction with the medical profession and research (see, for example, Dumit 2006; Dickson, Knussen, and Flowers 2007). My relationship with my participants was constructed through their terms allowing me to gain a level of initial rapport.

The anonymous online survey comprised an introduction page, 18 questions, and a completion page thanking respondents for their participation in the survey and the opportunity to contact

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<sup>15</sup> This research project gained ethical approval on the 29<sup>th</sup> April 2017 from the Victoria University of Wellington Human Ethics Committee (0000024547).

me via email if they wished to complete interviews for further research.<sup>16</sup> The choice of the respondents to complete the survey indicated their consent to be part of this research. Moving away from a more traditionally structured survey of tick boxes and predetermined answers, this survey largely consisted of essay boxes allowing detailed responses. The survey was focused on the qualitative data that it could produce. I posted the survey online via Facebook.<sup>17</sup> I also placed fliers on notice boards around Victoria University of Wellington advertising the survey. Within the first week the survey received 55 responses (44 that were valid)<sup>18</sup> and I received seven emails from respondents who wanted to take part in interviews with me.<sup>19</sup>

Although anthropological research primarily adopts long-term ethnographic research using participant observation, key informant interviewing using survey methods is understood to enrich anthropological fieldwork (Bernard and Gravlee 2014, 467). By using a survey method researchers can potentially gather more sensitive responses to key research questions that may not have been discussed or disclosed in more personalised qualitative research methods, likely due to the anonymity of online surveys (Westmarland 2001). The decision to use a survey as my first method in fieldwork was guided by the knowledge that they can reach respondents in 'hard to reach groups' (Bernard 2011, 205). I considered my research group (people with IBS in New Zealand) hard to reach as they are not collectively bound to or associated with a single accessible place. For example, there are no meeting support groups for IBS that I could have attended and it is a topic that is not often discussed openly.<sup>20</sup> However, when discussions about IBS do occur they are usually online and therefore I chose to utilise an online presence to gain data and key participants.

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<sup>16</sup> This survey was created using a software called Qualtrics provided by Victoria University of Wellington. See Appendix A for the complete survey.

<sup>17</sup> The survey was posted online through my personal Facebook page, Vic deal's Facebook page, Massey deal's Facebook page, Health and Well-being NZ Facebook page, and the NZ IBS support Facebook page. When posting on the NZ IBS support page I contacted the administrator of the page prior and asked for permission to post the survey. This was because the page was private and could only be accessed once accepted by the administrator of the page. All other pages were open to the wider public.

<sup>18</sup> The survey tool (Qualtrics) counted all the surveys that had been completed and partially completed. I decided to remove the surveys that had been partially completed as it may have meant that the respondent had chosen to withdraw their participation in the research. This meant I ended up with 44 complete surveys as my data set from this method. In my proposal, I had aimed to gain 30 responses to the survey so removing these partial responses has not hindered my data.

<sup>19</sup> The survey was posted for a set duration of two weeks, however upon discussion with my supervisors we decided to take the survey offline after the first week as I had gathered sufficient survey responses and gained more participants than I could include in my research project due to the time limitations of a masters.

<sup>20</sup> I posted on social media sites linked to IBS in New Zealand asking if there were any IBS support groups that met on a regular basis. No one seemed to know of any. I got the same response when I asked my key participants, friends, and family.

## **My next steps into fieldwork**

Contrary to my expectations, many people were happy to talk about their IBS, and many of the survey responses were rich with detail. From the 44 responses to my survey four respondents identified as male and 40 respondents identified as female. My five key participants consisted of one male and four females. While I do not consider this sample to represent all of those who experience IBS these numbers do reflect the gathered data suggesting women are more affected by IBS than men. Approximately 70% of people diagnosed with IBS are female (Andrews et al. 2005; Ford and Talley 2012). However, it is important to note that these statistics have been gathered from the IBS population that have sought medical diagnosis and it is commonly stated that many more people could have IBS who do not seek medical advice and this could alter these gender statistics (Houghton et al. 2016, 1333; Luscombe 2000; Toner and Akman 2000). Toner and Akman (2000, 11) also note greater health-seeking behavior in women which could be a contributing factor to these statistics.<sup>21</sup>

The decision to limit the number of participants to five was made bearing in mind that I planned to do at least two interviews with each of my participants to gain in-depth medical and personal histories. I secured all primary interview dates by mid-May 2017 and then secondary interview dates by mid-August 2017. Catherine, Emma, Hanna, Hazel, and Lewis became my key participants. Interviews with Catherine, Emma, and Hanna took place in a booked room at the Victoria University of Wellington library. I met with Hazel at her work in the CBD as it was close to university and suited us both. She was kind enough to book one of their meeting rooms for our discussions. I met Lewis at a café for our first meeting and then his home for the second as he worked from home.

As all my participants were either sourced via social media, the internet, or fliers placed around Victoria University of Wellington, I understood that I might tap into a specific demographic of participants; university students. Indeed, three of the five were students with the remaining two working in the Wellington region. All key participants identify as New Zealand Pākehā and

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<sup>21</sup> In this thesis, I have specifically chosen not to engage with gender in relation to IBS. Though gender is an important aspect of illness experience participants did not identify their gender as a crucial aspect of their IBS unless prompted by a specific question. I felt that the thesis should focus on what my participants spoke about in relation to their illness experience namely, the diagnosis process, treatment, the self and body, and the frustration, delegitimisation, and stigmatisation that surrounds their illness.



are educated to a tertiary level. When meeting each participant for the first time, I tried to organise to meet them at a place other than where we would complete the interview. This meant that we could meet in a comfortable environment and have a chance to get to know each other away from the research. Following this we would then move to the room in which the interview would take place. When I could facilitate this, it worked well and helped to get conversation flowing before the interview began as well as reducing the barrier between the researcher and the researched. When I was not able to facilitate this I made sure we began interviews with general conversation.

## **The ethnographic interview**

The nature of IBS and its relation to the gut makes it an uncomfortable illness to experience, disclose, and discuss with others, leaving those who experience it with few ways in which to express and share their illness experience without the threat of perceived and actual stigmatisation, judgement and delegitimisation. This research aimed to gain in depth medical and life histories from participants through semi-structured ethnographic interviews as they facilitate the style of conversation that is needed to discuss sometimes sensitive topics and create a space for the ‘elicitation of life histories’ (Gusterson 2008, 103).<sup>22</sup> Hockey and Forsey (2012, 83) state that:

Interviews conducted with an ‘ethnographic imaginary’ commit the researcher to understanding the lived experience of the participant/interlocutor by asking about and listening closely to the beliefs, the values, the material conditions and structural forces that underwrite the socially patterned behaviors of all human beings, along with the meanings people attach to these conditions and forces.

Ethnographic interviews allowed my participants to maintain a level of privacy for their bodies and illness, mitigating any sense of intrusiveness that participant observation might provide in relation to such a topic. Additionally, they allowed me to listen to how my participants experienced their IBS in their own terms gaining an insight into how they understood their interactions with biomedicine and society.

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<sup>22</sup> Written consent for all interviews was acquired before the first interview for each participant. See Appendix B for list of interviews.

As Okely (2015, 145-146) expressed in her chapter, *Dialogues with Anthropologists*, my interviews were also dialogues rather than ‘formal interrogations’, and ‘reciprocal exchanges of experience’ allowing for conversation to be filled with past experiences, present musings and future considerations. Rapport (2015, 176) highlights that the interview is best understood as a ‘talking-relationship’ emphasising that ethnographic interviews are often not between strangers but instead ‘talking-partners’ where trust and mutual knowledge is formed. When completing my interviews, I understood them not as a tool to gain data but instead as encounters and events that situate themselves within other events in the lives of myself and my participants. Through organising and completing this research I formed new relationships in which researcher and participant became a part of one another’s lives.

Participants often wanted to know what we might cover in the interviews, clearly seeking some structure to our interactions. Bernard (2011, 173) notes that although unstructured interviews are often considered best for communicating freely with key informants they are not always successful and some people do not like the unstructured interview format. During my research, participants readily responded to questions that I had planned to ask and tended to be less focused and attentive when discussing events and experiences that they thought were less linked to their IBS. This highlighted the fact that participants wanted to engage with the research questions to produce something meaningful that might help others and further research on IBS. Catherine explicitly stated this during one of our interviews saying, ‘when I saw your post I thought that is really interesting! If I can produce something interesting just by talking about it, you know, if I can give you data, I am up for it’. Staples and Smith (2015, 2) posit that interviews play a crucial role in allowing a discussion of topics that would not usually be discussed in everyday life and conversation. Two interviews were completed with each participant to allow time to discuss multiple experiences of IBS, the illnesses progression, and to address issues that came up during the first interview in the second. This also gave the participants a chance to spend time thinking about their illness in between discussions.

Interviewing is considered one of the most important ways of knowing others because they require face-to-face interaction and discussion (Madden 2010, 67). The initial interviews were only loosely structured and many of the questions were based around Spradley’s (1979) grand tour questions to induce longer and more continuous responses, such as ‘Can you talk me through your diagnosis process?’ This allowed participants to take the discussion in any

direction they wanted within the parameters of the topic. Even though quite a few of the questions were general questions about their lives and experiences, participants consistently related what they were saying to IBS in some form, even if encouraged to talk freely and generally about other experiences. Perhaps this illustrated that participants wished to and make sure their experience of IBS was heard.

The second interviews were more structured around focused questions and follow up questions, but still allowed for informal conversation and the ability to veer away from this structure. The different approaches to the interviews allowed participants to get used to being asked conversation based open questions rather than the interviews being formal and structured processes (Madden 2010, 67-68). Though I had written questions that might be asked I planned to stray from these questions as needed which allowed for a more conversation style approach and meant the interview was flexible to move in the direction that participants chose to take. Participants often answered several questions in response to one topic, allowing me to pick up on certain aspects of their IBS experience that they commonly returned to and develop additional questions to expand aspects important to each participant.

Hockey (2002, 214) states that ‘interviews allow past and future to be accessed via the present and create space for what has been left unsaid and what remains invisible’. This statement has particular relevance for my research as I wanted participants to be able to discuss their past, present, and future in relation to their IBS, and in doing so identify what aspects of their illness remained unspoken. During initial interviews, questions about life before, during, and after diagnosis were asked as well as questions about the relationships that developed and changed within this process. Before beginning each interview, I made sure to emphasise that they did not have to answer any questions which they did not feel comfortable with, and they were welcome to ask me questions as well. This emphasised that the interviews could flow like a conversation rather than expecting concise answers to predetermined questions. I generally completed secondary interviews one month after the first as I wanted to allow time for the participants to reflect on their experience of the interview and to accommodate their busy lives. In the interviews, I made notes on aspects that could not be captured through audio recording such as surroundings and body language. I also made notes after every interview to record

anything that may have been missed once the audio recorder was turned off as well as how the interview went.<sup>23</sup>

## Positionality

It is the world between ourselves and others that brings reality to the field not the ‘unmediated world of others’ (Okely 1992, 1). Collins and Gallinat (2010, 10) argue that as anthropologists our experiences can often be highly relevant for doing and writing ethnography and that we should draw on ourselves as a methodological resource. They also state that those researchers who can be considered an ‘insider’ and can draw from personal experience, which may or may not be shared with their informants, will likely have a different perspective on the field than if they were an ‘outsider’. They further claim that this position in the field can bring about important insights that would not happen otherwise (Collins and Gallinat 2010, 10). Instead of understanding my movement from an ‘outsider’ to an ‘insider’ as a dichotomy and a one-way movement, I adopt Narayan’s (1993, 671) argument that anthropologists should be seen as holding shifting identities as they interact with communities and power relations that also overlap in the field and in life. Narayan (1993, 671) highlights that how and where we align with or are set apart from those who we study are numerous and always in flux. Coffey (1999, 59) states that ‘fieldwork is necessarily an embodied activity’. The ethnographers body helps to write the ethnographic script through the sensations, experiences and embodied knowledge it records (Madden 2010, 19). These passages encouraged me to be deeply reflexive in my research and throughout the writing process, and highlighted the importance of my positionality in this research to add a certain depth to my analysis. Initially I had a deep desire to avoid placing myself too much within this research and thesis, as the thought of discussing my own experience of IBS felt somewhat self-indulgent and delegitimising of my project. However, since reflecting upon my connection to IBS and my discussions with my participants, I now understand that this is a crucial part of my research and should not be compartmentalised as unimportant.

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<sup>23</sup> All interviews were recorded on a Dictaphone and iphone. They were then downloaded and stored on a secure laptop with password protection.

I went through the diagnosis process for IBS during my research after having self-diagnosed over a few years. While conducting my interviews I found myself being motivated and encouraged to seek diagnosis for my symptoms. Participants often told me that it was something I should pursue. And so, I did. Half way through my fieldwork I relaunched my attempts to figure out what was causing my gut issues.<sup>24</sup> Three weeks before I finished my research I was diagnosed with IBS, having gone through multiple tests and consultations over the last few months. Even though I had self-diagnosed for so long I was not prepared for how I would feel when a medical professional confirmed my diagnosis. I thought I was prepared due to doing this research and being involved with people who have IBS, however even that had not altered the power of diagnosis.

Throughout my research and process of diagnosis I have been aware of my experience as simultaneously an ‘insider’ and an ‘outsider’ constantly moving between these positions in relation to my different participants. Sheoran (2012, 5) posits that ethnographers have moments in which they become ‘insiders’ throughout their research however we are ultimately ‘outsiders’ as we always move back across this boundary to return to our space that is separate from our participants lives, the space in which we write about our research. Upon completing my research and transitioning to analysis and writing Sheoran’s statement described exactly how I felt. However, in knowing that I had established a connection with my participants and shared a unique relationship, I became comfortable with my identity as ‘insider’ and ‘outsider’ being in flux. By adding my own perspective to this research, I hope I will be able to help illuminate a broader understanding of an illness that is often misunderstood and dominated by biomedical discourse.

Many of my participants acknowledged that they were more comfortable talking to people who also experienced IBS. Hanna noted how difficult she sometimes found talking to others about her illness saying:

It’s very hard for someone who doesn’t experience it to relate to you and you have thoughts and feelings and you are like oh this is really abnormal so I am just going to keep it to

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<sup>24</sup> I sought medical help for IBS like symptoms in 2014, yet a year later nothing came of the tests and I felt compelled to stop asking questions.

myself...it's like even though people are very empathetic it is just completely different talking to someone who has it.

Though Hanna said she has come a long way in feeling comfortable with talking to people about her illness she still illustrates that talking to someone who has had a similar experience is much easier and more comfortable than if they had not. Due to my positionality, the potential boundaries and challenges that this research provided were different to those that might have arisen if I were not someone who experienced IBS. Through our common ground of IBS and living within the same culture and society, my participants and I developed a unique connection and familiarity.

## **Analysis**

I adopt the interpretive approach developed by Geertz (1973) to analyse my participant's narratives allowing a style of analysis that facilitates an understanding of how people with IBS interpret themselves and their own experiences through ethnographically thick description. Schwandt (1998, 221) states that an interpretivist approach aims to understand 'the complex world of lived experience from the point of view of those who live it'. This approach is fundamentally concerned with ways of knowing and being rather than the methods used in research (Schwandt 1998, 222). Using survey and ethnographic interviews, I aimed to explore how the realities of my participants 'are constructed, authorised, and contested in personal lives and social institutions (Good 1994, 5). This approach informed my analysis by leading me to interpret my participants' narratives within the social structures and institutions that influence their experience of IBS.

I also utilise a grounded theory approach in which theory is developed through a 'continuous inductive interplay between analysis and data collection' (Strauss and Corbin 1994, 273). Charmaz (1990, 1162) notes that 'by starting with data from the lived experience of the research participants, the researcher can, from the beginning, attend to how they construct their worlds. That lived experience shapes the researcher's approach to data collection and analysis'. Each of these approaches focus on the experiences of participants and how they construct and understand their lives. By utilising these methodological approaches my research is participant led and explores how my participants experience IBS and how they understand their illness

from their own perspectives. Through this research participants could describe and interpret what IBS meant for them and reflect on an illness that they are not often asked to talk about outside of a biomedical setting.

In using a survey and ethnographic interviews as methods I gained data about illness experience that were both written and spoken. I analysed my survey data as each response was logged developing an interplay between analysis and data that allowed theory to arise whilst doing research (Strauss and Corbin 1994, 273). I used this same approach as I conducted interviews. Because I completed two interviews with each participant I could transcribe initial interviews and engage in an analysis of them prior to our secondary interviews. This allowed me to pull out themes that arose in their narratives and could be further discussed during our next meeting. Once my research was completed I began a more detailed analysis of my participants experiences by reading my transcriptions and written responses line by line and coding them into experiences that fell within groups of pre-diagnoses, diagnosis, treatment, social interactions affected by IBS and how IBS was seen to affect participants' futures. Within these broad categories I then highlighted commonalities across each participants' narratives developing the themes that would be discussed throughout this thesis including an interaction with biomedicine, neoliberalism, and social expectations of the body and social participations that helped to shape how my participants experienced their IBS.

Combining these methods, and working with the data enabled me to draw out the themes discussed in this thesis, as discussed in the following chapters. For Catherine, Emma, Hanna, Hazel, and Lewis IBS is a part of daily life. Their stories are central to this thesis, and are supported by the responses gathered from my anonymous online survey. During our interviews participants spoke about aspects of their IBS which they had not previously considered. Many participants felt that they had had IBS symptoms for a long time prior to their medical diagnosis but that diagnosis solidified their illness for others.

## Chapter Three

### Seeking diagnosis

In this chapter I explore my participants' experience of their diagnosis and highlight the relationships that helped to form these experiences. For all participants, their diagnostic process was dominated by the biomedical model with its influence clear in how the illness is understood and approached by individuals themselves, family, and physicians. Through a discussion of how lay knowledge, family, and the patient-doctor relationships inform the diagnostic experience of IBS, I highlight how self-diagnosis and understandings of illness are informed by biomedical knowledge; and discuss the authoritative power of medical diagnosis in society. I posit that though participants occasionally challenged biomedical knowledge they simultaneously relied on it to gain societal acceptance of their illness and symptoms. Diagnosis provided all my participants some form of relief however they soon came to realise the double bind of their diagnosis in terms of treatment and society's understanding of IBS. Participants and survey respondents described their diagnosis as a lengthy, uncertain and often a delegitimising experience, detailing multiple visits to multiple physicians and multiple tests with inconclusive results. They often felt that their final diagnosis was the only one that was left on the 'doctor's list to tick off'. Gaining a diagnosis and explanation for their symptoms was important for all participants as it was seen to legitimise their experience of their illness and provide a label by which to explain their illness to others.

I situate this chapter within the literature in medical anthropology focused on diagnosis, the patient-doctor relationship, and biomedical practice. Through my participants' narratives I illustrate how participants came to understand, experience, and legitimise their illness. Misdiagnoses led them to consider whether the pain was in their mind, and often led to feelings that family members and physicians were questioning their illness experience. During diagnosis, the patient-doctor relationship was often strained and medical authority was sometimes challenged or discredited with participants realising that biomedicine did not have answers for everything.

Before I venture into the diagnosis of IBS it is important to define what is meant by illness, disease, syndrome, and medically unexplained symptoms. Illness can be defined as the



patients' subjective experience of a disease, disorder, syndrome or condition (Fortin, Gomez, and Gauthier 2013, 72). The understanding of disease as being located within the anatomical frame forms the basis of biomedical knowledge and clinical practice (Foucault 1976). Kleinman (1988, 3) describes disease as the primary concern of medical practitioners and as a biophysical event whereas illness 'refers to how the sick person and members of the family or wider social network perceive, live with, and respond to symptoms and disability'. Nettleton (2013, 76) notes that this idea of disease as originating in the 'interior space of the body' still pervades medical and popular discourse. The definition of disease does not fit an illness that is comprised of medically unexplained symptoms such as IBS. IBS challenges biomedicine's and society's ability to understand, believe, and accept the illness experience of those who have such symptoms. IBS is a syndrome; a collection of signs and symptoms that combine to characterise a specific health affliction and fall under a diagnostic label.

IBS is a chronic illness and this chronicity was an aspect that my participants threaded throughout their narrations, not only referring to the persistence of an illness that has no cure but also to the chronic pain and symptoms. From the point in which symptoms arise and the decision to seek diagnosis, people with long-term conditions become caught up in the chronicity and undulations of their illness experience (Manderson and Smith-Morris 2010, 16-17). For my participants, the chronicity of their symptoms is what led them to seek self-diagnosis through online medical websites and medical diagnosis, thus entering the biomedical process of diagnostic assessment and formulation. Seeking diagnosis is an effort to 'invoke' an effective response from others to an illness and a space in which those who have chronic illness try to undo or address the suffering that symptoms cause them (Good 1994, 128). Dumit (2006) discusses the struggle and uncertainty that people with Chronic Fatigue Syndrome (henceforth CFS) and Multiple Chemical Sensitivity (henceforth MCS) experience within aspects of diagnosis and treatment in his paper, *Illnesses you have to fight to get*. Each of these illnesses have many similarities to IBS and similar struggles are met by my participants as those described by Dumit (2006). As with CFS and MCS, IBS is a chronic illness that does not fit into an acute disease model where diagnosis is definitive and results in effective treatment, legitimised membership of the sick role, and a clear outline of treatment and health care costs (Dumit 2006, 578). My participants felt that they often had to fight or struggle for their diagnosis and push through biomedical barriers to legitimise their illness experience both simultaneously dependent on biomedicine for solutions and pushing back against biomedical authority by developing their own knowledge about IBS.

The symptoms of IBS are medically unexplained and therefore IBS is a medically unexplained syndrome. Nettleton (2013, 76) states that medically unexplained syndromes sometimes secure medical labels, yet the diagnosis remains contested.<sup>25</sup> Many of my participants felt this about their diagnosis noting that it was a label that categorised them yet provided little explanation and help in terms of treatment. However, the label provided in diagnosis can ensure a sense of categorical identity and relief (albeit momentarily for my participants); as well as access to any potential support groups or specialist clinics for possible treatment (Nettleton 2013, 76). As IBS does have a label, people who experience it have the luxury of a defined diagnostic category which enhances their ability to communicate their illness to others, find relevant information, potential treatments and gain support (Nettleton 2006, 1168). Dumit (2006, 582) notes that people who do not fall under an accepted category of illness are open to judgments of faking and malingering from others. As biomedicine has not been able to identify any causes or immediate markers for IBS it is more broadly considered not a disease but rather a functional gastrointestinal disorder<sup>26</sup>. The disjuncture between a syndrome that has multiple unexplained symptoms, no medically identifiable cause or cure yet a defined diagnostic label, was expressed through frustration, confusion and annoyance with biomedicine and physicians.

Diagnosis is a 'clinical act' and 'is an event that places the doctor in front of the patient, drawing on a deep and specialised knowledge base in order to identify the cause of a specific case of human discomfort or dysfunction, and to identify a remedy' (Jutel and Dew 2014, 1). During the diagnosis process for Hanna, Hazel, and survey respondent D, this statement rang true in terms of the doctor being placed in front of the patient with authority, yet there was no remedy provided or cause of illness explained. Hanna felt the physician's specialised knowledge was more of a 'guess', while Hazel felt the physicians were not listening to her account of her illness. The uncertainty within my participants' diagnostic processes seemed to be shared by both themselves and their physicians. Olson and Abeysinghe (2014) discuss the effect of uncertainty in diagnosis on patients and physicians alike, where the patient enters into what Corbin and Strauss (1985, 51) term a 'diagnostic limbo'. While patients are within this 'diagnostic limbo' they can experience stigma, guilt, shame and anxiety. Many participants

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<sup>25</sup> Such as Myalgia Encephalomyelitis (ME), and in this case Irritable Bowel Syndrome (IBS)

<sup>26</sup> A functional gastrointestinal disorder is defined as 'gastrointestinal dysfunction in the absence of apparent physiological lesions' (Fortin, Gomez, and Gauthier 2013, 71).

experienced a diagnostic limbo as they moved through multiple physicians, medical tests, misdiagnoses and doubt about their illness experience.

## **The diagnostic experience**

The relationships that help to create a diagnosis highlight how society reacts to certain illnesses and when narrated illuminate the interpersonal experience of illness. The diagnosis of IBS for my participants often began with forms of self-diagnosis via information on the internet, followed by family encouragement to seek medical diagnosis, and finally resulting in consultation with medical physicians. The process of medical diagnosis from there involved multiple tests and consultations.

### **Self-diagnosis**

Self-diagnosis of IBS is relatively common due to the availability of biomedical knowledge on the internet. Jutel (2011, 8) notes that access to medical knowledge that was once restricted to medical professions but is now available to the public has allowed a far more prominent role of lay knowledge within diagnosis. Before seeking medical diagnosis many of my participants spoke of being aware of IBS and thinking they might have it due to information they had read on the internet or had gained through discussion with others. Emma highlighted this by saying, ‘I had heard about IBS and I thought I might have it because my symptoms are very similar. And then I went to the doctor.’ The extent to which participants legitimised their lay diagnosis varied in relation to their own confidence in the diagnosis and whether family supported it. For example, Emma thought that she might have IBS before consulting a doctor, however there was still some uncertainty. On the other hand, Catherine felt confident in her self-diagnosis saying things like:

My mum has IBS as well, so she was kind of like, “this seems like IBS”, so we decided to put myself on the FODMAP diet<sup>27</sup>... So yeah, I was on the FODMAP diet and I was feeling a bit better and you know the internet is fantastic so I was like I am pretty sure I have got IBS,

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<sup>27</sup> This requires an eating pattern that reduces or eliminates foods that are high in FODMAPs (Fermentable, Oligosaccharides, Disaccharides, Monosaccharides and Polyols) (Lacy et al. 2016, 1397).

reading lots of things...I saw the gastroenterologist after nine months and he was like, “you’ve got IBS you should probably go on the FODMAP diet”, and it’s like awesome, tell me something I don’t know.

Compared to Emma, Catherine not only had someone who supported her self-diagnosis but also someone who had been previously diagnosed with IBS that confirmed her experience of her symptoms as IBS like. With the addition of thorough research on the internet Catherine solidified her self-diagnosis in her mind and then had it confirmed by a medical physician perhaps encouraging her ability to correctly identify her condition but possibly also delegitimising biomedicine’s ability to offer her any new information. Jutel (2011, 8) states that public access to medical information has produced an expert patient who more confidently discusses, challenges and contests medical authority. Another example of the role of self-diagnosis within my participants’ narratives is provided by Hanna. Unlike Emma and Catherine, she sought self-diagnosis after her medical diagnosis to legitimise her physician’s knowledge due to her waning confidence in her physicians to provide a diagnosis. Hanna noted:

Initially we went to our family doctor and he was pretty good. I think he put us onto someone like a pediatrician or specialist, I can’t remember what they were. And they did some more tests and we went through that diagnosis process again. But I think it was a bit of a guess as well. Like oh we will just put you in this group [IBS category]. It wasn’t until later down the track that I did my own research and talked to other doctors and put a few things together that I was like this is IBS.

Hanna questions her diagnosis due to the uncertainty and lack of clarity that her physicians provided. She later noted that only through her own research and further discussions with other physicians did she come to accept the diagnosis of IBS. This highlights the role of lay knowledge in diagnosis and how diagnosis in contemporary society is achieved through an increasing collaboration between patient and physician (Jutel and McBain 2012, 1534). Hanna essentially challenged the biomedical process of diagnosis and its authority over her illness. She did not just want to be told what her symptoms were; she wanted her diagnosis to fit her illness experience.

Self-diagnosis by my participants often led to discussions with family and friends about symptoms. In turn they encouraged participants to seek medical diagnosis reinforcing the

authority that biomedical knowledge has over legitimising an illness and its potential ability to provide social acceptance of symptoms and beneficial treatment.

### **Family reactions to illness**

As has already been identified family played a key role in the diagnostic process for many of my participants. Usually after the discussion, or illumination, of symptoms with a family member, participants were encouraged to seek out a medical diagnosis to identify their illness. Hanna recounts her diagnosis process highlighting her family's role within it saying:

I remember when I was 10 or 11 I started having stomach pains. I just remember always having a sore stomach and it would be to the point where I didn't want to go to school. Then I got taken to the doctor a few times and had scans done and all that kind of stuff and nothing showed up. And so, it kind of got pushed to the side and because there was nothing really there [a physical marker] it was like oh it might be to do with growing or your starting to hit puberty. And then I think mum and dad were just like, "no it's not right", and so they were kind of persistent with the doctors and I ended up going to see a pediatrician at the hospital and they did some more tests. I remember getting diagnosed there... I can remember in the period of being diagnosed just being in pain like 95% of time and I remember thinking am I ever not going to have a sore stomach?

Hanna's diagnosis occurred at a younger age than my other participants. She recalled her symptoms developing during a stressful period in which her parents were separating. Her diagnosis not only involved navigating the medical encounter and patient-doctor relationship but also involved navigating her diagnosis through family upheaval at a young age. Though her early engagement with seeking medical help resulted in little other than dismissal, her parents were also living with Hanna's illness and pushed to find answers to her symptoms. Kleinman (1980, 72-73) notes that illness involves 'communication and interpersonal interaction' with family members and those in wider social networks, noting that 'illness is the shaping of disease into behavior and experience and that disease affects the individual while illness also affects others associated with the individual. For Hanna, her parents played an instrumental role in gaining a diagnosis. They supported her and pushed her physicians to provide answers to their child's discomfort. Similarly, Emma noted that her diagnosis was kicked started by her parents reacting to her symptoms. She said, 'one day my parents were

like, “you have to go to the doctor, you need to sort this out”. Though Emma discussed a lack of support from her family in relation to her IBS she did acknowledge that they had encouraged her to seek a medical diagnosis and occasionally accompanied her to consultations.

I posit that the actions of family pushing for a medical diagnosis highlight how people are embedded in socially legitimated systems such as biomedicine. I suggest this in relation to Hahn’s (1995, 131) argument that biomedicine is a cultural system that informs society about what is valued and what is not; what is right and what is wrong; how to behave and how to judge the behavior of others. Hahn (1995, 132) further states that biomedicine is a subculture of western societies that outlines the conditions of health and sickness and how they are caused, treated, and how to behave in relation to them. Biomedicine informs how people approach signs of illness, and within my participants experiences it seems that seeking medical diagnosis is socially the right thing to do. The dominance of biomedicine over society’s interaction with illness highlights the medical model’s authority over medical knowledge and enhances the power of those who practice it within the diagnosis process. Although this is clearly true it is not to say that lay people do not challenge biomedical authority and knowledge. My participants instead simultaneously accepted and contested medical knowledge and authority throughout their illness and particularly within their encounters with physicians.

### **Patient-doctor relationship**

The patient-doctor relationship is clearly an important relationship in the illness experience, however for my participants it was often fraught with conflict and perceived stigma. Glenton (2003, 2251) likens the role of the physician to a gatekeeper who holds the key to diagnosis and therefore controls access to further health care, social acceptance and benefits, suggesting that as long as the physician holds this power, patients must ‘strive to live up to doctor’s expectations’. When medically unexplained symptoms arise, they provide a source of frustration for both the physician and patient as they test the credibility of both parties. The physician is challenged by the inability to identify and label the patient’s illness narration, and the patient is challenged by the notion that symptoms could be understood as ‘not real’ or ‘made up’ (Jutel 2010, 229). Hazel had to navigate multiple misdiagnoses and different physicians to gain a diagnosis that aligned with her illness experience and offered potential treatment. She recounted her diagnosis, saying:

The [pain] eventually got to a point where I went to see a few doctors and they said I had a variety of interesting medical diagnoses. One said, “you have got acid reflux so take Losec”, another one said, “oh you are just hormonal don’t worry about it”- that was the worst one; I detest that doctor. And then the first time that I went to see, actually it was the doctor from my childhood. I had kind of moved away to see a different doctor once I started dealing with more adult lady problems, so I started seeing a female doctor. But I went back to him because he had the appointment and I just couldn’t take anymore and he said to me, “do you experience this? Yes. This? Yes. And this? Yes [listing a variety of IBS symptoms]”. And he was like, “oh I think you have Irritable Bowel Syndrome”. And I actually cried in the doctor’s surgery because I was just so grateful that somebody had actually listened to me and had been able to describe accurately what it was that I was feeling and then set me on a path to actually make it better or more manageable.

Hazel’s diagnostic process took over three years. During the initial years, Hazel found that doctors dismissed her, providing diagnoses that only related to one of her symptoms, making her feel that her physicians were not listening to her properly. It wasn’t until she was forced to take an appointment with her childhood doctor out of desperation that she felt someone had heard, and understood her illness experience.

The lengthy and frustrating process of diagnosis and the often difficult patient-doctor relationship resonated through all my participant and survey respondents’ narratives. Survey respondent D recounted their experience of diagnosis writing:

It’s very frustrating. Over the years, I have seen four GPs, one nurse, one nutritionist, two gastroenterologists and one dietician. None of them were much help. Some seemed reluctant to provide any diagnosis. GPs in particular didn’t appear to have much knowledge about gut issues. The first GP I saw was baffled - she twice asked me whether I had drunk water from a well or taken any Chinese medicine. I have done many tests but have received few answers.

This quote illustrates the multiple medical consultations that a diagnosis can require and the frustration that develops for the individual in having to organise and pursue so many medical encounters. This survey respondent alludes to the frustration of not being listened to and questions the ability of physicians to provide what is expected from biomedicine; a diagnosis. It is important to note the difficulties that physicians face when they encounter patients with medically unexplained symptoms. As the aetiology of IBS is unknown and the medical

knowledge surrounding it is relatively limited, the diagnosis process is difficult terrain for the physician as well (Kirmayer et al. 2004, 663). However, given the wide spread authority in popular discourse it is not often that we think of biomedicine as not being able to explain an illness.

## **The brief relief of diagnosis**

Diagnosis has been considered the root of medicine's claim to authority (Freidson 1972, 244). It mediates 'judgements of legitimacy' both in medical and social worlds by providing explanation and normalisation (Buchbinder 2011, 457-458; Jutel 2010, 229). Womack (2010, 82) notes that diagnostic labeling can be considered a form of healing as it helps to establish order in the presence of disarray. In the case of IBS, diagnosis does not mean a cure however, for my participants it did provide relief and solidity to their frustrating array of symptoms and diagnosis process. Due to the limited biomedical knowledge about IBS one of the most important aspects of its diagnosis seems to be the assertion by physicians that it is a real condition (Buchbinder 2011, 465). Through gaining a diagnosis, participants felt that this acknowledged their illness as a real condition, providing relief and illustrating the power of diagnosis to legitimise. For many participants, the diagnosis of IBS was a relief as they could put a name to their symptoms, know it was not a terminal illness, and know that they weren't making it up. However, this relief was often short lived as participants soon realised that the diagnosis meant little in terms of effective treatment, nothing in terms of a cure, and often resulted in ambivalence from others. This was an aspect of diagnosis that Åsbring and Närvänen (2002, 154) identified in the experiences of people who have CFS and Fibromyalgia. They noted that the diagnosis of both often provided implications for stigmatisation and ambivalence highlighting that is it other's knowledge of, and attitudes towards, a diagnosis that informs how an illness is received and treated by others (Åsbring and Närvänen 2002, 154). My participants commonly felt that once they were given a somewhat hollow diagnostic label they were then left to fend for themselves against the disruptive, painful, chronic and frustrating symptoms of IBS. Below, Hanna recounts the moments after she received her diagnosis and what the diagnosis meant to her stating:

I can picture myself sitting in the doctor's room and them telling me [I had IBS] but not really explaining what it was and then leaving and being like ok so now what? Then after that I'd go



to the doctor quite regularly because the symptoms wouldn't subside, they didn't really give me any coping mechanisms... I think I was relieved in a sense that I knew what it was, so these stomach pains were something and I wasn't crazy. But then we were kind of like ok it's IBS but now what? What do I do? You don't just take a pill and it immediately goes away and I did struggle with telling people. Cause when you say Irritable Bowel Syndrome they just think you poo all the time or something.

Hanna clearly felt initial relief when she was finally given a diagnosis as it meant she knew what her symptoms were and that the pain she was feeling was legitimate. Her diagnosis meant she could assert that her illness was a physical reality while simultaneously rejecting psychological explanations (Ware 1992). As noted by Glenton (2003, 2246) in her study of chronic back pain sufferers, a diagnosis was important as it led to 'explanations of cause and suggestions for further action, as well as access to welfare benefits and social services' providing some relief for sufferers. In the case of my participants, diagnosis was important because it legitimised their illness experience, however it did not provide explanations of causation, effective treatments, or a cure, or access to any benefits or services. For Hanna diagnosis also came with new challenges of how to treat multiple symptoms as well as how to tell people that she had IBS without being or feeling stigmatised, judged, or having her illness delegitimised and misunderstood due to other's assumptions about illnesses related to the bowel.

Hazel and Emma also felt relief when they were diagnosed with IBS. Hazel recounted her reaction after a lengthy diagnosis saying:

When I was diagnosed, there was this massive feeling of gratitude that somebody had listened to me and actually tried to understand my problem, instead of just writing me off as stressed or hormonal or something equally as belittling. Yeah, when someone said, "it is [IBS]", it was just this feeling of, oh thank god and relief because I know what it is and I can do something about it now.

For Hazel diagnosis meant that there was a way forward with her illness and she could improve her symptoms to some extent. She felt that her struggle with biomedicine to gain an explanation and name for her illness was over even though the cause could not be explained. Emma on the other hand had a similar reaction to diagnosis as Hanna. When asked how she felt after she

was diagnosed she said, 'I mean it was good to put a name to it but it still sucks having a condition like this. One that's not curable.' Emma is very clear about her understanding of her diagnosis noting that the label was useful, however the reality of that label meant little in terms of easing her symptoms and improving the impact of IBS on her life.

Physicians often take the blame for the initial lack of information surrounding IBS and how to ease symptoms. Previous research on patients' perceptions of IBS suggests that 'physicians are perceived to be providing inadequate medical information or support for patients with IBS' (Bertram et al. 2001, 521). Though many participants felt that their physicians did not provide much support or advice once a diagnosis was gained they were still relieved to have a diagnosis. For Lewis, another participant, the sense of relief that he associated with diagnosis was based around the fact that it meant his illness was not terminal. He said:

I was at an age where there were other conflicts in my life and having yet another syndrome or another discomfort, illness, call it what you like was quite distressing. And so, I guess at the time I felt quite relieved that from the description from the doctor that this was not a terminal or an unrepairable situation. And so, when I had that sort of confidence I did feel a lot better. So, she did instill that with me.

Diagnosis made Lewis somewhat confident about his illness and like Hazel he felt he could now move forward with his illness and work on improving his illness experience through treatment. In hearing and understanding the diagnostic label of IBS, Lewis and many other participants were relieved to understand that their symptoms were not linked to a terminal illness. Jutel (2014, 78) notes that in labeling an illness we also predict and communicate its outcome. For IBS, perhaps the most important and relieving information attached to its label is that it is not terminal. Diagnosis changes how life is lived and understood and once a diagnosis is given the individual changes becoming different from the self that first walked in for a consultation, dividing life into 'before' and 'after' (Jutel 2014, 78-79). Jutel (2014, 78-79) posits that diagnosis provides transformative relief or dread highlighting how each individual understands their diagnosis differently. For Hanna, Emma, Hazel and Lewis the diagnosis of their IBS meant they did not have a life threatening illness such as bowel cancer providing some relief, however they faced learning to live with a disruptive chronic illness highlighting the double bind of their diagnosis.

## Conclusion

In this chapter I have explored my participants' experiences of the diagnostic process and the medical relationships that inform their illness experience. For all my participants and survey respondents the diagnosis process provided frustration with the biomedical framework that dominates the understanding of and approach to illness both in medical and popular discourse and practice. Participants engaged with multiple physicians and medical tests within biomedicine to gain a diagnosis. Their attempts to self-diagnose were framed by the biomedical knowledge available on the internet and their search for medical diagnosis illustrates the authoritative power that biomedical knowledge has over explaining illness in society today. Though participants occasionally challenged this biomedical knowledge, they also relied on it to gain social acceptance of their illness and to legitimise their symptoms. The diagnosis of IBS is gained through working toward a diagnosis that fits participants' experiences of their bodies and illness. The process of diagnosis often left participants feeling stigmatised and delegitimised while also forcing them to consider if their own experiences of symptoms and pain were real. The patient-doctor relationship and the relationship with family members that informed the diagnosis process helped to gain a diagnostic label in the end yet along the way these relationships caused additional challenges for participants. Gaining the diagnosis of IBS was a relief for many participants, however they soon acknowledged that the diagnosis meant little in way of a cure and instead meant that they might live with IBS for the rest of their lives. After this realisation participants' focus moved to find ways to manage their IBS through multiple treatments to reduce its impact on their lives. Participants often struggled with that fact that IBS is considered a 'named syndrome' in which there is no pathological explanation for its symptoms but a diagnosis can still be given (Nettleton 2006, 1168). This form of diagnosis results in a difficult and unclear treatment regime which does not work for everyone (Nettleton 2006, 1168). My participants were relieved to be able to put a name to their illness yet frustrated that this name and diagnosis seemed almost hollow in that treatment was not straight forward and often ineffective, as explored in the next chapter.

## Chapter Four

### Managing treatments

I remember when I got my referral letter saying they would get me an appointment with a gastroenterologist. I remember crying because I thought that he could magically fix me you know, there is always that hope where you're like yes, I have got IBS, I have been reading all these things online about how it can take years and years to go away and I thought you know, maybe, maybe he can help me. And then I went and he said, "you have got IBS". Yes, I know that! I mean it was good but the reality is you can't fix IBS.

Catherine

As mentioned in chapters two and three, Catherine's IBS symptoms began after a severe gastrointestinal infection. Eventually she and her mother diagnosed post-infectious IBS<sup>28</sup>, and then this was confirmed by her doctor. Catherine has been living with IBS since 2015 and feels she has become a lot better at managing her symptoms over this time. She trialed many treatments suggested to her by family and various physicians while also carrying out her own research into therapies that she understood might ease the symptoms of IBS. Her experience of struggling for effective treatment spanned several years and is ongoing but she has always held out hope that a new treatment might be developed, perhaps even a cure. Her family supported her as she navigated a trial and error approach to treatment, various medical and layman advice, and developed her own personal regime for symptom management. Catherine's current management regime consists of a low FODMAP diet, digestive enzymes, supplements, acupuncture, Chinese herbal medicine, Gastro-Soothe<sup>29</sup>, and probiotics when needed. She also makes sure to manage her sleep and exercise according to how her body feels.

In this chapter I discuss the multiple treatments of IBS through my participants' experiences of engaging with multiple health sectors, dealing with challenges to their responsibility for health and the consumerisation of treatments, dealing with society's expectations of treatment, and a new relationship with food. I illustrate how the management of IBS is influenced by many people in my participants' social and medical networks, as well as the social expectations

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<sup>28</sup> IBS that appears after a gastrointestinal illness (Simrén et al. 2013, 163).

<sup>29</sup> An antispasmodic that helps to relieve cramps and spasms of the gut (Lacy et al. 2016, 1398).

around treatment developed within a biomedical and neoliberal context. It is evident through my research that each of my participants has a different way in which they manage their IBS and that their strategies have been influenced by their individual symptoms, access to potential treatment, access to IBS information and support groups, and their social and physical environment.

As with diagnosis, many people are involved in the treatment of IBS. Not only does the individual have to learn to manage their illness, but also the input and support required from family, friends, society, and physicians. The diagnosis of IBS did not mean that my participants could deal with treatment on their own. Instead after diagnosis their illness experience often became more complicated. It introduced them to a new social category of someone with a chronic illness. Jutel (2010, 229-230) points out that diagnosis essentially controls and compels people to become 'obedient to a new set of normative obligations including incapacity and therapeutic compliance', but also noting that without diagnosis one does not have access to an explanatory framework, treatment options, the sick role or the legitimisation of their symptoms. Through treatment physicians and practitioners offering alternative therapies manifested important roles in the lives of my participants. Treatment became an ongoing management of symptoms and a series of social encounters that shaped the experience of their illness.

The management of IBS is a daily occurrence. Participants have to navigate their symptoms within social encounters as well as in relation to social, biomedical and neoliberal expectations of effective and efficient treatment. IBS demands an engagement with multiple treatments and approaches that address not only physical aspects of the illness but also mental, social, cultural and environmental aspects. This pushes physicians and people with IBS to look beyond the biomedical framework toward a more holistic understanding of illness, the body, and treatment. As the causes of IBS are unknown and no cure has been identified, treatment is comprised of managing symptoms and testing out a variety of potential therapies (Bertram 2001, 522). Even after a diagnosis was achieved, my participants faced the challenge of investigating treatment options. Participants often reflected on the length of time it took to find any form of relief from their symptoms and found that some treatments only reduced particular symptoms. They spoke of frequently returning to physicians or consulting additional physicians in the hope that they could offer new information or treatment. We must also consider what ineffective treatments also mean for people's relationship with their physicians. Glenton (2003, 2243) notes that when effective treatment is not provided by a physician the patient's dependence on the

physician in many cases is prolonged rather than decreased. This prolonged dependence may also be an artefact of the way in which the physician plays a central role in legitimising illness and acting as a gatekeeper to explanatory frameworks of illness, effective and tested treatments, and new research (Glenton 2003, 2244). New treatments for IBS were trialed by my participants in the hope for relief but often within a process of a potentially life long search for more effective treatment.

## **Managing multiple health sectors**

Catherine, as well as other participants, spoke about trying out and adopting various treatments from different sectors of health care. Kleinman (1980, 49-50) identified three sectors of health care – the popular sector, the folk sector and the professional sector. I use these three sectors to illustrate the different types of knowledge, social assumptions, and people that influence treatment. All participants have engaged with each sector to develop their own individualised management regimes. The popular sector is the lay, non-professional, non-specialist realm of society in which illness is identified and defined and the point from which health care activities originate (Kleinman 1980, 50). It encompasses all the treatment options that are used without consultation with medical professionals or alternative therapy specialists. Popular sector treatments include self-treatment/medication; advice or treatments provided by family, friends or others from social networks such as self-help groups; and any discussion or consultation with a lay person who has personal experience of an illness or treatment (Helman 2007, 82). The popular sector is generally the primary site of health care in society. Many illnesses and physical states are identified and treated within this sector.

The folk sector is situated between the popular and the professional sectors and refers to specific individuals that are specialists in forms of healing and treatment that can be considered sacred or secular or a mixture of the two (Kleinman 1980, 59).<sup>30</sup> Helman (2007, 84) offers examples of folk healers ranging from ‘secular and technical experts such as bone-setters, midwives, tooth extractors or herbalists, to spiritual healers, clairvoyants and shamans’. It is important to note that while in the past much of the medical profession has been suspicious and dismissive of folk healers and alternative medicine there has been an increased recognition by

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<sup>30</sup> The folk sector is often more closely related to the popular sector (Kleinman 1980, 59).

the medical profession that there are some benefits to these treatments for patients and their families which has led to a form of professionalisation for some folk healers (Helman 2007, 90; Brierly and Kelber 2011, 604).

The professional sector encompasses the organised, legally sanctioned healing professions: those developed from modern scientific medicine also known as biomedicine (Kleinman 1980, 53). It includes physicians of various types, specialist as well as paramedical professions including nurses, midwives and physiotherapists (Helman 2007, 94). Though these three sectors seem as though they are individually defined, they overlap in multiple and changing ways, and in relation to different cultures. Kleinman (1980, 50-51) illustrates these sectors as overlapping circles and discusses how the individual patient moves back and forth between them throughout their lives in order to gain differing treatments and evaluate the benefits from each sector for different aspects of ill health.

My participants spoke about engaging with multiple treatments from some or all the health care sectors simultaneously and that this exposure to multiple treatments (which have either failed or were in some way beneficial) developed their confidence and knowledge to become expert patients. Guell (2012, 518) states that care related to chronic illness requires the person with the illness to be their own full time caregiver in order to manage their symptoms and that they must work to integrate this management into their everyday life. Guell (2012, 518) also notes that they become expert patients through their constantly developing knowledge and practice of health care and management. Participants understand complex treatments and then make decisions on which therapeutic paths to take sometimes with little assistance from the professional sector. Catherine illustrates how and why she engaged with these three sectors of health care during her search for effective treatment saying:

Post, self-diagnosis and being on the FODMAP diet, I started taking Aloe Vera capsules. I felt that anything that will make me feel better [is worth it]. I was also getting acupuncture and I was taking Chinese herbs in addition with that. I have no idea if that helped me but I felt so much better so I kept doing it. That helped a lot with the fatigue and the brain fog. I don't care if it is a placebo effect, I felt better. My GP really was not into that, she said that I didn't need to have acupuncture. But I felt she was not offering me anything that made me feel better so I kept doing it. It's interesting the natural health thing. Then I saw my mum's specialist doctor

and he is into that sort of thing so day to day now when I eat meals I take digestive enzymes, so like Pepsin and stuff like that for my stomach.

Though Catherine felt some conflict when telling her physician that she was experimenting with alternative medicine to treat symptoms she felt that there was little more her physician could offer and that she had no other option but to engage with the popular and folk sectors of health care.

Like Catherine, Hanna also engaged with different health sectors to manage her IBS:

I found that foods were just not agreeing with me and so I got given the FODMAP diet to try a few times, which is really challenging to do. I didn't see great effects from it. I have done it a couple of times. Then I remember trying, this was through a family friend who had them, I think they are called Minteck tablets, like mint oil. You buy them from the pharmacy. I tried taking those, but they were really expensive. Being like a 14-year-old, I remember mum and dad being like, "do they actually work? I don't want to buy these for you if they don't". I think that's pretty much all the advice I got - oh I think actually they [the medical physicians] may have mentioned to me about going to a counselor to get the stress under control. But I hated talking back then, so I was like, "hell no!".

In both Catherine's and Hanna's narratives there is evidence of how family impact the management of IBS and engagement with different health care sectors. For Hanna, there was a clear economic factor influencing her treatment options and she felt pressured to know whether certain treatments such as the Minteck tablets were working perhaps even before her body had time to react to them. The economic impact of seeking treatment across all three health sectors was evident in all my participants' narratives.

## **Neoliberal influence on treatment**

For each participant, the access to multiple treatments across the three sectors was clearly available. This is perhaps due to the capitalist market in which medicines and treatments have become more readily available and promoted. Nettleton (2013, 226) suggests that 'perhaps the defining feature of contemporary health care both in the UK and other post-industrial nations is the grip of neoliberalism, most particularly the emphasis on choice, individualism,



commercialism and competition'. Catherine and Hanna's narrations illustrate some of the values that neoliberalism encourages, such as the right to have individual choice and the right to develop an individual management regime. They also engage with the commercialisation of medication and treatments by trying out different remedies developed under brand names like Mintek and Gastro-Soothe. Commercialisation highlights a powerful process within modern society that helps to reinforce social 'norms' (Dew and Kirkman 2002). Dew and Kirkman (2002, 102-104) state that the commercialisation of medical practice and the direct-to-consumer advertising of drug companies can be placed within the context of the neoliberal revolution in New Zealand. Within this neoliberal context markets are seen as the most efficient way to allocate health resources and competition across health services and pharmaceuticals is encouraged. This competition is meant to provide better services and products at lower cost and transform patients into consumers that have a choice within the marketplace.

The neoliberal grip on health care has seen an increase in the pressure for individual responsibility to maintain and effectively manage health, as well as the development of the patients becoming consumers in their receipt of care (Nettleton 2013, 226-227). These aspects also influence health promotion. Ayo (2012, 100-101) notes that the increased promotion of healthy lifestyles since the 1980s has developed to reinforce the ideal of the responsible, health conscious citizen that is expected to buy into the 'healthy lifestyle culture'. He further notes that this 'healthy lifestyle culture' which has developed within western societies can be understood as a moralistic one in which values of 'prudence, hard work, responsibility and asceticism' are encouraged (Ayo 2012, 100-101). My participants manage their IBS within these aspects of neoliberalism. They chose to engage with multiple treatments from competing health sectors and pharmaceutical companies while also striving to maintain a healthy lifestyle in the eyes of society so as not to draw attention to their illness.

After diagnosis, many of my participants felt they then became solely responsible for finding effective treatment across competing health care providers and medications. They were surrounded by the multiple treatment options suggested in advertising on the internet, from physicians, family, friends, and strangers. Ayo (2012, 101) emphasises that neoliberalism is not just an economic or political term but it is also a social and moral philosophy informing how individuals should participate in society. Rose (2013, 349) notes that responsibilisation and increased choice in health services and products seems difficult to argue against. However, he highlights that through responsibilisation and commercialisation individuals are obliged to

manage nearly all aspects of their lives in the pursuit of health; further suggesting that when individuals are unable to or unwilling to do this, feelings of guilt may arise and others may view them as culpable for their own illness even if in reality there is little they can do to manage or prevent it (Rose 2013, 349-350). Trnka and Trundle (2014) suggest that responsibilisation is not just placed on the individual under neoliberal values but is also enhanced within social obligations, dependencies and reciprocities when being transferred from the state to the individual. Though we are individuals we still exist within social networks and these networks reinforce the responsibilisation view of functioning.

But who really decides what treatment is best or investigated and who influences those choices? Garro's (1998, 319) work on decision models of treatment choice suggests that it is important to look at not only the culturally based rationality behind choices but also the personal, social and cognitive processes that inform meanings about the occurrence of illness, and therefore how these meanings influence treatment choices. My participants often made treatment choices which were identifiably influenced by their cultural and social worlds. These choices could be seen to be made and acted upon by the individual however it is clear that family, friends, physicians, and even total strangers played a role in reaching these decisions and solidifying their choices. Good (1986, 164) questions the assumption that individuals have the freedom to make personal voluntary decisions and suggests that this framework of understanding decisions limits the attention that should be paid to the social constraints that may influence decisions and choice.

Neoliberal policy is stated to have negative consequences for health as it increases social and income inequality and reduces social cohesion in society as a result of competition (Turner 2007, 184). Coburn (2000) notes that due to these developing inequalities and reduction in social cohesion the health of individuals erodes. Both Catherine and Emma highlight how the cost of managing their illness has affected their illness experience and the extent to which they can utilise health services and products. Catherine discussed the difference in medical consultations within the public and private sectors saying:

My gastroenterologist referred me [to a nutritionist] through the public health system. Which is cool because they were like, "well you can see someone in private if you don't want to wait this long". And I thought, I don't really have the money to do that, it's like \$300 a session so. So, I waited.

Catherine ended up waiting a year and a half to see a nutritionist due to administration problems and wait lists within the public health system. She again referenced the cost of treatment for her IBS when discussing the enzymes, probiotics, and supplements she consumed on a regular basis. She hoped that she would not have to take these prescriptions for the rest of her life saying, ‘they are expensive. It is \$200 every time I see the doctor and then probably \$90 a month [for enzymes, probiotics and supplements]’.

Emma spoke about finding it difficult to treat her IBS even in relation to food and the requirements of the low FODMAP diet. She commented on the low FODMAP diet saying, ‘it is so depressing, oh my god! Especially because I don’t have much money and my family doesn’t have much money either so there’s very little that we could get. So, just rice crackers my entire life’. For Emma even trying to treat her symptoms through food proved difficult due to its restrictions that tend to eliminate cheaper processed and staple foods. Having an illness such as IBS that can be partially managed through food in turn medicalises food. IBS not only changed the relationship my participants have with food, but it also changed the food that they can eat re-conceptualising it as ‘a medication’ that requires enhanced management and scientific knowledge.

## **Expectations of treatment**

As for IBS, Dumit (2006, 578) notes that CFS and MCS are ‘therapeutically diverse’ in that treatment encompasses a wide range of possibilities including those from alternative medicines and yet where each therapy does not guarantee efficacy; also stating that the illnesses have ‘fuzzy boundaries’ and are often linked with other emergent illnesses and comorbid conditions. The term comorbid refers to co-occurring illnesses (Weaver 2016, 506). For example, four of my participants and many of the survey respondents divulged that they had either Endometriosis, Chronic Fatigue Syndrome, chronic pain, or other disruptive symptoms that had not been placed under a diagnostic label such as feelings of toxic shock, severe headaches, strange abdominal pain, and shaking. My participants were often unsure where symptoms of one illness ceased and where those for another began, seeking to find treatments that relieved multiple symptoms across these illnesses rather than individually.

In considering comorbidity it is important to acknowledge the critiques of this term in relation to the illness experience. Weaver (2016, 506) discusses the biomedical definition of comorbidity (independent, co-occurring disease entities) and notes that the term has been critiqued by medical anthropologists ‘because diseases that co-occur in a single body are never experienced as multiple independent forces’. Although I accept this view, in my research I use the term comorbid to denote the diagnosis of multiple illnesses which have similar symptoms and which my participants believed affected one another. My participants reported that diagnosis and treatment of these multiple illnesses were often kept separate by physicians creating an initial understanding that they had to manage them differently and separately. However, often after individual research and prolonged experience of the comorbid illnesses, participants came to understand that their illnesses were linked and influencing one another. This then allowed them to consider therapies that could relieve symptoms experienced across these illnesses aligning more with how they experienced illness within their own bodies rather than how the illnesses had been explained to them by others and through biomedical discourse.

Glenton’s (2003, 2249) work on chronic back pain highlights that a lack of effective treatment options for those with chronic illness can result in fears about being thought of as a ‘hypochondriac, mental case or malingerer’, and can cause frustration, anger, and feelings of worthlessness for those who have a chronic illness.<sup>31</sup> Frustration, anger, and worthlessness were all feelings expressed by my participants when talking about treatment and IBS in general. Many participants and survey respondents expressed concerns about others belief that their symptoms were not real when treatments did not work even though they had been given a diagnosis. The failed efficacy of treatment over a prolonged period might also be interpreted by others as a sign of unwillingness to correctly manage illness or make the required effort (Glenton 2003, 2250). This illustrates the social pressure underpinning the search for effective treatment and the actual and perceived stigma that can arise during this search in chronic illnesses such as IBS.

When talking to Catherine about how others responded to her requirements around food as part of her management regime, she noted that people often tried to suggest ways to better manage

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<sup>31</sup> Also see Hanna’s quotes in Chapter Six, for an example of this fear. She often spoke about being worried that others perceived her to be making up her symptoms which in turn led to her own self-doubt about her illness.

her illness essentially questioning her own management regime and ability to manage her illness. She recalls people giving her advice about treatment saying:

You know when people offer advice that they think is helpful and it's really not helpful at all. Saying, "oh have you tried being gluten free?" You're like, "yes I have" and they're like, "have you tried taking these probiotics? I'm sure it will fix you".

When Catherine spoke to others about her symptoms she noticed that because her illness was not seen as cured or managed correctly they interpreted this as an unwillingness or lack of knowledge around how to correctly manage her IBS. In encounters like these Catherine felt her illness and her ability to look after her body was delegitimised. Hazel encountered similar reactions. However, her frustration resulted from perceived stigma during her medical encounters when treatments did not work. Below Hazel narrates what she thought her physicians thought of her when she came back after trialing a treatment that was unsuccessful:

I would be like I had no - nothing changed by taking this medication and they would say, "oh really?". You know like the don't believe you. I just feel like there is no customisation of the treatment to the patient so it's like they either think you are making stuff up or being difficult. I don't even know, I just feel so disappointed all the time. I just feel so disappointed. I believe in science, I believe in medicine.

Hazel was frustrated at her physicians and biomedicine for not being able to provide her with treatments that work, but also because she felt that they did not believe she was either experiencing her symptoms or completing treatments correctly. In this quote, Hazel is referring to the three types of medication that her physician offered after diagnosis. Hazel trialed each medication one after another to little effect, however, her physician did not follow up with her after each medication trial, so she had to return to discuss other options. Eventually she became so disheartened by her medical encounters that she stopped going to back. Hazel felt that her medical encounters with her physicians delegitimised her knowledge and experience of her own body. She felt that her physicians did not believe her and questioned her morality in relation to treatments as well as her will to get better.

Some participants often felt that when discussing their IBS their efforts to find effective treatment were delegitimised and questioned particularly when offered treatments that the

others thought they had not tried or undertaken incorrectly. This difficult interaction between individuals who are considered sick and others who are part of their social network is explained poignantly by Jackson (2005). When discussing chronic pain Jackson (2005, 332) notes that people with this symptom ‘threaten the normal routines of biomedical treatment and the expectations governing ordinary face-to-face interactions between individuals labelled ‘sick’ and other members of their social world’ as they are seen to transgress that division between the mind and the body as well as ‘confound the codes of morality surrounding sickness and health’. These same statements can be made in relation to IBS, not only because chronic pain is one of its symptoms, but also because of its prolonged, potentially ineffective and diverse treatment options, and the way in which this affects understandings of expected treatment behaviors. For example, Hazel noted that, ‘people get really confused when you say, “I am gluten intolerant so I can’t eat this”, and they are like, “but you ate a piece of cake earlier”, and I have to say, “yeah so, I am not allergic, I am intolerant”’.

When Hazel challenged the assumptions that people had about IBS and the cause of specific symptoms, she felt that she had to explain her reasons to reduce their misunderstandings and negative views. For many of my participants managing their food intake through low FODMAP diets provided a significant level of doubt from others about their illness despite this often being the most effective treatment. The social expectations of valid treatments impacted the illness experience of my participants. Ablon (2002, S5) states that the types of treatments and treatment practitioners sought out by those with special health conditions can be source of stigma. Alternative healers and treatments are seen as less legitimate and are often disputed by society; the general public might see engagement with these types of treatments and health sectors as ‘superstitious, useless, fraudulent, or illegal’, essentially resulting in judgement of the moral character of the person engaging with them (Ablon 2002, S5). Within a society dominated by biomedical and neoliberal values participants felt that their treatment regime and how they managed their bodies were often questioned and required to be better thus, developing perceived stigma within their illness experience.

## **Conclusion**

My participants’ desperation and determination to find various treatments that could manage their symptoms led to their interaction with the three sectors of health care outlined by

Kleinman (1980); the popular, folk and professional sectors. Moving between these sectors they developed their personal IBS management regimes whilst interacting with biomedical and neoliberal expectations of achieving effective treatment and individual responsibility for health, and engaging with the multiple treatments available due to the commercialisation of health services and products. Various treatments were brought to their attention via people in the three health sectors and it was up to the participant to trial these to create their current and individually effective management regime.

The treatment of IBS is very personalised however the social and cultural factors involved in creating and maintaining an individual's management regime are complex. Not only did my participants have to negotiate complex social and medical interactions they also had to navigate multiple medications, lifestyle and dietary changes, alternative therapies, psychological therapies, their own bodies, and new relationships with food. The longevity of treatment is daunting and the hope for a more effective and less time-consuming treatment or cure is constant. Living with IBS means the constant management of symptoms and navigating society with this chronic illness is challenging. Perhaps the most important similarity to note across all the participants' narratives is the perseverance in seeking effective treatment and relief from symptoms involving a process of trial and error and varying individual responses to treatments, as well as their need to manage other's reactions to this process. In trialing, multiple treatments and trying to understand how their bodies reacted to them my participants felt that they often had no control over their body causing a tension with their expectations and desire to improve symptoms.

## Chapter Five

### Body and self in tension

I walked briskly down the hill toward the high-rise building in which I was to meet Hazel. My body was hot and I could feel a squeezing in my stomach, a common reaction to any impending social interaction. I felt a sharp pain in my lower abdomen as I walked into the elevator and knew that my bowels were moving. I hoped that the movement would not result in needing to find a bathroom quickly, though I knew Hazel would understand. Slowing my breathing I tried to calm my body to hinder any further movement. I remembered what Hazel had said during our last interview: “I was hyper aware of how my body was responding to the situation”, and thought how my body might impact our interview and why my body acted despite my desired feelings.

Fieldnote vignette (31/5/17)

Navigating life with a chronic illness results in constant awareness of the body and how it challenges individual and social expectations. This opening vignette recounts how I felt in the moments leading up to my secondary interview with Hazel and how I tried to gain control over my body in the hopes to control its impact on our meeting. Conversations that developed with participants during our interviews commonly revolved around stories about the lack of control they felt over their bodies and how they managed and failed to manage or control their bodies and symptoms in certain situations. Their actual experience of their body was often in conflict with their own individually held expectations, and the body was commonly referred to as an autonomous actor in which the self had no control over or unity with. This chapter explores my participants’ experience of a disconnection between the self and the body, highlighting the body as deviant from the self. Participants spoke about their bodies as threatening to expose them and their illness. The tension between the self and the body illustrates societal expectations that have been influenced by biomedical understandings of the body; the expectation of a well-functioning body that allows participation as desired in society. Those unable to meet these expectations due to chronic symptoms of IBS experience perceived stigma and isolation. Through research with people who have rheumatoid arthritis, Bury (1982) concluded that when living with chronic illness assumptions about the body, life, and the future are disrupted, as everyday behaviors often change and the body emerges painfully into everyday awareness.



The body has been a core component of anthropological research for many years and conceptions of the body are integral to medical anthropology. It is the inevitably ever-present in all social and cultural interaction and is the cornerstone of 'taboos, prejudices, and judgements' that inform how bodies are perceived within society (Thomas and Ahmed 2004, 1). Chronic illnesses in their various forms assault the body in multiple ways and threaten the integrity of the self, interrupting daily life and undermining the self and identity (Charmaz 1995, 657). Kestenbaum (1982) notes that a person's sense of unification between the self and body as well as the self and the world is threatened by illness. My participants discussed the self, body and society as often conflicting components of their illness experience highlighting a constant struggle to control the body and align it with the self so that they could function within society as desired and expected. Yet, this was easier said than done.

The self and the body are considered inseparable by some scholars (Gadow 1982; Charmaz 1995). The body and what it feels affects the mind and consciousness, and the mind and consciousness is contingent on being in a body (Charmaz 1995, 659). However, although self and body are inseparable it is key to understand that this does not mean they are identical and that the connection between self and body becomes especially problematic for those who experience chronic illness (Charmaz 1995, 659). Charmaz (1995, 659-660) expands on the relationship between self and body in chronic illness noting that people who experience bodily losses also experience repeated challenges in the relationship between self and body. The unity between self and body felt by an individual fluctuates with the experience of new and chronic symptoms and increased intensity of symptoms (Charmaz 1995, 659-660). For my participants' a constant fear of intensified symptoms informed their social interaction and daily thought processes. For them the relationship between self and body is in constant flux and unity between self and body was a desired attribute that was also plagued by uncertainty, doubt and mistrust.

Scheper-Hughes and Lock (1987) highlight how Cartesian dualism has shaped western medical practice and more broadly how individuals experience, think and talk about the body and self. It separates body from mind, real from unreal, and spirit from matter (Scheper-Hughes and Lock 1987, 8). My participants experience the self and the body in tension and therefore inherently refer to this Cartesian dualism while simultaneously explicitly and implicitly referring to the movement away from the dualism towards a more mindful and holistic approach to body

and self. Scheper-Hughes and Lock (1987, 10) highlight the difficulty in moving away from these dualisms when they are so ingrained in our language:

We lack a precise vocabulary with which to deal with mind-body-society interactions and so are left suspended in hyphens, testifying to the disconnectedness of our thoughts. We are forced to resort to such fragmented concepts as the bio-social, the psycho-somatic, the somato-social as altogether feeble ways of expressing the myriad ways in which the mind speaks through the body, and the ways in which society is inscribed on the expectant canvas of human flesh.

This quote highlights the difficulties that arise in the expression of pain and symptoms through language. Charmaz (2002, 310) observes that physical experience of pain and suffering can usurp speech in that no words can describe the experience correctly and that this ‘experience feels strange, alien, apart from life’. In trying to describe the pain and experience of symptoms my participants formed narratives that spoke of a disconnection and tension between the self and the body; feeling estranged from their bodies and resulting in the need to isolate one’s self from society due to their perceived stigma through feeling deviant.

The formation of their narratives show the struggle between the Cartesian dualism that informs the foundations of biomedicine, and the more recent societal interest in mindfulness and a holistic approach to health. As soon as a separation from the body is mentioned the Cartesian dualism of body and mind is implicitly acknowledged, yet in stating their struggle with this tension they are also commenting on what is desirable; unity of body and self.

Participants were very aware of the social expectations that surround the body through their IBS and the way it manifests. They have had to adjust to the knowledge that their bodies will act unpredictably and could betray them at any moment, exposing them and their illness to others. The experience of a lack of control over the body and a unity between body and self has made participants talk about their body as if it is autonomous from the self and an individual actor with whom they try to reason. The uncertainty that the body facilitates for my participants results in personal disconnection between self and body, yet constant awareness of the body and its potential to shame. In this chapter I use Hazel’s narratives to illustrate tension between the self and the body, but this was also evident in the narratives of other participants’ and I use supporting quotes from them to illustrate the commonality of this tension and analyse how biomedicine and neoliberalism has influenced this tension. I also examine how the body and

self in tension highlights desired traits which are influenced by social expectations of the body and how one should function as a social actor.

## **The body as deviant**

Hazel developed IBS during her last year at university and has since been trying to limit its impact on her life by adapting to how her body functions while working to maintain her social interactions, love of dance, and striving to achieve her work ambitions. I first met Hazel on a grey Wednesday morning at her work. She greeted me with a big smile and an outstretched hand. Hazel came across as confident, professional and friendly. I thought of her as someone who seemed very comfortable in their body, yet I was to find out that she felt a constant struggle with her body and how it acted despite her desires. During our conversations, it became clear that Hazel often felt she had little control over her body due to her IBS symptoms. Below she discusses the core emotions that she attaches to her IBS and this loss of control over her body and ability to manage her illness:

When your body starts acting up its frustrating, because there is nothing you can do, you just have to ride it out. There is a little bit of self-loathing too, you know, if I hadn't eaten that extra hamburger I wouldn't be here. I guess there is probably that fear of your symptoms exposing you. And then there is the frustration at the medical profession. Like why will no one help me? Or, why can't I find an answer to this? Or, why is this happening to me still? And then the despair of, why is there nothing that I can do? Why can I not make this better? Why does it have to be this way?

Hazel identifies her body as something that acts as if it was an individual and in turn challenges her self-perception. Her frustration with her IBS stems from not being able to control or manage effectively what her body does and the lack of available assistance in finding out how she might do this more effectively.

Hazel also indicates that there is a level of self-blame that she experiences with her IBS calling into question her own actions and ability to look after her body. This blame may stem from neoliberal values. In their work on male infertility and chronicity in Israel and Lebanon, Inhorn and Birendaum-Carmeli (2010, 94) highlight how the neoliberal values of individual 'rights',

‘choice’, and ‘freedom’ invests the individual with increased responsibility for their health and illness and develops an expectation for the individual to care for themselves and always work toward a better quality of life. They also state that through these neoliberal values people with chronic conditions are expected to seek effective treatment and if that fails, to find an effective way to manage and overcome such a condition’s effect on their lives (Inhorn and Birendaum-Carmeli 2010, 94). People who are seen to fail at achieving either of these expectations risk being blamed for not trying hard enough or not taking advantage of the choices of the healthcare marketplace that neoliberalism provides (Inhorn and Birendaum-Carmeli 2010, 94). Though they talk about this blame coming from the other I propose that it may also come from the self. Hazel’s words illustrate how IBS can assault the self by making her question her ability to function as other people do, make the right choices, and have control over her body. As with Hazel, Emma highlighted how she felt a loss of control over her body when recounting what goes through her mind as she embarks on a challenging physical activity:

I hike and I took the train out to, um, where is it? Simla Crescent and did Mount Kau Kau at the start of the year. And it is sort of weird making the decision to climb up a massive mountain not knowing whether or not your body is going to betray you half way up.

Emma, feels vulnerable when doing activities such as hiking and which challenge her desire to complete self-fulfilling activities and requires the self and body to work in unison. Emma described IBS as ‘...your intestines hating you all the time and your life basically being ruled by your colon’, illustrating a clear frustration with her symptoms and body and their control over her life, essentially giving them agency that surpasses the agency of the self.

Hazel suggests that the mind also has a role to play in how she experiences the body when commenting on the unity between her mind and body saying, ‘I was thinking about it and I actually have such a disconnection between my brain and my body. And sometimes my body is trying to tell me something quite loudly and my brain is just like ‘do da do da do doing or thinking something else.’ In this moment, Hazel realised that the disconnection she feels between her body and mind goes both ways and that the body is not always the actor that makes this unity so turbulent. However, she does see the body as the ultimate cause of her pain. She briefly discussed a recent visit with a physiotherapist who explained to her that people with IBS generally have a hard time building core muscles because their body does not want to tighten the space in which the gut can expand. She recalled thinking ‘I am glad my body is not

trying to cause me extra pain!’ This comment illustrates that Hazel thinks of her body as the sole cause of her pain and that her body acts with agency and is separate from herself yet it informs her experience of pain and in turn her interaction in society. Reischer and Koo (2004, 307) note that the body is conceived as an ‘active agent in the social world, on the grounds that our bodies inescapably mediate our relationship to the world around us’. For Hazel and other participants, the body is spoken about as acting and thus transcends the understanding of the body as object and instead holds the self and body as subjects that interact. For my participants, IBS intensifies this interaction by allowing them to perceive the body not only as an individual agent but as an agent that challenges the self and creates difficulties in social interactions. There is recognition of the threat that the body poses by exposing their illness and the potential to facilitate stigma in their illness experience. Lewis discussed one of his most challenging symptoms highlighting the fear that IBS can instill:

I used to have what some people call just brown water. I mean I would have motions that were just evacuations. And they were instantaneous and scary and god knows where you could be. I had those unpredictably for a year or two.

For Lewis, the symptom of immediate and uncontrollable bowel movements posed the most threat when interacting within society and made him constantly aware of his body. After having IBS for multiple years, he found that this symptom reduced in severity and his bowel movements became more ‘predictable’, however he still lives with the knowledge that his body might act differently than what he desires:

I still get things wrong though. I watched a comedy show the other day and the comedian said he shat himself. Well that’s happened to me too because I got something wrong, mistimed it, mistimed the call and mistaken wind for something else. So that’s in the mix still.

Lewis understands that his symptoms still have the potential to place him in difficult and socially unacceptable situations. By referring to and linking his experience of soiling himself with a comedic performance Lewis comments on the humor and undesirable nature of uncontrollable bowel movements but also implicitly works to reduce the stigmatising nature of the symptom by noting that others experience it too. My participants are constantly aware of their body and constantly considering how to manage themselves with a body that seems to act on its own.

## Talking to the body

The unpredictability of the body is a pervasive aspect of IBS and one which not only affects the self physically but also mentally. Hanna highlighted this during one of our interviews saying:

I reckon when I have really bad attacks of IBS I feel quite down and it is just, there's an effect of it being that unpredictable. It is draining, like being in pain and uncomfortable and not kind of knowing what your body is going to do.

The narratives of my participants indicate a total preoccupation with the body alongside a perceived disconnection between the body and the self. Chronic illnesses challenge and change taken-for-granted assumptions that we have about having a 'smoothly functioning body', and disturbs assumptions about the relationship between the body and the self and a feeling of wholeness (Charmaz 1995, 657). In many ways, my participants talk about their *own* bodies but also talk about their bodies as if they are *individual actors* that can be reasoned with. Hazel, for example said:

I love doing conferences and presentations! But they rip my stomach apart because I get nervous about them and anxious in what I prepared. Going to conferences my stomach is just ripping itself apart. It's like, "I enjoy this though! Can you stop it?!".

Hazel speaks to her body as if to reason with it when it is 'acting up' and challenging her ability to participate in something that she otherwise enjoys. Talking to the body as if it were an individual capable of conversation was relatively common during my conversations with Hazel and in discussion with other participants. This, I suggest, is partly due to the difficult nature of verbally explaining experiences of IBS and how one feels about the body when it acts in tension with your desires and expectations. During a discussion about bloating, Hazel mentioned the immense pain this regular symptom caused her as well as the unusual movement in her body she could feel as the symptom developed. She illustrated her frustration with it by trying to reason with her body saying 'what are you doing in there?! Just calm down!' In his book, *Modernity and Self-Identity* (1991, 59) Giddens discusses the relationship between the body and self, stating:

Most people are absorbed in their bodies, and feel themselves to be a unified body and self. Too radical a discrepancy between accepted routines and the individual's biographical narrative creates what Laing calls a false self – in which the body appears as an object or instrument manipulated by the self from behind the scenes.

I argue that my participants do not feel their body and self to be unified when experiencing IBS, and rather than the self acting through the body, in moments of discrepancy participants felt that the body acted upon and against the self. Although my participants feel frustration with their bodies they also illustrate and reflect on the ways in which their illness shapes them as a whole.

In many ways, my participants aim to hide their IBS however, they also consider how IBS has shaped their self-perception. Many of my participants reflected on how IBS and its manifestation in the body had facilitated or diminished specific personal attributes and how they felt about and managed these changes to the self. Though Emma did not refer to her body directly, as Hazel had, during our conversations she did discuss how she tries to navigate the tension between the body and the self by changing the self. Emma discusses how her IBS flares up in particular situations and not in others and how for her this relates to when she can pretend to be someone other than herself:

My IBS reacts somewhat to stress and anxiety. But I am a professional actor and it doesn't as much when I am acting which is really strange. But it definitely reacts with social situations, like going to interviews and going to parties and stuff, I get so - I feel so terrible most of the time. I think a lot of my anxiety sort of stems from myself and if I am playing on stage I am not me. So, I don't get anxious about that sort of thing.

Through her acting Emma can dissociate and create a new self in which IBS does not play a role. She notices that when she is being another self her general anxiety is less and her body does not feel as terrible. Emma acknowledges that tension between the self and the body is not caused solely by the body or the self but rather both as they are in flux. Her quote above highlights her wish to be free of IBS and mirrors a link that many of my participants have made between their personal, emotional, and relational tendencies and their IBS. Emma considered what she might be like without IBS which comments on how she sees herself with IBS. She said, 'I would probably be a more social person if I didn't have IBS, I have definitely cancelled

going to things because I feel terrible’. Emma acknowledges that her IBS and how it manifests itself in the body through multiple disruptive symptoms, affects her ability to participate in social interaction and that there appears to be a complex psychological component to this. In order to manage her disruptive symptoms Emma often avoids social events and when she did try to organise meeting friends she planned them in advance in the hope that she could reduce her anxiety and manage her IBS more effectively leading up to the event.

## **Realigning self and body**

Charmaz (1995) discusses how people with chronic illness are forced to adapt to new illness experiences throughout their lives and ‘losses’ particularly in relation to the self. My participants discussed how new or common symptoms can come on at any moment due to the unpredictable nature of IBS. This knowledge about their illness heightens tension between the body and self. Although participants commonly spoke of their body as autonomous, separating it from the self, in some cases they have tried to accept this tension and work on realigning the self to the body to gain some control and understanding amidst the chaos of symptoms. Hazel spoke of future aspirations by accepting the limitations that her IBS poses for her future, in the hope that her future self can reason with them. During one of our interviews she said:

I was thinking about it the other day, you know, where do I want to go in my career and what do I want to do? And I thought about it and I actually don’t think that I could go into a very high stress job even though that is kind of what I would want to do. I think that over time, I don’t think my body would be able to handle it.

Hazel realises that her future aspirations and the functioning of her body do not align and that she will need to rethink her future by factoring in her IBS and how it affects her in certain situations. Through acknowledging the limitations IBS places on her future, Hazel works towards gaining some control over her body and matching her aspirations to its functioning. Hanna also discussed realising that she needed to adjust to her body by listening to it and working to its limitations before she could move forward with managing her IBS and life, stating:



I'm bad because I will be like, nah I just have to get through the pain. But I am learning more to listen to my body and be like, no, I actually do need to take myself away from a social situation and tell myself I am not going to miss out, and that my body needs to rest...I just definitely need to listen to my body more and be like, nah, this is not a good idea I need to go home. I have been trying to meditate, if I get a period of symptoms or if I feel it coming on I will try and meditate and see if that slows the process down. But it doesn't always work.

Hazel and Hanna both realise that in order to gain some control over the body they have to create unity between the body and self which has been disrupted by chronic illness. Through adjusting expectations of the body and learning to manage it when it is 'deviant' the self and the body can begin to realign. As stated by, Lewis who has had IBS for over 20 years, he is now able to consider how IBS has in fact added to the self and provided him with some socially desirable attributes. He stated:

I think it has made me more tolerant both in myself and the discomfort it causes and the realisation that this is part of life and to move on. And I think that possibly makes me a more tolerant person generally. And the empathy that goes with that tolerance, self-empathy, you know.

In this quote, Lewis sheds light on how a chronic illness can enhance the self and how a new understanding of the body and self can be reached after many years of navigating illness experience. My participants certainly consider the negative impacts IBS has had on their lives and discussed these openly but they also acknowledged that IBS can add to the sense of self and often stated that IBS had made them a stronger person through the challenges and chaos discussed in this chapter.

Scheper-Hughes and Lock (1987, 6) state that understanding how the body is conceptualised and understood is a key component of medical anthropological enquiry. In their discussion, they highlight that the 'individual body', can be understood as the lived experience of the body-self and that though we all share a sense of embodied self we also experience the parts of the body in highly variable ways (Scheper-Hughes and Lock 1987, 7). They state that the constituent parts of the body – mind, matter, psyche, soul, and self, and how they interact vary for each person highlighting that how the body is experienced in sickness is also varied (Scheper-Hughes and Lock 1987, 7). My participants experienced their illness as facilitating a

tension between the body and self. This feeling of disconnection between the body and self experienced by my participants evidences biomedical commitment to the Cartesian dualism and illustrates how the values of the biomedical model have become part of my participants' illness experience. Scheper-Hughes and Lock (1987, 7) suggest that through an analysis of the 'social body', 'the body in health offers a model of organic wholeness' while 'the body in sickness offers a model of social disharmony, conflict, and disintegration'. I suggest that the tension between the body and self, felt by my participants reflects the tension they experience within a biomedical and neoliberal context that encourages responsabilisation and increased participation in the commercialisation of health services and products, as discussed in the previous chapter, in order to participate in society as a healthy individual. The tension between the body and self also illustrates my participants' inevitable inability to always adhere to these social expectations and the blame they place on themselves for this.

## **Conclusion**

In this chapter I examined the tension between the body and the self that my participants experience through having IBS. Though the body and self are inseparable they are not identical and often inform one another. My participants commonly spoke about a lack of control over their bodies when experiencing IBS symptoms and discussed how this hindered their ability to participate in society and day to day activities. This chapter argues that social expectations about the body and social interaction affect the illness experience by informing the self of how a healthy body should function in society, resulting in tension between the self and the body when these expectations are not met. The expectation of maintaining a healthy lifestyle that has developed under a neoliberal and biomedical context informs how the healthy body should participate in society. When my participants have not been able to maintain their own expectations of a healthy and balanced lifestyle they become simultaneously frustrated with the self and body. My participants felt that their illness changed the self and the body in undesirable ways and when the body was viewed as inadequate and faulty this resulted in perceived stigma and increased social isolation.

## Chapter Six

### Stigma of IBS

IBS is associated with a high level of perceived stigma that can either intentionally or unintentionally lead to actual stigma when the illness is revealed (Dancey et al. 2002; Jones et al. 2009). In this chapter I explore the perceived and actual stigma experienced by my participants. I examine how social and biomedical expectations of the well-functioning body and the neoliberal values of responsabilisation, maintaining a healthy body, and productivity, have informed what is stigmatising for my participants. I argue that IBS challenges social expectations of diagnosis, treatment, social engagement, bodily control, responsibility, productivity, and health. When these social expectations are challenged then deviance is experienced resulting in perceived and actual stigma. However, interestingly and encouragingly, after experiencing IBS for several years each of my participants reported becoming more accepting of their illness, themselves, and their bodily patterns. My participants did not feel that IBS was an overarching part of their identity, however, they all discussed the way IBS had made them interact differently within society. Participants did acknowledge that IBS is part of their lives which they must deal with on a daily basis. For example, Lewis said ‘I just live with it, it’s just part of my routine’. Similarly, during our first interview Emma said, ‘I just live with it I guess’.

Throughout our daily lives, people navigate society through differing encounters. People learn to adapt to interactions in a multitude of social situations and make efforts to avoid displaying any detrimental or stigmatising characteristics. Those who live with long term medical conditions face stigmatisation that is shaped by social, cultural, and environmental factors (Dew, Scott, and Kirkman 2016, 127). The unpredictability and uncontrollability of IBS and its limited treatments make it an illness that is susceptible to stigmatisation (Bertram et al. 2001). Goffman (1963, 2) defines stigma as ‘an attribute that is deeply discrediting’ and states that when such an attribute is attached to an individual’s identity they are reduced ‘from a whole and usual person to a tainted, discounted one’. Yang et al. (2007, 1525) state that social identity is constructed within a certain social context and what is devaluing to identity is specific to that social group. I suggest that any personal attributes that could identify a person as ill, lazy, irresponsible, unproductive, unwilling to participate in society, and as experiencing

a loss of control of the body has the potential to provoke stigmatising reactions. Stigma is understood as embodied within the interpretive engagements of social actors which involves cultural meaning, roles, ideal types, and affective states (Yang et al. 2007, 1528). The way chronic illnesses such as IBS are navigated and understood is heavily influenced by the social and cultural beliefs and values of a particular society. New Zealand society is influenced by biomedical and neoliberal ideologies and has a very strong cultural focus on work ethic, 'can-do' attitude, and stoicism. It is crucial to consider how IBS is experienced within these contexts. Like Scheper-Hughes and Lock (1987, 7), if we assume that the body is both naturally and culturally produced and is secured within a particular historical context, then we must seek to understand how my participants experience and understand their body and illness within the current context of New Zealand.

In referring to stigma I consider two types of stigma discussed by Glenton (2003); actual stigma and perceived stigma. Actual stigma 'refers to the discrimination of the individual', while perceived stigma 'refers to the fear of such discrimination' (Glenton 2003, 2244). In the case of my participants perceived stigma was the most common and perhaps illustrates the internalisation of neoliberal concepts. Kleinman et al. (1995, 1319) discusses how both types of stigma can 'lower the sufferer's self-esteem, creating the inner sense of being discredited or discreditable, which over time spoils his or her identity'. Ablon (2002, S2) highlights that stigma is the negative evaluation of certain features or behavior by society. She discusses stigma in relation to epilepsy, however, she uses this illness to highlight more broadly the differing aspects of medical conditions that can create stigma. Ablon (2002, S2) posits that the dimensions of medical conditions that can result in stigma include, the 'nature of an illness, it's history, and attributed characteristics.' I discuss how the nature of IBS is stigmatising due to its symptoms, due to assumptions that IBS is not a real illness, and due to challenges to social obligations and expectations. Chronic illnesses associated with bowel function such as IBS are socially disruptive, unappealing, and can be isolating.

Stigma develops from social interaction and the social and cultural values of a certain group. Defenbaugh (2013, 161) notes that stigmatisation is not solely caused by the other but that it requires an interaction between the self and the other in which the self recognises the negative judgement and in turn stigmatises the self through acknowledging it. Stigma is a pragmatic and tactical response to what one may consider a threat or danger and to the fear that surrounds the unknown, making it difficult to address and allowing it to perpetuate within society (Yang et

al. 2007, 1528). What is considered a threat or danger depends on the social context and can be both perceived by the self and the other. Beatty (2017, 37) highlights that the discreditable person must manage their identity's knowing that others may become threatened or uncomfortable with the knowledge of their mark. This in turn creates uncertainty and ambiguity in social interactions and can affect self-perception (Beatty 2017, 37). The strategies in which my participants have chosen to conceal their IBS have affected their social interactions and self-perception and in a double bind also have the potential to create stigmatising reactions.

## **Hiding IBS**

IBS is largely an invisible illness, something that comes with advantages and disadvantages. On the one hand an invisible illness can be hidden from others, and its impact on how they are perceived by others therefore limited. However, the effort to hide an illness such as IBS can be constantly challenging and draining, especially when unpredictable, and can limit legitimisation of illness and social opportunities. Through IBS my participants became painfully aware of their bodies, illness, and how each social interaction had to be calculated and carefully navigated. Goffman (1963, 42) highlighted the challenges associated with managing an invisible stigmatised identity when he wrote:

The issue is not of managing tension generated during social contacts, but rather that of managing information about his failing. To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where.

Hazel described how social interaction was often an 'awkward dance' in which she had to choose what information about her IBS to divulge without giving too much away:

Yes, I try to hide my IBS. Especially if you start dating someone and they are like, "let's go here [to a restaurant]", and you are like, "oh, yes let's [hesitation]". Once a guy I was dating made a bowl of ravioli, it was really special ravioli and I was like oh god! And so, I ate it, it was delicious but man I was sick for like three days after that, it was bad! So, yeah it is an awkward dance when you are in a situation with food and others. Sometimes if you are at a restaurant with someone new, you will pick and choose what you ask the waiter about. It is really weird because you don't want to ask them like can you recommend something that doesn't have gluten, or onion, or garlic, and is low in dairy.

When I asked Hazel in our second interview whether she considered herself to be normal her response highlighted the stigmatising reactions that she aimed to avoid by doing this ‘awkward dance’:

Um no I wouldn’t. Just based on the reactions that I get from people when I ask does this food have this in it? Other people are like, “oh what? Why? What do you mean?”, and then you tell them about FODMAP’s and they are like, “what the hell are FODMAP’s?”, and you go through its list and they say, “what can you eat?”. You know, that response to your situation as looking at you as though you are some kind of weird strange person but you appear outwardly normal. Unless you have just eaten something bad for your gut and you look like 6 months pregnant. But for the most part it is like, “what is wrong with you? How did that happen to you?”.

Hazel’s avoidance of talking about her IBS stems from the fear that she will have to deal with a stigmatising reaction. Another participant Emma discussed why she hides her IBS for much the same reasons:

Yeah, I think there is definitely stigma around this kind of thing because you can’t discuss it and you can’t say to your friend, “oh I can’t meet today because I am feeling shitty, here’s why”. Because it’s not the sort of illness that you talk about. And if you have got the flu you can say, “oh I have got the flu”, but this is bigger and harder to talk about especially uncomfortable you know.

Much of the stigma around IBS develops from the divulgence or revealing of the illness, its effect on social and bodily function, and from its physical traits. When stigma arises, it is often felt by the individual to attack the self and their identity within society and in personal relationships. The act of revealing a hidden chronic illness can be risky and place the individual in a vulnerable situation (Defenbaugh 2013, 159). For people with IBS revealing one’s illness comes with unique challenges due to the assumptions associated with the syndrome.

IBS symptoms in their unpredictability and multiplicity, threaten the effort that my participants put into concealing their illness from others on a daily basis. With the potential for these symptoms to create embarrassing encounters in which participants feel they may lose face they constantly scan their bodies and their surroundings for any potential triggers. Navigating personal relationships can be particularly difficult as participants must decide at what point in

a relationship it becomes necessary to share the illness and manage their sense of vulnerability this creates. In the quote below Lewis discusses some of these issues:

I was in a new relationship and that was uneasy. For a variety of reasons, I mean A, you don't want to be somebody in a new relationship who is showing sickness, and B, just the nature of IBS is slightly embarrassing, especially in a new relationship. So yea it did affect me.

All of my participants' discussed the uncomfortable nature of bowel habits and how even though it is a daily occurrence for all humans it produces disgust and revulsion when spoken about. Douglas (1966, 120) discusses how bodily functions such as bowel movements, urination, and bleeding are often seen as taboo or dirty as they transverse the boundaries of the body and are associated with disease. Hazel highlighted how such bodily functions are never spoken about because it is understood as impolite. She said, 'some people are so weird about talking about bodily functions, it really freaks them out. It's not considered polite conversation even though literally kings, queens, soldiers, and ladies all shit.' In this quote, Hazel brings to light the social rules that inform talking about bodily functions in New Zealand and eludes to the reaction people have if these rules are broken. Like Hazel, Van der Geest (2007b, 75-76) questions why people are often restrained by 'trivial codes of decency' that posit talking openly about bowel movements as dirty and childish. Van der Geest (2007b, 77) points out that learning what is dirty and what is clean and how to distinguish between these is needed to function correctly and as expected in society. I suggest that if the boundaries around these rules are crossed including in conversation then you are seen to challenge social rules and can become open to negative judgements about your moral character.

Participants often chose to hide their IBS due to the perceived stigma associated with the bodily function of defecation. Though IBS encompasses many symptoms and affects each person in a different way, the knowledge that it is an illness affecting bowel movements heightens the fear of stigmatising reactions from others. For example, Catherine said:

I have never had anyone do anything rude to my face, but I am always just like what if I tell people and they are like, "ugghh bowel girl", you know?! It is just not a very - I am way more comfortable telling people I have endometriosis and talking about my uterus than being like, "I have got IBS" – "what's that stand for?" – "oh Irritable Bowel... Yeah".

Hazel spoke about her biggest fear in relation to IBS. She said, ‘I haven’t pooed myself yet so we will put that on the unwanted bucket list. Yeah, embarrassing bodily functions in public, that would be my biggest fear.’ Hanna additionally highlighted the perceived stigma she felt in relation to the diagnostic label of IBS stating what she thought others would think about her when she revealed her illness. Hanna noted:

When you say Irritable Bowel Syndrome they just think you poo all the time or something... they just look at you and be like, “so you poo all the time?!”, and it’s like no, it’s one of the factors but yeah it’s not just that.

My participants try to avoid stigma by concealing their illness. Åsbring and Närvänen (2002, 155) discuss concealing illness as a coping strategy for managing stigma in relation to people who have CFS and Fibromyalgia as a means to minimise negative judgements about their illness. Similarly, I argue that my participants conceal their IBS to minimise actual stigma and employed different ways to conceal various aspects of their illness in relation to their perceived stigma. However, I also note that there is a double bind to concealing the aspects and effects of IBS where in looking and acting healthy in contrast to how one feels allows for increased delegitimisation and stigmatisation of an illness when it is revealed. Lipson (2004, 205) notes that people with MCS usually appear to be healthy and consequently others delegitimise their illness. In relation to IBS many of my participants also felt that others judged them negatively because they looked healthy and therefore could not be sick. In other words, because their illness is relatively invisible it is discredited by others.

## **Disbelief of IBS**

During my interviews with Hanna she constantly expressed feeling stigmatised and delegitimised by others when they made remarks about her illness and assumed she was fabricating her symptoms. Hanna said:

I kept my IBS to myself for ages but I remember saying to people that I had sore stomachs quite often and eventually they would be like, “you don’t have a sore stomach, that’s just an excuse”. So, there is that whole belief that you are making it up.



Hanna felt unable to discuss her IBS for a long time and found that simple explanations of her symptoms was not enough to get people to understand that pain prevented certain tasks or activities. Instead due to the chronic yet often invisible nature of IBS symptoms, others developed disbelief in her illness and put it down to her unwillingness to participate in society and fulfil societal obligations.

Glenton (2003, 2244) suggests that the acceptance of one's illness experience is linked to the level in which that illness experience is seen as common sickness. For example, IBS symptoms that others most often accept are feeling nauseous or having diarrhoea. When my participants explained that they were sick to others in this way it was generally accepted. However, after repeated claims of the same sickness and symptoms participants felt that their illness experience then became less accepted and might be thought to be fabricated. On several occasions during our interviews Hanna noted others stopped believing her when she said she wasn't feeling well. Several survey respondents also expressed feelings and concerns of stigmatisation due to assumptions about IBS. When prompted with the question, are you comfortable with telling others about your IBS? Two responded writing:

Not really. Because there is some sort of stigma that it's not a real issue.

Survey respondent F

Only those I'm close to. I tend to say, "sensitive tummy" as it is perceived as less "gross". Also, I think [IBS] got branded around as a term to capture varying degrees of sensitivity and I didn't like the stigma that went with saying, "I have IBS", as I felt a lot of people used it as a term without proper diagnoses or managing food sensitivity. So, I didn't want to be seen as just "another on the band wagon".

Survey respondent G

In these quotes the respondents felt that there were several assumptions held by the general population about their illness and therefore they preferred not to talk about their IBS. The last quote highlights the misuse of the IBS label which essentially delegitimises the illness experience and works towards perpetuating the assumptions that IBS is not a real illness.

Scambler (2009, 441) discusses the notion of health-related stigma stating that, 'stigma is typically a social process, experienced or anticipated, characterised by exclusion, rejection,

blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or group'. Hanna discussed how she often felt delegitimised and stigmatised during her medical encounters. Much of the perceived stigma resulted from her own judgements, however, it was also facilitated by her interactions with physicians and the many inconclusive results that came from her medical tests:

I remember seeing a couple of doctors that looked like they couldn't care two shits about what I was saying. I remember having thoughts like, am I making this up? Is this in my head? Am I actually not in pain? And then I think I mentioned something to my doctor at the time about me coming in all the time and she was like, "it is absolutely fine, I just want you to feel comfortable". So that made me feel quite good. But I feel like a problem and that is probably because of all the other things that I have got. I reckon when I was younger though, I don't know what they would have thought of me. I think because they just didn't do too much I just didn't have that much faith in them and so I just remember thinking that maybe they think I am making it up. Because you have tests and nothing shows up and it is just your word that they are taking for it...It's a horrible thought to be like I don't think they are taking me seriously. I am feeling really crap but am I making it up? Is it actually in my head?

Many of Hanna's interactions with physicians were negative in the sense that she felt they thought she was making up her illness, that she was wasting the physicians time, and that she was being a difficult patient. Though she did have one physician that supported her and told her that her illness was real, she still felt the stigmatisation and delegitimation from others. When Hanna felt that her illness experience was being questioned by biomedicine and its authoritative knowledge, she then developed a sense of self-doubt which devalued her experience and highlighted the importance of a diagnostic label in order for others to accept her experience as a social legitimisation of an illness.

Like Hanna, Emma has experienced feelings of stigma and delegitimation in relation to her illness. However, hers were due to family reactions to IBS. In our first interview Emma discussed her relationship with her parents and how it impacted her experience of IBS. When I asked Emma about how her parents reacted to her diagnosis of IBS she replied saying:

Well they are not sort of great about it. I think my parents just think it's a mental thing. I am here most of the time anyway. I don't go home that often so when I do they get a little bit pissy [sic] about me having to have certain foods and all that. But yea, you have got to live with them.

In our second interview Emma spoke of her parents again saying, 'I know that when I go home for Christmas and stuff I am [going to be] so ill because my parents don't really think IBS is a thing. And they cook food I can't really eat'. Emma's relationship with her parents has been affected by IBS and their lack of support clearly affects her illness experience and symptoms. She feels that her parents do not believe that her illness is real and she has begun to avoid going home for the sake of her own health. Though her parents pushed her to get a diagnosis they did not support her once she received the diagnosis essentially delegitimising her illness experience. Ablon (2002, S4) states that family attitudes towards illness can be very destructive to relationships as well as the illness experience. When people have to contend with perceived or actual stigma from their families as well as from physicians and society their illness experience is made even more difficult and provides another aspect of ill health needing to be navigated. Hanna also felt stigmatised by her family in the early stages of her IBS. When I asked how her siblings reacted to her symptoms Hanna said:

I think they thought I was a bit of a drama queen and were like, "oh yeah whatever, it's made up, she will do anything to get time off school". I don't think it was until they actually understood later down the track that it wasn't made up. But it makes you feel shit and like do I actually have a sore stomach?

For Hanna, this type of negative judgment from her siblings made her illness experience even more difficult and like her physicians' reactions made her question if she was making up the symptoms. However, her family have come to accept her illness over time. Trundle, Singh, and Bröer (2014, 169) highlight that people without a medically accepted diagnosis struggle to get support and sympathy from family and friends often resulting in the experience of stigma due to shame because their experiences do not match accepted definitions of illness. However, even with diagnosis, the lack of response to treatments can perpetuate negative feelings from significant others.

## Challenging social values and expectations

People with IBS strive as much as they can to limit the impact of their illness on their lives. Unfortunately, despite their efforts many of my participants found that IBS had a firm influence on how they could go about their lives. Emma for example discusses how IBS affects her work opportunities:

I just feel terrible all the time which isn't great and it definitely means I can't do things I want to do in the morning. Finding a job is hard because I especially can't work in the mornings due to my symptoms.

Although Emma notes the limitation in relation to work, I argue that this also inhibits her ability to adhere to the social expectations ingrained in our neoliberal society; thereby challenging her ability to be a 'good', hardworking and 'healthy' citizen (Ayo 2012, 100-101). My participants were very aware of their inability or choice not to adhere to societal norms and expectations. In this way, my participants identify aspects of actual and perceived stigma that might be produced by their IBS within their everyday lives.

We are taught through social conditioning to see things in certain ways. We see life through the eyes of our society and through the history, ideologies, and beliefs that have been passed to us. These ideas are created by those who hold power; those who hold power create our culture (Caron 2008, 18).

This section highlights how IBS can rub up against social values and expectations within New Zealand society developed from neoliberal aspects of responsabilisation, hard work, and the expectation to always strive for a healthy body.

People who have chronic illness often require changes to daily routines such as extra rest breaks, constant bathroom breaks, or flexible work hours to accommodate and manage their symptoms (Driedger and Owen 2008, 7; Beatty 2017, 36). Driedger and Owen (2008, 7) note that these changes in routine can be difficult to manage in the workplace where there are expectations of being present at your workspace, high job performance, and the pressure to look busy at all times. In his work on living with chronic illness in a productive world, Hay (2010) looks at how cultural expectations are used by people with chronic illness to judge,

measure, and value themselves in their worlds. Hay (2010, 259) illustrates that a cultural expectation of productivity in the United States affects illness experience and challenges those with chronic illnesses ability to meet societal and personal expectations creating stigmatisation by the self and others. The drive to be seen as if we are working hard ignores the fact that sometimes working from home or managing work hours to fit personal energy and concentration levels is far more productive.

Under a framework of neoliberalism that aims to make ‘good’ and ‘healthy’ citizens, people are required to partake in a culture that foregrounds ‘values such as prudence, hard work, responsibility, and asceticism’, and the healthy well-functioning body (Ayo 2012, 100-101). Ayo (2012, 101) notes that contemporary western neoliberal societies are moralistic. As Kleinman and Hall-Clifford (2009, 418) state stigma is embedded in moral experience and maintaining moral status in society is ‘dependent on meeting social obligations and norms’. Being a good and healthy citizen in society is linked to an individual’s ability to meet fundamental social expectations, the ability to work, contribute, and take part in subsistence activities (Levin and Browner 2005, 746). Chronic illness is highlighted and made to matter when society is structured in a way that makes it matter, an example of this is the societal value placed on the ‘ability to be productively involved in full-time paid employment’ (Caron 2008, 18-19). The above components of neoliberalism impact how people with IBS struggle with the expectations of society and of themselves under this ideology, particularly in relation to productivity (Bertram 2001, 523). Survey respondent E, noted how IBS impacted their ability to be productive writing, ‘I’ve missed days at work and opportunities to understand crucial parts of my study due to brain fog and the constant battle to understand and remember information. My kids miss out on active opportunities too’.

During our first interview Hazel illustrated her struggle to adapt her IBS to her work and in turn how her work exacerbated her IBS symptoms:

At the start of 2015 I started a new job that was mostly desk bound, so sitting down a lot and my IBS got really bad. Over the space of a month it was just intolerable. I had extreme physical pain at the end of the day, constantly between two to five pm and sometimes further on.

Hazel found that her work productivity was being affected by her IBS but also acknowledged that her work environment was exacerbating her symptoms. Her IBS was disruptive and

threatened her ability to work as efficiently as her co-workers. This also threatened her personal sense of adherence to the social expectations and obligations of hard work and responsibility. Emma found that her peers judged her for missing out on school which developed stigma around her illness and inability to participate fully in society. She said, ‘the rest of my friends don’t care. I did get ridiculed a lot for being off so much at high school. My friends just didn’t understand’. Many of my participants feel that at some point they have had to navigate judgement and stigmatising remarks made by peers, friends, and family in relation to their IBS. Often these accusations were related to their ability to fully participate in society and arose when participants were unable to fulfil work or social obligations due to their IBS.

As discussed in chapter four, *Managing treatment*, neoliberal policies structure how the individual is expected to participate in society encouraging their responsibility to manage all aspects of life in the name of health (Ayo 2012, 101; Rose 2013, 349). Neoliberal policies not only influence economic and political aspects of life, they also influence the moral framework of how individuals should participate in society (Ayo 2012, 101). And when people can not meet these expectations negative judgements can be made about that person’s morality by others producing stigmatisation. Yang et al. (2007, 1524) posit that stigma is essentially a moral issue and that if we interpret and analyse stigma through this approach we can identify what informs judgements of morality that create stigma; and move an understanding of stigma away from an individualised focus and instead towards stigma’s social aspects. In doing so we can then understand how stigmatising reactions and perceptions develop from social, cultural, and interpretive processes and how in relation to these processes anti-stigma interventions can be developed (Yang et al. 2007, 1524; 1535). Rose (2013, 349-350) highlights that when an individual is unable to manage all aspects of their life in the pursuit of health feelings of guilt can arise and others might see them as guilty and culpable for their own illness. I posit that while my participants’ lives are dominated by the pursuit of health and the wish to be rid of IBS they are often seen by others as culpable for their illness essentially delegitimising their illness experience, and questioning their morality and willingness to participate in society as others do.

## **Conclusion**

This chapter explores that perception and experience of stigma that participants and survey respondents have encountered throughout their illness experience. It has discussed how the nature of IBS is stigmatising due to its symptoms, assumptions that IBS is not a real illness, and IBS related challenges to social obligations and expectations. These are all aspects of stigma that participants and survey respondents alike have had to contend with at some point during their illness experience. Though stigma is an inescapable aspect of IBS my participants often spoke of how over time they have come to accept and understand their illness in different ways and have developed a confidence and an active attempt to reduce their perceived stigma. Perhaps over time the constant exposure to perceived stigma from others has allowed them to reduce its effect.

## Chapter Seven

### Conclusion

This thesis contributes to the literature in medical anthropology focusing on the lived experience of chronic illness and the social and cultural aspects that inform this experience. It explores how the concept of stigma and what is stigmatising in modern society is defined in relation to current ideologies of biomedicine and neoliberalism.

The illness experiences of the participants within this research provide an insight into how people interact with chronic illness, specifically IBS, in New Zealand, highlighting the relationships and ideologies that help inform that experience. Though all participants experienced their IBS in varying and subjective ways, there were similarities across their experiences such as conflict within a biomedical approach to diagnosis and treatment, a tension between the body and self, vulnerability during social interactions and activities, and perceived and actual stigma about their IBS. By differentiating between illness – specifically, the relationships and social networks within which illness is perceived and understood –, and disease – a biophysical event –, I have sought to illustrate that illness is interpreted through social meaning and interpretations that are associated with categorisations of experience. In understanding, what informs social expectations of the body and illness we can identify how the experience of an illness is shaped through social and cultural contexts. I posit that in seeking to understand how IBS is experienced within New Zealand it must be explored within the context of the dominant biomedical model and neoliberal policies that inform New Zealand society today.

In exploring the narratives of my participants, I also sought to identify where stigma arose in their illness experience and what influenced perceived and actual stigma. As IBS is an illness associated with bowel movements and bodily functions there are stigmatising aspects of the illness that are perceived as taboo and dirty. However, in seeking to understand a broader sense of how stigma played a role within the experience of IBS, the relationships, interactions, and limitations involved in my participants' illness experiences, and the assumptions people were though to make about IBS were explored. The unpredictable nature of IBS symptoms, its effect



on social behavior, its challenge to societal expectations of illness, and its affect how my participants feel in their bodies are all factors of IBS that provoke perceived and actual stigma.

The process of diagnosis and treatment of IBS exists within a biomedical model and neoliberal context. Participants not only interacted with family, friends, physicians, and complete strangers in their illness experience but they also interacted within these ideologies that inform New Zealand society. All participants and survey respondents found the diagnosis process frustrating, often delegitimising, and eventually disheartening. Participants engaged with multiple physicians and medical tests within biomedicine to gain a diagnosis. Their attempts to self-diagnose were framed by the biomedical knowledge available on the internet and their search for medical diagnosis illustrates the authoritative power that biomedical knowledge has over explaining illness in society today. Though participants occasionally challenged this biomedical knowledge they also relied on it to gain social acceptance of their illness and to legitimise their symptoms. Gaining the diagnosis of IBS was a relief for many participants however they soon acknowledged that the diagnostic label meant little in way of a resulting cure and instead meant that they might live with IBS for the rest of their lives. Then began a series of treatment trials and symptom management strategies eventually resulting in individually designed proactive and reactive management regimes. This process and the resulting regimes caused challenges along the way due to neoliberal concepts of responsibility, stoicism, and meeting life, social, and workplace expectations.

A tension between the body and the self was evident in my participants' experience of IBS. Though the body and self are inseparable they are not identical and often inform one another. My participants commonly spoke about a lack of control over their bodies due to their IBS symptoms and discussed how this hindered their ability to participate in society and day to day activities. Social expectations about the body and social interaction affect the illness experience of my participants by informing the self of how a healthy body should function in society, resulting in tension between the self and the body when these expectations are not met. My participants felt that their illness changed the self and the body in undesirable ways and when the body was viewed as inadequate and faulty this resulted in perceived stigma and increased social isolation. The perception and experience of social judgement is a constant aspect of my participants' illness experiences. The nature of IBS can be understood to be stigmatising due to its symptoms, assumptions that IBS is not a real illness, and because it challenges social obligations and expectations of a well-functioning, healthy body implicit in a neoliberal

approach. I posit that the illness experience of my participants and what is stigmatising for them must be understood not only in relation to its physical manifestations but also in relation to the biomedical and neoliberal influences that inform social expectations of the body and social participation. Further, participants experience their IBS simultaneously resisting and participating within these influences to make sense of and manage their illness in a way that aligns with their lived experiences while also reducing the stigma associated with it.

This research has focused on the experiences of people who have IBS and has revealed the struggle with diagnosis, treatment, and dealing with other's reactions as well as the ultimate acceptance and commitment to best long term self-management of symptoms. Future research might usefully examine how physicians experience the diagnostic and treatment process of IBS, gain perspectives from treatment providers, and explore actual interaction within patient consultations, with the aim of developing a more effective approach to responding to this chronic illness. Additionally, another fruitful focus to research might be analysing how family members, work places, and those associated with people who have IBS understand and respond to IBS to work toward more positive and effective support for those experiencing symptoms and therefore contribute to their best engagement with life, social, relational, and workplace activities.

All my participants took part in this research with the hope that they could help others who had IBS, and work toward destigmatising the illness allowing others to talk about their symptoms, gaining answers sooner rather than later. Catherine illustrated the lack of knowledge and misunderstanding she felt society had about IBS during our first interview. She said:

I think with IBS people don't often look that sick. Even though we don't look sick it can be really hard. I think it is hard for people to be like, "oh, but it's just your stomach". Because it affects my brain too, I can't think properly, and I am tired all the time. I also think people find it hard to think that you have just got a bit of diarrhoea, and surely that can't affect your whole life that much.

My hope and expectation is that this thesis goes some way toward broadening how IBS is understood and in this way, responds to my participants' desire to help the population of those experiencing IBS or supporting those experiencing IBS.

## Reference List

- Ablon, Joan. 1981. "Stigmatized Health Conditions." *Social Science and Medicine* 15B: 5-9.
- Ablon, Joan. 2002. "The Nature of Stigma and Medical Conditions." *Epilepsy and Behavior* 3: S2-S9.
- Andrews, E., S. C. Eaton, K. A. Hollis, J. S. Hopkins, V. Ameen, L. R. Hamm, S. F. Cook, P. Tennis, and A. W. Mangel. 2005. "Prevalence and Demographics of Irritable Bowel Syndrome: Results from a Large Web-based Survey." *Alimentary Pharmacology and Therapeutics* 22 (10): 935-942.
- Åsbring, Pia, and Anna-Liisa Närvänen. 2002. "Women's Experiences of Stigma in Relation to Chronic Fatigue Syndrome and Fibromyalgia." *Qualitative Health Research* 12 (2): 148-160.
- Ayo, Nike. 2012. "Understanding Health Promotion in a Neoliberal Climate and the Making of Health Conscious Citizens." *Critical Public health* 22 (1): 99-105.
- Barbezat, Gil, Richie Oulton, Barry Milne, Stuart Howell, J Paul Fawcett, and Nicholas Talley. 2002. "Prevalence and Correlates of Irritable Bowel Symptoms in a New Zealand Birth Cohort." *The New Zealand Medical Journal* 115 (1164): 1-8.
- Beatty, Joy. 2017. "Chronic Illness Stigma and It's Relevance in the Workplace." In *Stigmas, Work and Organizations*, edited by Bruce Thomson and Gina Grandy, 35-54. New York: Palgrave MacMillan.
- Bernard, Russell. 2011. *Research Methods in Anthropology: Qualitative and Quantitative Approaches*. California: AltaMira Press. ProQuest Ebook Central.

- Bernard, Russell, and Clarence Gravlee, eds. 2014. *Handbook of Methods in Cultural Anthropology*. California: Rowman and Littlefield Publishers. ProQuest Ebook Central.
- Bertram, S., M. Kurland, E. Lydick, G. Locke, and B. P. Yawn. 2001. "The Patient's Perspective of Irritable Bowel Syndrome." *Journal of Family Practice* 50 (6): 521-525.
- Brierly, Stuart, and Olaf Kelber. 2011. "Use of Natural Products in Gastrointestinal Therapies." *Current Opinion in Pharmacology* 11: 604-611.
- Brown, Peter, and Svea Closser. 2016. "Understanding Medical Anthropology: Biosocial and Cultural Approaches." In *Understanding and Applying Medical Anthropology: Biosocial and Cultural Approaches*, edited by Peter Brown and Svea Closser, chapter 1. Walnut Creek, CA: Left Coast Press. Google Books.
- Buchbinder, Mara. 2011. "Personhood Diagnostics: Personal Attributes and Clinical Explanations of Pain." *Medical Anthropology Quarterly* 25 (4): 457-478.
- Bury, Michael. 1982. "Chronic Illness as Biographical Disruption." *Sociology of Health and Illness* 4 (2): 167-182.
- Caron, Charlotte. 2008. "Water Wearing on a Stone: The Role of Shame in the social Construction of Chronic Illnesses." In *Dissonant Disabilities: Women with Chronic Illnesses Explore their Lives*, edited by Diane Driedger and Michelle Owen, 17-28. Toronto: Canadian Scholar's Press Inc./Women's Press.
- Casiday, Rachel, Amritpal Hungin, Charles Cornford, Niek de Wit, and Mwenza Blell. 2009. "Patients' Explanatory Models for Irritable Bowel Syndrome: Symptoms and Treatment more Important than Explaining Aetiology." *Family Practice* 26: 40-47.
- Charmaz, Kathy. 1990. "'Discovering' Chronic Illness: Using Grounded Theory." *Social Science and Medicine* 30 (11): 1161-1172.

- Charmaz, Kathy. 1995. "The Body, Identity, and Self: Adapting to Impairment." *The Sociological Quarterly* 36 (4): 657-680.
- Charmaz, Kathy. 2002. "Stories and Silences: Disclosures and Self in Chronic Illness." *Qualitative Inquiry* 8 (3): 302-328.
- Coburn, David. 2000. "Income Inequality, Social Cohesion and the Health Status of Populations: The Role of Neoliberalism." *Social Science and Medicine* 51 (1): 135-146.
- Coffey, Amanda. 1999. *The Ethnographic Self*. London: SAGE Publication Ltd.
- Collins, Peter, and Anselma Gallinat. 2010. *The Ethnographic Self as Resource: Writing Memory and Experience into Ethnography*. New York: Berghahn Books.
- Corbin, Juliet, and Anselm Strauss. 1985. "Managing Chronic Illness at Home." *Qualitative Sociology* 8 (3): 224-247.
- Dancey, C. P., S. A. Hutton-Young, S. Moye, and G. M. Devins. 2002. "Perceived Stigma, Illness Intrusiveness and Quality of Life in Men and Women with Irritable Bowel Syndrome." *Psychology, Health and Medicine* 7 (4): 381-395.
- Deed, Bron. 2007. "Theories and Models of Healthcare." In *Health in the Context of Aotearoa New Zealand*, edited by Dorothy Broom, Bron Deed, Kevin Dew, Mason Durie, John Germov, Allison Kirkman, Judith Macdonald, Paul Moon, Julie Park, Bryan Turner, and Sue Walke, 27-29. Melbourne: Oxford University Press.
- Defenbaugh, Nicole. 2013. "Revealing and Concealing Ill Identity: A Performance Narrative of IBD Disclosure." *Health Communication* 28 (2): 159-169.
- Dew, Kevin, and Allison Kirkman. 2002. *Sociology of Health in New Zealand*. Melbourne: Oxford University Press.

- Dew, Kevin, Anne Scott, and Allison Kirkman. 2016. *Social, Political and Cultural Dimensions of Health*. Switzerland: Springer International Publishing.
- Dickson, Adele, Christina Knussen, and Paul Flowers. 2007 "Stigma and the Delegitimation Experience: An Interpretive Phenomenological Analysis of People Living with Chronic Fatigue Syndrome." *Psychology and Health* 22 (7): 851-867.
- Douglas, Mary. 1966. *Purity and Danger: An Analysis of the Concepts of Pollution and Taboo*. New York: Routledge.
- Douglas, Mary. 1970. *Natural Symbols: Explorations in Cosmology, with a New Introduction*. New York: Routledge.
- Driedger, Diane, and Michelle Owen. 2008. "Introduction." In *Dissonant Disabilities: Women with Chronic Illnesses Explore their Lives*, edited by Diane Driedger and Michelle Owen, 1-13. Toronto: Canadian Scholar's Press Inc./Women's Press.
- Drossman, Douglas. 1999. "Review Article: An Integrated Approach to the Irritable Bowel Syndrome." *Alimentary Pharmacology and Therapeutics* 13 (2): 3-14.
- Dumit, Joseph. 2006. "Illnesses You Have to Fight to Get: Facts as Forces in Uncertain, Emergent Illnesses." *Social Science and Medicine* 62 (3): 577-590.
- Enders, Giulia. 2015. *Gut: The Inside Story of Our Body's Most Under-rated Organ*. London: Scribe Publications.
- Ford, A. C., and N. J. Talley. 2012. "Irritable Bowel Syndrome." *British Medical Journal* 345: e5836.

- Fortin, Sylvie, Liliana Gomez and Annie Gauthier. 2013. "Functional Gastrointestinal Disorders: An Anthropological Perspective." In *Pediatric Neurogastroenterology: Gastrointestinal Motility and Functional Disorders in Children*, edited by Christopher Faure, Carlo DiLorenzo and Nikhil Thapar, 71-76. New York: Springer.
- Foucault, Michel. 1976. *The Birth of the Clinic: An Archaeology of Medical Perception*. London: Tavistock.
- Freidson, Eliot. 1972. *Profession of Medicine: A Study of the Sociology of Applied Knowledge*. New York: Dodd, Mead and Company.
- Gadow, Sally. 1982. "Body and Self: A Dialectic" In *The Humanity of the Ill: Phenomenological Perspectives*, edited by Victor Kestenbaum, 86-100. Knoxville: University of Tennessee Press.
- Gallinat, Anselma. 2010. "Playing the Native Card: The Anthropologist as Informant in Eastern Germany." In *The Ethnographic Self as Resource: Writing Memory and Experience into Ethnography*, edited by Peter Collins and Anselma Gallinat, 25-44. New York: Berghahn Books.
- Garro, Linda. 1992. "Chronic Illness and the Construction of Narratives." In *Pain as Human Experience: An Anthropological Perspective*, edited by Mary-Jo DelVecchio Good, Paul Brodwin, Byron Good, and Arthur Kleinman, 138-168. Berkeley: University of California Press.
- Garro, Linda. 1998. "On the Rationality of Decision-Making Studies: Part 1: Decision Models of Treatment Choice." *Medical Anthropology Quarterly* 12 (3): 319-340.
- Geertz, Clifford. 1973. *The Interpretation of Cultures: Selected Essays*. New York: Basic Books.

- Geertz, Clifford. 1983. *Local Knowledge: Further Essays in Interpretive Anthropology*. New York: Basic Books.
- Gerson, Mary-Joan, Charles Gerson, Richard Awad, Christine Dancey, Pierre Poitras, Piero Porcelli, and Ami Sperber. 2006. "An International Study of Irritable Bowel Syndrome: Family Relationships and Mind-body Attributions." *Social Science and Medicine* 62: 2838-2847.
- Giddens, Anthony. 1991. *Modernity and Self-Identity: Self and Society in the Late Modern Age*. Cambridge: Polity press.
- Glenton, Claire. 2003. "Chronic Back Pain Sufferers – Striving for the Sick Role." *Social Science and Medicine* 57: 2243-2252.
- Goffman, Erving. 1963. *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon and Schuster Inc.
- Good, Bryon. 1986. "Explanatory Models and Care-seeking: A Critical Account." In *Illness Behavior: A Multidisciplinary Model*, edited by Sean McHugh and T. Michael Vallis, 161-172. New York: Plenum Press.
- Good, Byron. 1994. *Medicine, Rationality, and Experience: An Anthropological Perspective*. Cambridge: Cambridge University Press.
- Guell, Cornelia. 2012. "Self-care at the Margins: Meals and Meters in Migrants' Diabetes Tactics." *Medical Anthropology Quarterly* 26 (4): 518-533.
- Gusterson, Hugh. 2008. "Ethnographic Research." In *Qualitative Methods in International Relations: A Pluralist Guide*, edited by Audie Klotz and Deepa Prakash, 93-114. New York: Palgrave MacMillan



- Hahn, Robert. 1995. *Sickness and Healing: An Anthropological Perspective*. Connecticut: Yale University Press.
- Hay, Cameron. 2010. "Suffering in a Productive World: Chronic Illness, Visibility, and the Space Beyond Agency." *American Ethnologist* 37 (2): 259-274.
- Health Navigator New Zealand. 2016. "Irritable Bowel Syndrome." Last modified September 23, 2016. <https://www.healthnavigator.org.nz/health-a-z/i/irritable-bowel-syndrome/>.
- Helman, Cecil. 2007. *Culture, Health and Illness: Fifth Edition*. London: Hodder Arnold.
- Hockey, Jenny. 2002. "Interviews as Ethnography? Disembodied Social Interaction in Britain." In *British Subjects: An Anthropological Britain*, edited by Nigel Rapport, 209-222. Oxford: Berg.
- Hockey, Jenny, and Martin Forsey. 2012. "Ethnography Is Not Participant Observation: Reflections on the Interview as Participatory Qualitative Research." In *The Interview An Ethnographic Approach*, edited by Jonathan Skinner, 69-88. London: Berg.
- Houghton, Lesley, Margaret Heitkemper, Michael Crowell, Anton Emmanuel, Albena Halpert, James McRoberts, and Brenda Toner. 2016. "Age, Gender, and Women's Health and the Patient." *Gastroenterology* 150: 1332-1343.
- Hunt, Linda, and Nedal Arar. 2001. "An Analytical Framework for Contrasting Patient and Provider Views of the Process of Chronic and Disease Management." *Medical Anthropology Quarterly* 15 (3): 347-367.
- Inhorn, Marcia, and Daphna Birenbaum-Carmeli. 2010. "Male Infertility, Chronicity, and the Plight of Palestinian Men in Israel and Lebanon." In *Chronic Conditions, Fluid States: Chronicity and the Anthropology of Illness*, edited by Lenore Manderson and Carolyn Smith-Morris, 77-95. New Brunswick: Rutgers University Press.

- Jackson, Jean. 2000. "Social Anthropology and the Practice of Public Health Medicine." In *Anthropological Approaches to Psychological Medicine: Crossing Bridges*, edited by Vieda Skultans and John Cox, 145-171. London: Jessica Kingsley Publishers Ltd.
- Jackson, Jean. 2005. "Stigma, Liminality, and Chronic Pain." *American Ethnologist* 32 (3): 332-353.
- Jones, Michael, Joseph Dilley, Douglas Drossman, and Michael Crowell. 2006. "Brain-gut Connections in Functional GI Disorders: Anatomic and Physiologic Relationships." *Neurogastroenterology and Motility* 18: 91-103.
- Jones, Michael, Lauries Keefer, Jason Bratten, Tiffany Taft, Michael Crowell, Rona Levy, and Olafur Palsson. 2009. "Development and Initial Validation of a Measure of Perceived Stigma in Irritable Bowel Syndrome." *Psychology, Health, and Medicine* 14 (3): 367-374.
- Jutel, Annemarie. 2010. "Medically Unexplained Symptoms and the Disease Label." *Social Theory and Health* 8 (3): 229-245.
- Jutel, Annemarie. 2011. *Putting a Name to It: Diagnosis in Contemporary Society*. Baltimore: Johns Hopkins University Press.
- Jutel, Annemarie. 2014. "When the Penny Drops: Diagnosis and the Transformative Moment." In *Social Issues in Diagnosis: An introduction for Students and Clinicians*, edited by Annemarie Jutel and Kevin Dew, 78-92. Baltimore: Johns Hopkins University Press.
- Jutel, Annemarie, and Kevin Dew. 2014. "Introduction." In *Social Issues in Diagnosis: An Introduction for Students and Clinicians*, edited by Annemarie Jutel and Kevin Dew, 1-14. Baltimore: Johns Hopkins University Press.
- Jutel, Annemarie, and Lynn McBain. 2012. "Do We Really Need to Know?" *Journal of the American Medical Association* 308 (15): 1533-1534.

- Kestenbaum, Victor. 1982. "Introduction: The Experience of Illness" In *The Humanity of the Ill: Phenomenological Perspectives*, edited by Victor Kestenbaum, 3-38. Knoxville: University of Tennessee Press.
- Kirmayer, Laurence, Danielle Groleau, Karl J Looper, and Melissa Dominice. 2004. "Explaining Medically Unexplained Symptoms." *Canadian Journal of Psychiatry* 49 (10): 663-672.
- Kleinman, Arthur. 1980. *Patients and Healers in the Context of Culture*. Berkeley: University of California Press.
- Kleinman, Arthur. 1988. *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York: Basic Books.
- Kleinman, Arthur, and Rachel Hall-Clifford. 2009. "Stigma: A Social, Cultural and Moral Process." *Epidemiol Community Health* 63 (6): 418-419.
- Kleinman, Arthur, Wen-Zhi Wang, Shi-Chuo Li, Xue-Ming Cheng, Xiu-Ying Dai, Kun-Tun Li, and Joan Kleinman. 1995. "The Social Course of Epilepsy: Chronic Illness as Social Experience in Interior China." *Social Science and Medicine* 40 (10): 1319-1330.
- Lacy, Brian, Fermín Mearin, Lin Chang, William Chey, Anthony Lembo, Magnus Simren, and Robin Spiller. 2016. "Bowel Disorders." *Gastroenterology* 150: 1393-1407.
- Levin, Betty, and Carole Browner. 2005. "The Social Production of Health: Critical Contributions from Evolutionary, Biological, and Cultural Anthropology." *Social Science and Medicine* 61: 745-750.
- Lewis, Gilbert. 1993. "Double Standards of Treatment Evaluation." In *Knowledge, Power and Practices: The Anthropology of Medicine and Everyday Life*, edited by Shirley Lindenbaum and Margret Lock, 189-218. Berkeley: University of California Press.

- Lipson, Juliene. 2004. "Multiple Chemical Sensitivities: Stigma and Social Experiences." *Medical Anthropology Quarterly* 18 (2): 200-213.
- Lock, Margaret. 1993. "Cultivating the Body: Anthropology and Epistemologies of Bodily Practice and Knowledge." *Annual Review of Anthropology* 22: 133-155.
- Longstreth, George, Grant Thompson, William Chey, Lesley Houghton, Fermin Mearin, and Robin Spiller. 2006. "Functional Bowel Disorders." *Gastroenterology* 130: 1480-1491.
- Loudon, J. B. 1975. "Stools, Mansions and Syndromes." *Royal Anthropological Institute of Great Britain and Ireland* 10: 1-5.
- Luscombe, Faye. 2000. "Health-related Quality of Life and Associated Psychosocial Factors in Irritable Bowel Syndrome: A Review." *Quality of Life Research* 9: 161-176.
- Macdonald, Judith, and Julie Park. 2005. "The Culture of Health and Illness." In *Health and Society in Aotearoa New Zealand*, edited by Kevin Dew and Peter Davis, 86-98. Melbourne: Oxford University Press.
- Madden, Raymond. 2010. *Being Ethnographic: A Guide to the Theory and Practice of Ethnography*. London: SAGE Publications Ltd.
- Manderson, Lenore, and Carolyn Smith-Morris. 2010. "Introduction: Chronicity and the Experience of Illness." In *Chronic Conditions, Fluid States: Chronicity and the Anthropology of Illness*, edited by Lenore Manderson, and Carolyn Smith-Morris, 1-20. New Brunswick: Rutgers University Press.
- Mayer, Emeran. 2008. "Irritable Bowel Syndrome." *The New England Journal of Medicine* 358: 1692-1699.

- Ministry of Health, Manatū Hauora. 2017. "Giardia." Last modified December 12, 2017. <https://www.health.govt.nz/your-health/conditions-and-treatments/diseases-and-illnesses/food-and-water-borne-diseases/giardia>.
- Moyer, Eileen, and Vinh-Kim Nguyen. 2017. "Editorial Note: Is the 21<sup>st</sup> Century the Age of Biomedicalization?" *Medical Anthropology Theory* 3 (1): i-vii.
- Nagata, Noriyuki, Deborah Marriott, John Harkness, John Ellis and, Damien Stark. 2012. "Current Treatment Options for Dientamoeba Fragilis Infections." *International Journal for Parasitology, Drugs and Drug Resistance* 2: 204-214.
- Narayan, Kirin. 1993. "How Native Is a 'Native' Anthropologist?" *American Anthropologist* 95 (3): 671-686.
- Navarro, Vicente. 2007. "Neoliberalism as a Class Ideology; Or, The Political Causes of the Growth of Inequalities." In *Neoliberalism, Globalisation, and Inequalities: Consequences for Health and Quality of Life*, edited by Vincent Navarro, 9-26. New York: Baywood Publishing Company, Inc.
- Nettleton, Sarah. 2006. "'I just want permission to be ill': Towards a Sociology of Medically Unexplained Symptoms." *Social Science and Medicine* 62: 1167-1178.
- Nettleton, Sarah. 2013. *The Sociology of Health and Illness: Third Edition*. Cambridge: Polity Press.
- Okely, Judith. 1992. "Anthropology and Autobiography: Participatory Experience and Embodied Knowledge." In *Anthropology and Autobiography*, edited by Judith Okely and Helen Callaway, 1-28. London: Routledge.
- Okely, Judith. 2015. "Dialogues with Anthropologists: Where Interviews Become Relevant." In *Extraordinary Encounters: Authenticity and the Interview*, edited by Katherine Smith, James Staples, and Nigel Rapport, 128-156. New York: Berghahn Books.

- Olson, Rebecca, and Sudeepa Abeysinghe. 2014. "None of the Above: Uncertainty and Diagnosis." In *Social Issues in Diagnosis: An Introduction for Students and Clinicians*, edited by Annemarie Jutel and Kevin Dew, 47-60. Baltimore: Johns Hopkins University Press.
- Rapport, Nigel. 2015. "Epilogue: Extraordinary Encounter? The Interview as an Ironical Moment." In *Extraordinary Encounters: Authenticity and the Interview*, edited by Katherine Smith, James Staples, and Nigel Rapport, 175-187. New York: Berghahn Books.
- Reischer, Erica, and Kathryn Koo. 2004. "The Body Beautiful: Symbolism and Agency in the Social World." *Annual Review of Anthropology* 33: 297-317.
- Rose, Nikolas. 1996. *Inventing Our Selves: Psychology, Power, and Personhood*. Cambridge: Cambridge University Press.
- Rose, Nikolas. 2001. "The Politics of Life Itself." *Theory, Culture and Society* 18 (6): 1-30.
- Rose, Nikolas. 2013. "Personalized Medicine: Promises, Problems and Perils of a New Paradigm for Healthcare." *Procedia - Social and Behavioral Sciences* 77: 341-352.
- Scambler, Graham. 2009. "Health-related Stigma." *Sociology of Health and Illness* 31 (3):441-455.
- Scheper-Hughes, Nancy, and Margaret Lock. 1987. "The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology." *Medical Anthropology Quarterly* 1 (1): 6-41.
- Schwandt, Thomas. 1998. "Constructivist, Interpretivist Approaches to Human Enquiry." In *The Landscape of Qualitative Research: Theories and Issues*, edited by Norman Denzin and Yvonna Lincoln, 221-259. California, Thousand Oaks: Sage Publications.

- Sheoran, Nayantara. 2012. "Once and Insider, Always an Outsider: (re)Negotiating Boundaries when Researchers Return 'Home'." *Anthropology News* 53 (2): 1-6.
- Simrén, Magnus, Giovanni Barbara, Harry Flint, Brennan Spiegel, Robin Spiller, Stephen Vanner, Elena Verdu, Peter Whorwell, and Erwin Zoetendal. 2013. "Intestinal microbiota in functional bowel disorders: a Rome foundation report." *Gut* 63: 159-176.
- Spradley, James. 1979. *The Ethnographic Interview*. New York: Holt, Rinehart and Winston.
- Staples, James, and Katherine Smith. 2015. "Introduction: The Interview as Analytical Category." In *Extraordinary Encounters: Authenticity and the Interview*, edited by Katherine Smith, James Staples, and Nigel Rapport, 1-18. New York: Berghahn Books.
- Strauss, Anslem, and Juliet Corbin. 1994. "Grounded Theory Methodology" In *Handbook of Qualitative Research*, edited by N. K. Denzin and Y.S. Lincoln, 273-285. Thousand Oaks: Sage Publications.
- Taft, Tiffany, Laurie Keefer, Caroline Artz, Jason Bratten, and Michael Jones. 2011. "Perceptions of Illness Stigma in Patients with Inflammatory Bowel Disease and Irritable Bowel Syndrome." *Quality of Life Research* 20 (9): 1391-1399.
- Talley, Nicholas, Stuart Howell, and Richie Poulton. 2001. "The Irritable Bowel Syndrome and Psychiatric Disorders in the Community: Is There a Link?" *The American Journal of Gastroenterology* 96 (4): 1072-1078.
- Thomas, Helen, and Jamilah Ahmed. 2004. "Introduction" In *Cultural Bodies: Ethnography and Theory*, edited by Helen Thomas and Jamilah Ahmed, 1-24. Massachusetts: Blackwell Publishing Limited.
- Toner, Brenda, and Donna Akman. 2000. "Gender Role and Irritable Bowel Syndrome: Literature Review and Hypothesis." *The American Journal of Gastroenterology* 95 (1): 11-16.

- Trnka, Susanna, and Catherine Trundle. 2014. "Competing Responsibilities: Moving Beyond Neoliberal Responsibilisation." *Anthropological Forum* 24 (2): 136-153.
- Trundle, Catherine, Ilina Singh, and Christain Bröer. 2014. "Fighting to Be Heard: Contested Diagnoses." In *Social Issues in Diagnosis: An Introduction for Students and Clinicians*, edited by Annemarie Jutel and Kevin Dew, 165-182. Baltimore: Johns Hopkins University Press.
- Turner, Bryan. 2007. "Citizenship, Rights, and Health Care." In *Health in the Context of Aotearoa New Zealand*, edited by Dorothy Broom, Bron Deed, Kevin Dew, Mason Durie, John Germov, Allison Kirkman, Judith Macdonald, Paul Moon, Julie Park, Bryan Turner, and Sue Walke, 173-188. Melbourne: Oxford University Press.
- Van der Geest, Sjaak. 2007a. "The Social Life of Faeces: System in the Dirt." In *Wilderness and Sensation: Anthropology of Sinister and Sensuous Realms*, edited by Rob Van Ginkel and Alex Strating, 381-397. Apeldoorn: Het Spinhuis.
- Van der Geest, Sjaak. 2007b. "Not Knowing about Defecation." In *On Knowing and Not Knowing in the Anthropology of Medicine*, edited by Roland Littlewood, 75-86. Oxford: Berg.
- Vanner, Stephen, Beverley Greenwood-Van Meerveld, Gary Mawe, Terez Shea-Donohue, Elena Verdu, Jackie Wood, and David Grundy. 2016. "Fundamentals of Neurogastroenterology: Basic Science." *Gastroenterology* 150: 1280-1291.
- Ware, Norma. 1992. "Suffering and the Social Construction of Illness: The Delegitimation of Illness Experiences in Chronic Fatigue Syndrome." *Medical Anthropology Quarterly* 6 (4): 347-361.
- Weaver, Lesley. 2016. "Transactions in Suffering: Mothers, Daughters, and Chronic Disease Comorbidities in New Delhi, India." *Medical Anthropology Quarterly* 30 (4): 498-514.



- Westmarland, Nicole. 2001. "The Quantitative/Qualitative Debate and Feminist Research: A Subjective view of Objectivity." *Forum: Qualitative Social Research*, 2 (1): Art. 13.
- Womack, Mari. 2010. *The Anthropology of Health and Healing*. Lanahm: AltaMira Press.
- World Gastroenterology Organisation. 2015. "Irritable Bowel Syndrome: A Global Perspective." Last modified September 2015.  
<http://www.worldgastroenterology.org/guidelines/global-guidelines/irritable-bowel-syndrome-ibs/irritable-bowel-syndrome-ibs-english>.
- World Health Organisation. 2018. "Amoebiasis." International Travel and Health.  
<http://www.who.int/ith/diseases/amoebiasis/en/>.
- Yang, Lawrence, Arthur Kleinman, Bruce Link, Jo Phelan, Sing Lee, and Byron Good. 2007. "Culture and Stigma: Adding Moral Experience to Stigma Theory." *Social Science and Medicine* 64: 1524-1535.

## Appendix A: Survey

### **Introduction**

**Thank you for agreeing to take part in this online anonymous survey<sup>32</sup> which aims to understand how Irritable Bowel Syndrome (IBS) is experienced by New Zealanders.** The research has a particular interest in how stigma and the mind-gut connection are experienced and understood by you. In order to do this, this survey is aimed at collecting information about your history, experience and management of Irritable Bowel Syndrome as well as emotional, social and cultural factors that you identify as affecting your experience of Irritable Bowel Syndrome.

**The survey should take 10 - 15 minutes to complete.** This is an anonymous survey and your responses, thoughts and opinions will in no way identify you.

This survey will be used to complete research on Irritable Bowel Syndrome as part of a masters thesis, which will be available in the VUW library after submission. This research has been approved by the Victoria University of Wellington Human Ethics Committee, reference 24547.

Researcher: Bryony Cunningham-Pow, Master's student at Victoria University of Wellington.  
**Please complete this survey if you have or have dealt with Irritable Bowel Syndrome (IBS).**

### **Survey**

Q1: What is your age?

18 - 24

25 - 34

35 - 44

45 - 54

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<sup>32</sup> This was an online survey created through Qualtrics (a survey tool supplied by Victoria University of Wellington). For each question respondents could complete their answers to any length and detail or were provided with boxes to tick.

55 - 64

64+

Q2: What is your gender?

Q3: Where do you live?

Q4: How many people live in your household?

1 - 3

4 - 6

7 - 9+

Q5: Do you practice any religion? If so, what?

Q6: What is your average weekly income?

\$0 - \$500

\$600 - \$1000

\$1100 - \$1500

\$1600 - \$2000

\$2100+

Q7: In general how would you describe your health? Please explain.

Q8: Have you been diagnosed with IBS? If so, who diagnosed you?

Q9: How long have you had IBS?

1 - 6 Months

6 - 12 Months

1 - 3 Years

4 - 7 Years

8 - 11 Years

12+ Years

Q10: Please describe your experience of the diagnosis process.

Q11: How do you manage your symptoms?

Q12: Has IBS affected your relationships? If so, how?

Q13: Has IBS affected your life? If so, how?

Q14: How has your quality of life changed from having IBS?

Deteriorated significantly

Deteriorated somewhat

Stayed the same

Improved somewhat

Improved significantly

Q15: Are you comfortable with telling other about your IBS? Please explain.

Q16: Where have you found useful information on IBS? Why was it useful?

Q17: What would you say to a person who did not know about or understand IBS?

Q18: Is there anything else you would like to add about your experience of IBS?

## **Completion page**

**Thank you for your involvement in this survey.**

**Please contact me at [bryony.cunningham-pow@vuw.ac.nz](mailto:bryony.cunningham-pow@vuw.ac.nz) if you would like to take part in further research.** This would involve meeting me for a more in depth interview or interviews.

I welcome any enquires.

## Appendix B: Interviews

### **Primary interviews**

Lewis<sup>33</sup>: 9<sup>th</sup> May 2017, recorded, 45mins

Hanna: 17<sup>th</sup> May 2017, recorded, 1hr 20mins

Emma: 19<sup>th</sup> May 2017, recorded, 25mins

Catherine: 22<sup>nd</sup> May 2017, recorded, 55mins

Hazel: 31<sup>st</sup> May 2017, recorded, 1hr

### **Secondary interviews**

Hanna: 28<sup>th</sup> June 2017, recorded, 1hr 30mins

Lewis: 3<sup>rd</sup> July 2017, recorded, 1hr

Emma: 6<sup>th</sup> July 2017, recorded, 20mins

Hazel: 5<sup>th</sup> July 2017, recorded, 50mins

Catherine: 17<sup>th</sup> July 2017, recorded, 1hr 5mins

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<sup>33</sup> Pseudonyms have been used where requested by individual participants.