

Culture, Healing Practice Pluralism and Living with  
Inflammatory Bowel Disease

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## Acknowledgements

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During the last two weeks of writing up my thesis, I realised I would be submitting it almost exactly a year to the date my father passed away after he had suffered 40 years with Inflammatory Bowel Disease. I think he would have liked to hear me over the phone telling him that I had finally finished this marathon of over six years. Throughout my life, in particular this PhD experience, his advice, sense of humour and belief in me has kept me going. Watching and caring for him during his life was an inspiration for me to do this research in the first place.

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## Abstract

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Few studies exist on sufferers' perspectives of living with Inflammatory Bowel Disease (IBD) and on cultural influences of choices of alternative health practices, including Traditional, Complementary and/or Alternative Medicine (TCAM). This research explores how and why cultural influences affect how IBD sufferers look after themselves with particular healing practices, including TCAM. The research was underpinned by a conceptual framework of the cultural construction of illness and healing, developed by drawing on existing literature from medical anthropology and sociology.

The empirical phase of the study utilised a qualitative approach, involving eight participants. Two interviews were conducted with each participant; each was asked to complete a written diary for at least a month. Data was analysed using an inductive method guided by the conceptual framework and its four components: cultural influences; perspectives of Self; perspectives of illness and healing; and, healing practice pluralism.

Half of the participants (5 female, 3 male, aged between 23 and 72 years) were medically diagnosed with Ulcerative Colitis (UC) and the others with Crohn's Disease (CD). Insight is provided into the diverse approaches of how sufferers live with IBD and two key treatment decision points. The cross-case analysis identified eight key factors directly or indirectly guiding participants towards choosing non-medical healing practices, and enumerated a range of preventive and curative healing practices that participants used in relation to different parts of the Self.

Throughout their living with IBD, there is an on-going re-evaluation of the Self (personal preferences) in relation to self-management of illness. The research demonstrates the diverse ways of living with IBD, use of multiple preventive and curative healing practices and reinforces the value and strength of the conceptual framework. This study may prove useful in providing an explanatory model for other long-standing illness research as well as the combining of various healing practices in the context of healing practice pluralism.

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# CHAPTER ONE: Introducing the Research

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## 1.1 Overview

This thesis takes a qualitative approach to explore cultural influences shaping healing practices used by people with Inflammatory Bowel Disease (IBD); that is how and why those with IBD treat themselves (self-care) or are being treated (by someone including professionals) with particular healing practices. This work is underpinned by a conceptual framework of the cultural construction of illness and healing, which was developed by drawing on existing literature from medical anthropology and sociology. To date, few studies exist on sufferers' perspectives of living with IBD. The thesis aims to contribute to understanding how IBD sufferers heal themselves using many therapies simultaneously. In particular, it addresses how the use of such therapies together implies the use of strategies in coping with acute and non-acute phases of this long-standing illness on a daily basis. Finally, it adds to understanding about whether and how during the concurrent use of many therapies along with medicine, IBD sufferers gain knowledge of such therapies from cultural influences such as family members, community education, or professional healers.

## 1.2 What is IBD?

Within a bio-medical perspective, IBD is the name given to a group of inflammatory conditions affecting the gastrointestinal tract. There are two major types: Crohn's Disease (CD) and Ulcerative Colitis (UC). CD can affect anywhere from the mouth to the anus and UC is confined to the colon and rectum. While the aetiology of IBD is unknown, with only numerous conjectures made about possible causes, a range of epidemiological information is available. Kumar and Clark (2009: 285) comment that IBD in the UK has a similar incidence rate to other northern European countries, with *"the highest incidence rates and prevalence [being] reported from northern Europe, the UK and North America"*.

Further epidemiological details can be found for both UC and CD (Kumar and Clark, 2009). Although the incidence of CD varies between countries, it is approximately 4–10 per 100,000 annually, with a prevalence of 27–106 per 100,000. The incidence of UC is stable at 6–15 per 100,000 annually, with a prevalence of 80–150 per 100,000. CD is slightly more common in females (male to female ratio of 1:1.2) and occurs at a younger age (mean age of onset of 26 years) than UC (male to female ratio of 1.2:1; mean age of onset of 34 years). These figures belie considerable variability. For

example, for UC, a bimodal age of onset of symptoms is evident; at ages 15-30 and again, at ages 50- 80 years.

In terms of mortality, death rates from IBD seem to be similar to those in the general population. But there are two exceptions; people with severe colitis have a slightly higher mortality in the first year after diagnosis and as do people aged over sixty at the time of diagnosis. Although it is not clear whether people with CD have a slightly higher overall mortality, sufferers “*with extensive jejunal and ileal disease and those with gastric and duodenal disease have been shown to have a higher relative mortality*”. (Kumar and Clark, 2009: 295)

To provide further contextualisation for this thesis, a brief summary of possible causes and explanations for the incidence and prevalence of IBD and gaps in the literature is presented below. This was drawn from review of nine major clinical textbooks (Harrison, 1985; Bennett and Plum, 1996; Andreoli et al., 1997; Kutty et al., 1998; Stein et al., 1998; Thomson and Shaffer, 2000; Humes, 2001; Khot and Polmear, 2003; and Kumar and Clark, 2009), information from journal articles, acquired from searching the University of Leeds’ library catalogue and databases (including: OVID/AMED; OVID/CINHAL; ABI Global (Proquest Direct)/ Dissertations and Theses, ProQuest Dissertations and Theses - A&I; AIDS and Cancer Research/ CSA), patient self-help / support group websites (including DIPEX) and Google UK.

Firstly, while the *causes* of IBD are unknown, two common conjectures are evident in the literature.

- IBD has a *possible genetic predisposition*. For example, the majority of sources confirm an increased risk of occurrence in people with Ashkenazi Jewish heritage.
- IBD has a *possible diet and lifestyle predisposition*. Just under half of the sources reviewed noted an association with a ‘western’ diet and lifestyle.

Further evidence on this environmental dimension is evident from studies exploring people moving to a culture and country with a ‘western’ way of life, for example, Hispanic or Asian groups. Although further research is needed, ‘westernisation’ of originally non-western individuals seems to pivot towards emphasising that a higher fat and sugar diet and more stressful and/or sedentary lifestyle could predispose people to developing IBD.

Secondly, examination of this literature reveals an abundance of information on the *medical pathology* of disease and treatments available. Further insight into the bio-

medical perspective, diagnostic process, available treatments and negative effects forms the subject for the first section of Chapter Two. More generally, this range of sources suggests that epidemiological statistical estimates of incidence, prevalence and age of onset have not greatly changed over the last ten years.

Thirdly, and a central rationale for the focus of this PhD, is the demonstration of a focus of knowledge on bio-medical perspectives of IBD. While recognising that the sources consulted focused primarily on academic writing in the context of medical education and/or on the epidemiology of IBD, it was notable that there was no mention of Traditional, Complementary and/or Alternative Medicine (TCAM) approaches as a plausible option for treatment of IBD symptoms or as a pathway to health and healing.

### **1.3 Rationale for the PhD Study**

#### ***The Personal Dimension***

The decision to undertake a PhD study on IBD has sensitive personal dimensions. I have been suffering from UC symptoms and signs since 1997 when aged nineteen and, like other sufferers, experience recurrent relapses and episodes of severe, acute ill-health. In addition, my father also suffered for many years from this condition. Very sadly, he passed away in 2011. Especially during his later years, I acted as a source of advice and support to my father, both interpreting medical opinions for him and my mother and in searching for and seeking other ways to assist in his care and treatment.

My parents have been major influences on the way I look after myself in living with UC. One of these influences, in particular, is the use of healing practices other than Medicine in treating myself and in particular being treated with Traditional, Complementary and/or Alternative Medicine (TCAM).

My 'cultural' and 'ethnic' background embraces the *context* in which I have been developing my 'way of life' especially with regard to living with UC. My family is Swiss but my father is originally Italian and my mother originally Serbian. I grew up in Abu Dhabi, the capital of the United Arab Emirates but continually travelled with my parents and three sisters in a nomadic way from 'home' to 'home' visiting family and friends. I have lived in seven countries: Switzerland, Germany, Italy, Serbia, the United Kingdom, the U.A.E. and the People's Republic of China, during the first thirty years of my life. This cultural and ethnic background as well as the languages I speak is how and why I identify and express my 'Self'.

Within my 'cultural' context, my belief systems, upbringing and education, personal preferences, habits, tendencies, kin, social, professional acquaintances and

environment are influences which affect the way I look after myself. Naturally, being someone who suffers from a, sometimes debilitating, long-standing illness I have and will continue to experience a multitude of 'healthcare processes and treatments'. These 'cultural influences' inspire the way I perceive my suffering and healing and I feel that these influences, which change over time, are reasons why I opt for TCAM practices when alleviating my ill-health. This is the main inspiration to conducting this research.

### ***An Academic Inspiration – the Role of Culture***

The other inspiration for the particular thrust explored in this PhD lies in my academic studies. I studied Traditional Chinese Medicine (BSc) for five years in North London and Beijing, obtaining a certificate of clinical practice after a semester getting clinical experience in two major hospitals in Beijing. My studies equipped me with a depth of knowledge, understanding and practice expertise in Traditional Chinese Medicine, heightened my interest in the area and intellectual curiosity. This was followed by an MRes in Social Anthropology. Subsequently, an opportunity to pursue my intellectual curiosities further in an international policy setting arose within the first year of my PhD when I took a three-month suspension of studies in order to do an internship with the WHO, working as a research assistant for Dr. Xiaorui Zhang, Head of the TRM Unit (WHO Geneva).

The MRes in Social Anthropology in particular exposed me to the influential writings of two medical anthropologists, Professor Cecil Helman and Professor Arthur Kleinman, in particular, their arguments about the significant effect of culture on both constructions of illness and healing and use of different healing practices.

Interest in culture, in particular, the way that the culture that the individual lives in along with their social and family networks, and interest in illness and healing led naturally onto an interest in cultural influences on individuals' constructions and practices of healing in living with IBD. Such an interest also has a strong implication for the use of a qualitative approach to the research question, grounded within (social) anthropology. My own personal experience in seeking out information on different ways of living with IBD, and seeking out, trying and using a variety of healing practices also emphasised the limited knowledge base in this area from this cultural perspective.

### **1.4 Focus of the Thesis**

Taking these inspirations, I decided to commence my PhD research in October 2005 in order to understand what, how and why cultural influences affect the way other IBD

sufferers look after themselves with regard to using healing practices including TCAMs. In essence, my interest lay in finding out *how* and *why* IBD sufferers treat themselves (self-care) or were being treated (by a professional) with particular healing practices. To understand the meanings behind *how* and *why*, it is necessary to comprehend the sufferer's 'cultural' constructions of illness and healing. The latter is made up of four parts drawn out from the broader literature and explained in the thesis conceptual framework (Chapter Three).

The final research question and specific objectives are as follows:

### ***Research Question***

How and why do cultural influences affect how IBD sufferers look after themselves with particular healing practices, including TCAM?

### ***Specific Objectives***

- Find out how individual sufferers perceive living with Inflammatory Bowel Disease (IBD) relative to their cultural or ethnic background.
- Explore participants' perspectives of the healing practices they have used and which 'suit' their perspectives with regard to treating their ailments in the context of recommended treatments and their application.
- Uncover the reasons why sufferers use particular healing practices to manage their illness.
- Gain insight into the TCAM healing practice settings in which IBD sufferers are situated

## **1.5 Overview of the Structure of the Thesis**

The following chapters cover aspects of this study further addressing the research question and objectives. Chapter Two explores perspectives of IBD by reviewing two healing practices: Medicine and Chinese Medicine (CM) and their characteristics involving concepts of the Self, illness and healing. This is followed in Chapter Three by presenting the conceptual framework that underpins the thesis by exploring the four parts that make up the cultural construction of illness and healing, including other concepts like self-care and self-management. Chapter Four examines the study methodology, presents the methods adopted, and explains the process of analysis and interpretation, and reasons for their choice, providing an insight into how the study was conducted.

The next chapter (Five) illustrates the uniqueness of journeys and ways of coping with IBD that each participant experienced, whilst applying the conceptual framework with regard to parts of the Self (Body, Mind etc.). Chapter Six adopts a cross-participant approach to analysis and explores four dimensions: living with a 'dirty' disease, regaining control of illness and life, cultural influences on participants' decision-making in living with IBD, and current healing practice strategies in relation to life events and parts of the Self leading up to their use of a range of non-medical healing practices. The last chapter (Seven) draws out the empirical and theoretical contributions made in addressing the four research objectives, discusses the research findings, examines the usefulness of the conceptual framework, points out the main strengths and limitations of the study, describes personal experiences felt whilst conducting the research and suggests possible areas for future research.

## **1.6 Terminology**

In order to assist the reader, a brief note on the way that particular terms are used in this thesis is appropriate. The following thus offers a brief discussion and definition of some key terms used in the thesis.

### ***Acculturation***

Acculturation is where individuals from a cultural group learn or adopt aspects of another cultural group, which make it possible for the individuals to survive in that culture.

### ***Chinese Medicine***

Chinese Medicine is a healing practice originating in China with the first traces of therapeutic activities dating back to the Shang dynasty (14<sup>th</sup>–11<sup>th</sup> centuries) (Unschuld, 1985). It is a tradition of medicine which has its own system of diagnosis based on the theory of Yin and Yang Qi (life energies), where an imbalance of these interdependent energies leads to ill health. This practice uses one or a combination of the following treatments: Acupuncture (with or without Moxibustion), Chinese Herbal Medicine, Moxibustion, Cupping, Tui Na Massage and Qigong exercise techniques to address a wide range of health problems. It is described in the House of Lords (2000) report on complementary and alternative medicine (CAM) as an alternative healing discipline.

### ***Crisis Phases***

Crisis phases or periods are crucial life events occurring one or more times in the course of an IBD sufferer's life, where they come face-to-face with their mortality in

relation to severity of their illness. For example, when a sufferer needs to be hospitalised, needs surgery or has a life-changing experience affected by one or more cultural influences.

### **Culture**

Culture can be defined as *“a set of guidelines (both explicit and implicit) that individuals inherit as members of a particular society that tell them how to view the world, how to experience it emotionally, and how to behave in it in relation to other people, to supernatural forces or gods, and to the natural environment.”* (Helman, 2007: 2, 3)

These guidelines are transmitted to following generations by the use of *“symbols, language, art and ritual”* with individuals having their own distinctive cultures (ibid).

One could therefore understand culture simply as someone’s ‘way of life’ whatever the influences which change it may be labelled. The conceptualisation of culture adopted in this thesis is discussed in more detail, along with literature from Medical Anthropology, in Chapter Three.

### **Cultural Influences**

Cultural influences can be defined as factors existing in culture, society and/or the environment, which influence and in some ways shape our day-to-day lives (adapted from Helman (2007:4), within his list of *“influences on health-related beliefs and behaviours”*). Such influences include, for example, family members, a documentary on the use of Acupuncture or attending a Homeopathy course. The exploration of cultural influences and how they shape people’s healing practices are key in this study, and so are further discussed in Chapter Three.

### **Enculturation**

Enculturation is the process by which individuals learn their own culture through observing and experiencing it with instruction from others in the same group, particularly family.

### **Healing Practices**

A healing practice is defined in this thesis as any form of healing illness, restoring or maintaining health, given by one human being to themselves or another, whether that person is a healthcare professional or lay person (for example, Medicine and self-care).

### ***Healing Practice Pluralism***

People often use more than one healing practice over the course of their lives while living with IBD. Healing practice pluralism refers to the use of many healing practices either simultaneously or intermittently combined to restore or maintain health and includes lay as well as professional healing practices, such as home-made remedies, resting, Panadol or Chinese Herbal Medicine.

### ***Inherited Methods of Care***

Inherited methods of care are ways of looking after oneself or other individuals to heal illness or relieve suffering, that are directly encultured through kinship relations and are either practised by oneself or received from others with similar beliefs and ways of coping. Examples include taking Aspirin for a headache since your parents took Aspirin for their headaches as you were growing up, visiting a psychic healer who has been healing the family for generations.

### ***Life Events***

Life events are occurrences in someone's life (actively or passively, with or without their prior knowledge) in relation to a particular time. Examples are: a new job, the death of a loved one or being admitted into hospital. To gain an understanding of how and why cultural influences affect how IBD sufferers look after themselves, it is necessary to situate this within the context of their life events in relation to coping with their IBD.

### ***Medicine***

Medicine, also known as allopathic Western Medicine or Biomedicine, is the mainstream healing practice for IBD in the UK.

### ***Moxibustion***

A traditional Chinese Medicine therapy where practitioners burn 'moxa' or mugwort herb, usually packed into a cigar-shaped stick burnt over the regions on the body and acupuncture points, placed at the top of inserted acupuncture needles and/or burnt directly on the patient's skin. The intention of healing is to stimulate circulation on or around acupuncture points inducing a smoother flow of blood and Qi (life/vital energy).

## ***TCAM***

This acronym stands for Traditional, Complementary and/or Alternative Medicines, commonly referred to as CAM in the broader literature. It is defined in this study as a group of diverse health systems, practices, approaches, knowledge and beliefs that are not presently considered to be part of mainstream Medicine. These therapies can incorporate one or more plant, animal or mineral based medicines, spiritual, manual, diet or exercise therapies applied singularly or in combination. This broad definition has been constructed from considering the definitions of CAM provided by the National Centre for Complementary and Alternative Medicine (NCCAM), USA and the WHO.

As this research is interested in the perspectives from the point of view of sufferers, the latter are welcome to consider complementary or alternative medicines as 'traditional', for example, in the case of a healing practice that is considered part of that individual's way of life connected to their ancestral and/or cultural history such as Chinese Medicine for a Chinese national. In this case this type of healing practice is considered a 'tradition' in that person's life through personal, national or cultural history and enculturation so might be referred to as Traditional Chinese Medicine. The definition of CAM is an area of on-going debate and can be seen as both culturally and socially constructed in nature (Sharma, 1995).

## **CHAPTER TWO: Perspectives of IBD – A Comparison of Healing Practices**

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This chapter explores perspectives of IBD by reviewing a range of literature looking at healing practices and their characteristics involving concepts of the Self, illness and healing. As IBD is only able to be diagnosed accurately by going through the medical process of investigation, this chapter first examines this medical approach, also known as allopathic Western Medicine or Medicine, as the mainstream healing practice for IBD in the UK. To provide a comparative perspective, the healing practice of Chinese Medicine in treating IBD is explored. This healing practice uses a different healing lens and thus a different way of perceiving illness and healing.

The aim of this chapter is not only to provide an overview of these healing practices but also to illustrate the potentially stark differences in interpretations and strategies in resolving ill-health that other healing practices may present. Healing does not occur divorced from the wider socio-economic and cultural context of individuals' lives, including social networks, work and home life. Moreover, healing is interwoven with concepts of the Self, illness, healing and the 'culture' of healing practices. This perspective locates the thesis in a broader interpretation of the literature enabling a wider, multiple healing practices, worldview of living with IBD.

### **2.1 Medical Perspectives of IBD**

The medical process of clinically investigating IBD assesses three parts in the management and treatment of the disease:

1. *Symptoms and signs* – usually assessed during physical examination.
2. *Medical tests* – resulting in a differential diagnosis to help rule out other conditions.
3. Prescribing drugs or recommending surgery – to either 'cure' or prevent disease.

This following text explores each in turn. This overview of Medicine as a healing practice for IBD draws upon an assortment of literature of textbooks on Clinical Medicine (some for students of medical education) and general medical practice (aimed at general practitioners' clinical practice). To provide a critical commentary and to contextualise the medical view of illness and healing for those living with IBD, the following section also draws on sources from Anthropology and Sociology.

### **2.1.1 Symptoms and Signs of IBD**

Although IBD can be either Crohn's Disease (CD) or Ulcerative Colitis (UC) affecting different parts of the digestive tract, there are common symptoms and signs in both illnesses. Table 2.1 displays and describes the most common symptoms of both illnesses; each may occur with varying degrees of severity and occurrence as outlined in the literature reviewed (Harrison, 1985; Bennett and Plum, 1996; Andreoli et al, 1997; Kutty et al, 1998; Stein et al, 1998; Thomson and Shaffer, 2000; Humes, 2001; Khot and Polmear, 2003; Kumar and Clark, 2009).

**Table 2-1: Symptoms and signs commonly experienced in living with IBD**

<b>Symptoms &amp; Signs</b>	<b>Descriptions</b>
Diarrhoea	Has been described as a major, initial and/or the commonest symptom of IBD. It can occur at night, is associated with incontinence and urgency to defecate. It varies from mild to severe frequency of passing stools from less than four times up to thirty times per day. It varies in consistency and is also known as watery stool. GPs are advised to refer anyone with more than two weeks of this symptom.
Stool with blood	Has been described as a major, initial and common symptom (for CD only in colonic disease), which can vary in severity from mild to severe with fresh blood seen on physical examination. The amount can range from mild to dramatic quantities. GPs are advised to urgently refer anyone if this symptom appears.
Stool with mucus	Has been described as a major and initial symptom, also known to contain pus, varying in frequency with passing stools depending on the severity of disease (mild to acute). GPs have been advised to urgently refer anyone if this symptom appears.
Excreting blood & mucus alone	Has been described as occurring occasionally, often or frequently in small evacuations, which may contain pus. GPs have been advised to urgently refer anyone if this symptom appears.
Tenesmus	The feeling of constantly needing to pass stools even if the bowels are already empty. It has been described as a common symptom that usually occurs. GPs have been advised to refer anyone with more than two weeks of this symptom.
Abdominal discomfort/pain	Has been described as occurring occasionally and increasing as the severity of disease increases. Descriptions include: abdominal distension, abdominal cramping (common), abdominal pain relieved by defecation, a painful anus, flatulence, abdominal tenderness on palpation over the bowel yet this symptom is not typical unless disease is quite advanced. Sharp, localised abdominal pain is uncommon.
Loss of appetite	Appetite has been described as being possibly severely diminished in severe cases with occasional nausea and vomiting associated with defecation.
Skin complications	Include the following conditions associated with IBD: pyoderma gangrenosum, erythema nodosum and stomatitis.
Eye complications	Include the following conditions associated with IBD: uveitis, conjunctivitis, episcleritis, iritis.
Skeletal complications	Include the following conditions associated with IBD, joint complications are seemingly the commonest: type I + II arthropathy associated with uveitis, large joint arthritis, small joint symmetric arthritis, arthralgia, ankylosing spondylitis, inflammatory back pain, secondary amyloidosis, sacroiliitis, osteoporosis.

Liver complications	Include the following conditions associated with IBD: a fatty and enlarged liver, primary sclerosing cholangitis is common, pericholangitis, liver damage, portal tract inflammation, secondary biliary cirrhosis (although uncommon in mild/moderate disease), carcinoma of the bile duct, liver failure.
Anorexia	Has been described as a general symptom yet uncommon in the majority of IBD cases as it tends to manifest in severe disease. The following symptoms have also been included under this category due to their close associations: weight loss, possible growth retardation in children, dehydration, wasting commonly seen in severe disease. GPs have been advised to refer anyone if systemically unwell.
Malaise	Has been described as a general symptom and is associated with the following symptoms: looking ill, depression, night sweats. GPs have been advised to urgently refer anyone if systemically unwell.
Lethargy	Has been described as a general symptom. The following symptoms have also been included under this category due to their close associations: fatigue, feeling febrile, weakness, lassitude, exhaustion. GPs have been advised to urgently refer anyone who may be systemically unwell.
Fever	Has been described as a general symptom, which is common in severe disease and can be known as low-grade or moderate fever.
Tachycardia	Has been described as a symptom, which more commonly occurs in severe disease.

### ***Mechanistic perspectives of symptoms and signs***

The above symptoms and signs are mechanistic expressions of ill-health as they are labelled according to anatomical location or physiological associations with microbiological pathologies. For example, 'abdominal pain' or 'diarrhoea' means 'flows' through in Greek (Mosby, 2009). Severity of disease is measured by the frequency and intensity of symptoms and signs either on a physically observable level, for example, how many times one goes to the toilet, or a subjective experiential expression, for example, using pain scales. Every so often, symptoms and signs will have a rapid onset and be more severe during an acute resurgence of disease known as a 'flare up' or 'attack'. When symptoms and signs are milder and more 'under control', this means the disease is in a period of remission.

### ***Contextualising symptoms and signs of IBD***

What is not evident in the language and descriptions used in Table 2.1 is the everyday and long-term suffering of people living with their illness as well as the complexities of coping with these symptoms and signs, otherwise referred to by Sevcik (2004) as 'illness intrusiveness'. Sevcik's (2004: 86) quantitative study using three mostly structured questionnaires (including 21 brief questions on demographics, an Illness Representation/Implicit Models of Illness Questionnaire with 45 structured, 5-point scale questions and an Illness Intrusiveness Ratings Scale Questionnaire with 13 structured questions) gathered information from three groups of participants (31 people with IBD, 48 people in the IBD sufferers' social network and 67 college students) *"to understand how people with [IBD], their social networks and the general population make sense of IBD."*

In Sevcik's study, the sufferer was perceived not just as a combination of manifesting anatomical and physiological symptoms and signs but more as a social being who possesses a perspective of Self and others around them. Although her study was able to point out some of the inconvenient and embarrassing aspects of living with IBD with a less mechanistic view of illness, the structured questionnaire-based enquiry of the complex situation of living with this long-standing illness in the context of social interaction and familiarity of illness could have been better 'captured' using a more qualitative and/or in-depth interviewing approach, perhaps utilising a mixed-methods design.

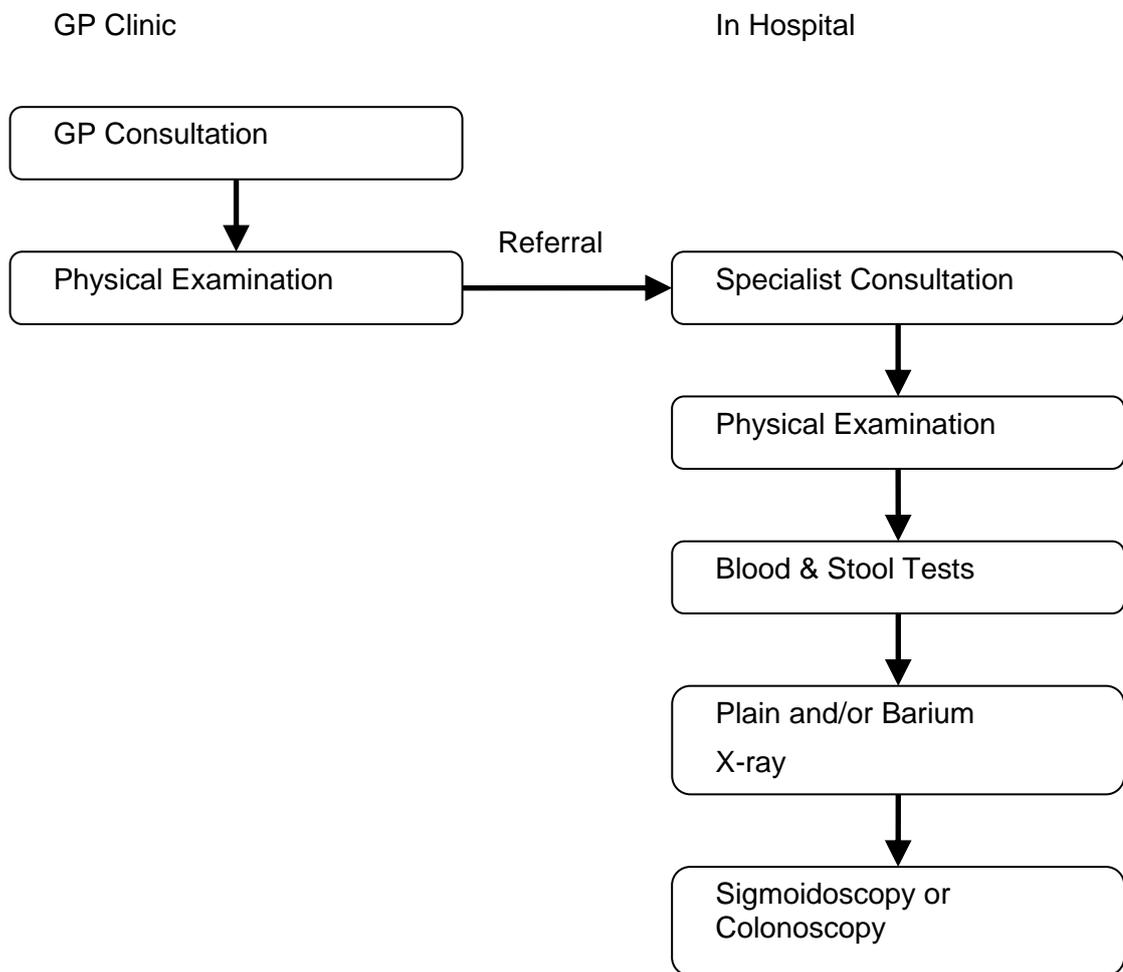
Sevcik (2004) and other medical sociological research (Frank, 1995) demonstrate three emotional states commonly experienced by people with IBD.

- *Embarrassment* – The first is the embarrassment and humiliation experienced from some symptoms and signs like smelly or noisy stools and flatulence, both of which make it uncomfortable for some sufferers to use public toilets where others are around. Another embarrassing aspect of living with IBD in connection to feeling accepted and comfortable in a social environment, is not being able to talk about stools and ‘accidents’ from incontinence with close friends and family due to the ‘taboo’ and ‘dirty’ nature of excrement. This characteristic view is similar to the “*polluting and shameful*” way menstrual blood is seen in some cultures (Helman, 2007: 429).
- *Anxiety* – This is another emotional state that makes living with IBD in a social context sometimes quite unbearable. It is mainly due to the unpredictability of urgently needing the toilet as well as the lack of understanding and the way others sometimes “*put [sufferers’] symptoms aside as trivial*” (Crohn’s and Colitis UK, 2008: 2).
- *Self-pity* – Feeling self-pity where “*troubles go all the way down to bottomless depths*” associated with not knowing the cause or ‘cure’ as well as living with loneliness from the lack of familiarity with other people’s lives, is accurately described by Frank in his description of the “*chaos narrative*” (1995: 99)

### **2.1.2 Medical Diagnosis of IBD**

The literature describing medical diagnosis of IBD comments: “*in 10% of cases of colitis a definitive diagnosis of either UC or CD is not possible*” (2009: 302). The process of examination a patient will experience is displayed in Figure 2.1 (Harrison, 1985; Bennett and Plum, 1996; Andreoli et al, 1997; Kutty et al, 1998; Stein et al, 1998; Thomson and Shaffer, 2000; Humes, 2001; Kumar and Clark, 2009).

**Figure 2.1: Process of Medical Diagnosis of IBD**



As depicted in Figure 2.1, the usual process of diagnosing UC or CD medically involves first a consultation with a patient with their general practitioner (GP) to determine symptoms and signs, followed by either a physical examination of the abdomen (or other affected area for example the mouth) and/or anus and rectum. If their condition is not seen as an emergency, a referral to see a specialist gastroenterologist (usually based at a large hospital) is recommended. However, as the literature reports, “*many patients report that their IBD diagnosis was only made after long periods of coping with difficult and distressing symptoms*” (The IBD Standards Group, 2011: 11). If their symptoms appear too severe and near fatal, the GP will call an ambulance so that the person is immediately brought to the accident and emergency unit in hospital where she/he will be admitted (Kumar and Clarke, 2009).

### ***Mechanistic perspectives in diagnosing IBD***

In a non-emergency case, the gastroenterologist recommends taking a variety of physical, stool and histological tests to determine a diagnosis and usually prescribes oral medication and nutritional supplements whilst waiting for the results. The same happens in emergency cases in hospital, yet with a more proactive 'control' of symptoms through intravenous administration as well as oral ingestion of medication and nutritional supplements given either intravenously or via a gastric feeding tube if necessary. (Kumar and Clark, 2009) With these more mechanistic perspectives, diagnosis is deduced as *"the practitioner reconfigures the patient's and family's illness problems as narrow technical issues, disease problems"*. (Kleinman, 1988: 6)

Whether an emergency or not, IBD sufferers normally initially visit their GP during an acute phase of illness since "flare-ups of the disease need active management instituted quickly to minimise the impact of the relapse on the patient's well-being and life". (The IBD Standards Group, 2009: 11) Without knowing the cause of illness, the underlying view is one that describes needing to 'control' an erratic or defective "alteration in biological structure or functioning" (Kleinman, 1988: 5, 6) of the body.

None of the tests are free of risk. Table 2.2 illustrates this for tests apart from physical, blood and stool tests. It presents both the benefits but also some risks involved in undergoing medical imaging and endoscopic diagnostic examinations in the context of acute illness. (Harrison, 1985; Bennett and Plum, 1996; Andreoli et al, 1997; Kutty et al, 1998; Stein et al, 1998; Thomson and Shaffer, 2000; Humes, 2001; Kumar and Clark, 2009). The last four rows describe four diagnostic procedures that make it possible to determine the thickness of the intestinal wall and diagnose changes in cellular tissue (abscesses, polyps, fistulae, cancerous growths etc.) that may be found protruding to the outside of the bowel into the abdomen. The first two procedures enable specialists to see inside the bowel to examine the inner lining of the intestines as well as detect any abnormalities both observable at the time of the procedures and afterwards from biopsies taken (during endoscopic examination).

Other than the risk of perforation, the personally *"invasive"* (Pineau et al, 2003: 1; Hur et al, 2004: 1) nature of endoscopic examination for initial diagnosis is only part of the exposure IBD patients experience. For example, they are advised, for preventive purposes, to undergo a colonoscopy every two years after ten years of having the disease to detect any structural abnormalities of the intestinal wall. (Kumar and Clarke, 2009).

**Table 2-2: Benefits and Risks of Diagnostic Procedures for IBD**

<b>Diagnostic Procedure</b>	<b>Benefits</b>	<b>Risks</b>
Barium X-Ray	It determines the extent of disease, demonstrates fine mucosal serrations, is indispensable in the detection of fistulous communications and should be performed annually to determine carcinoma.	It may precipitate toxic megacolon <sup>1</sup> , should not be performed on severely acute colitis, there is a risk of perforation.
Sigmoidoscopy & Colonoscopy	In the long-term it defines extent & activity of disease, use preventatively to exclude dysplasia & carcinoma, it assess the integrity of the mucosa directly, makes details of barium x-ray clearer, demonstrates extent of mucosal involvement, more sensitive than barium x-ray.	There is a risk of perforation of the bowel, it may precipitate toxic megacolon.
Abdominal Ultrasound	It determines the extent of disease, clarifies thickness of the abdominal wall, distinguishes abdominal masses.	Not mentioned
CT Scan	It is used for acute attacks, clarifies thickness of the abdominal wall, and distinguishes abdominal masses.	Not mentioned
Radionuclide Scan	It can assess colonic inflammation.	Not mentioned
Magnetic Resonance Imaging (MRI)	It evaluates perianal disease	Not mentioned

<sup>1</sup> Toxic megacolon is a life-threatening complication. It is characterized by a very inflated colon, abdominal distention, and sometimes fever, abdominal pain, or shock. (Medline Plus Encyclopedia, 2006).

### ***Making sense of illness***

Whilst figuring out what type of condition a sufferer has, it is also important to rule out other conditions. For example, IBD is often misdiagnosed as Irritable Bowel Syndrome (IBS). As the aetiology of IBD is not known, medical diagnosis is based on the pathological processes taking place in the bowel wall from the examination of biopsies taken during a colonoscopy. This way of perceiving and making sense of illness is looking more at physiological bio-chemical changes in the body as well as the anatomical location of disease. This is demonstrated in Table 2.3, drawing on the literature reviewed. (Harrison, 1985; Bennett and Plum, 1996; Andreoli et al, 1997; Kutty et al, 1998; Stein et al, 1998; Thomson and Shaffer, 2000; Humes, 2001; Kumar and Clark, 2009).

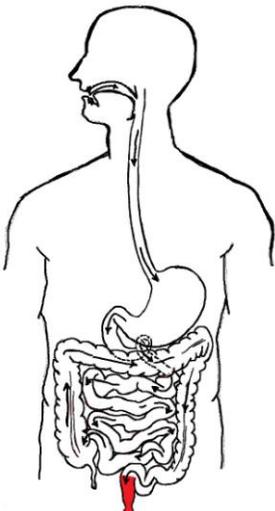
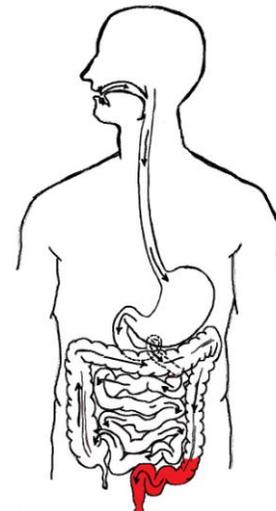
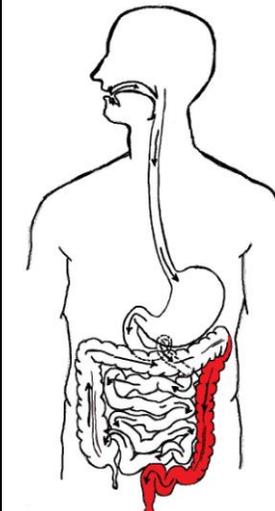
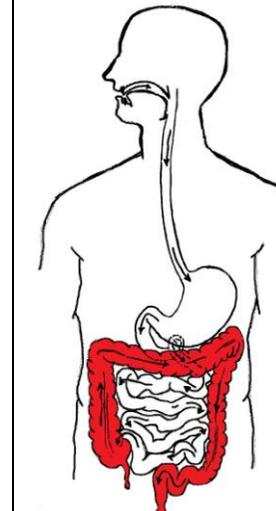
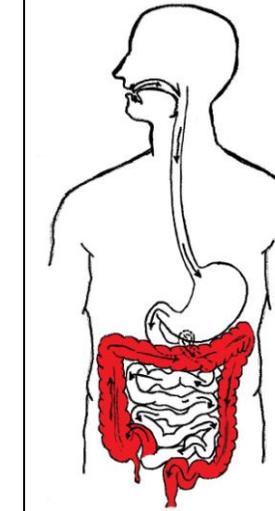
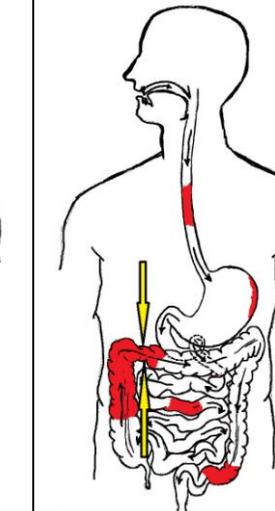
Table 2.3 shows five out of eight types<sup>2</sup> of IBD, with the last column showing an example of CD. The first row shows the names given to each type of condition, the middle row includes diagrams demonstrating the location of disease and the last row contains the anatomical locations affected by disease. As one can see, there is a clear link between the anatomical location of disease and the label of the condition, highlighting the mechanistic view of disease affecting the body. Severity of disease is not just measured by the frequency and intensity of symptoms and signs but also by the extent of how much of the digestive system is affected.

During a colonoscopy, a gastroenterologist is able to examine the inflamed areas of the bowels to help determine whether the patient has UC or CD. Crohn's disease can affect any part of the gastrointestinal tract from the mouth to the anus but normally affects the terminal ileum (end of the small intestine) and the ascending colon (the beginning of the colon). Kumar and Clarke describe one of CD's main characteristics, "*skip lesions*", where diseased bowel is separated by "*multiple areas with relatively normal bowel in between*". (2009: 287) Due to the depth of inflammation of the bowel wall, people with CD can also have strictures (narrowing) of parts of the bowel (pointed out by the yellow arrows in Table 2.3). UC on the other hand can affect the rectum alone and extends proximally up the colon as a continuous inflammation.

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<sup>2</sup> There are three types of microscopic inflammatory colitis: Microscopic Ulcerative Colitis, Microscopic Lymphocytic Colitis and Microscopic Collagenous Colitis detected only through abnormal "*histopathological findings on biopsy*" (Kumar & Clark, 2009: 294).

**Table 2-3: Diagnosis related to anatomical location of disease**

ULCERATIVE COLITIS					CROHN'S DISEASE
Proctitis	Proctosigmoiditis	Left-side Colitis	Pancolitis	Backwash Ileitis	
					
Anus & rectum	Anus, rectum & sigmoid colon	Anus, rectum, sigmoid & descending colon	Anus, rectum & entire colon	Anus, rectum, entire colon & terminal ileum	Anywhere from the mouth to the anus

Aside from the location of disease, the other main histological and symptomatic similarities and differences between CD and UC, seen in Table 2.4, demonstrate the mortality risks of these illnesses. These include local infections (abscesses) or perforation of the bowels from abnormal passageways between organs (fistulae) or toxic megacolon from long-term inflammation and destruction of cellular tissues leading to fatal conditions like sepsis. The other danger is “*an increased incidence of developing [bowel] cancer*” after ten years of having IBD, which without endoscopic examination and biopsies is impossible to detect. (ibid: 293).

**Table 2-4: Other Main Histological and Symptomatic Similarities and Differences between CD and UC**

	Ulcerative Colitis	Crohn’s Disease
Ulceration	larger, reddened ulcers that bleed easily, in a continuous distribution	pinhead-sized ulcers forming clusters in a patchy distribution
Depth of inflammation	shallow, mucosal layer of the gut	transmural, deep into tissues
Granulomas	rare	common
Fissures	anal	anal
Fistulae	seldom occurs (same locations as CD)	commonly occurs in the anus, rectum, colon
Haemorrhoids	common	common
Skin tags	common	common
Abscesses	less common and usually anal	anal, rectal, colon

In examining the commonly used terms in medicine as well as the intention behind strategies to heal the sufferer, it is essential that the context be acknowledged in which these procedures and labels are used. The uniqueness of living with long-term illness is mainly concerned with the experience of everyday struggles and finding coping mechanisms whilst making sense of illness. The following points emphasise the need for a broader outlook on making sense of illness and not just looking at the anatomical and physiological changes in the body.

1. *Identifying aggravating factors* – Although “*there is absolutely no evidence to suggest that IBD is caused by stress*” (Colitis and Crohn’s UK, 2008: 2), some IBD sufferers have expressed a link between emotions and stress as directly affecting their bowels (Soivio, 1999).
2. *Making life style changes* – This may include things like changing an occupation or personal attitudes since “in the context of the life story [IBD] poses a

potential threat to accomplishing life projects and conducting a ‘normal’ life” (Soivio, 1999: 99).

3. *Finding strategies to cope with struggles* – In the case of people living with IBD, this involves pragmatic solutions to everyday problems like knowing where the toilets are (Sevcik, 2004) before visiting a place, for example, a restaurant or a tourist site.

### **2.1.3 Treatment of IBD**

After medical diagnosis, the main disease management strategies used to treat IBD are centred on microbiological pathology by:

- Reducing inflammation
- Suppressing immune reactions
- Controlling any infection
- Supplementing any biochemical deficiencies

These more mechanistic strategies are achieved by the use of a variety of medical treatments. A patient is normally: prescribed medication; recommended, if their case is critical, to have surgery; offered psychological support; and given dietary and lifestyle advice, for example, stopping or continuing smoking. Table 2.5 outlines the benefits of the main medical treatments for UC and CD and what they are usually used for. The first column on the left hand side in Table 2.5 lists the main categories of types of medical treatments for IBD. The second column shows the name of the commonly used types of medical treatments for UC or CD. The third and last columns present the range of treatments used for in both conditions. The first three categories of drugs in Table 2.5 as well as the surgery options are the most commonly used medical treatments for IBD.

**Table 2-5: Main medical treatments for UC and CD**

	List of treatments	UC	CD
Steroids	Prednisolone	Inducing remission	
	Budesonide		
	Hydrocortisone		
Aminosalicylates	Olsalazine	Inducing remission & maintenance of remission	Maintenance of remission (colonic disease only)
	Sulfasalazine		
	Mesalazine		
Immunosuppressive drugs	Azathioprine	Maintenance of remission	
	Mercaptopurine		
	Mycophenolate mofetil		
Antibiotics	Ciprofloxacin	Control bacterial overgrowth in the gut	Used for perianal disease
	Metronidazole		
Antidiarrheal drugs	loperamide	Control diarrhoea	
	codeine phosphate		
Surgery	Colectomy	Eradicating diseased bowel	
	Ileostomy		
	Ileo-anal anastomosis		
Supplements	Vitamin B12, folic acid, iron (only for malabsorption) or occasionally erythropoetin	Supplementing deficiencies particularly anaemia	
Miscellaneous	Smoking	Stopping smoking has been shown to cause aggravation of UC	Smoking should be stopped to avoid aggravating CD

Having understood the way medical treatments treat IBD on a physiological and anatomical level with more mechanistic views of illness and healing, it is important to give an overview of the drawbacks to the most commonly used medical treatments. These are shown in Table 2.6 below and help to contextualise the reality of living with medical treatments. The first column shows the four most commonly used categories of medical treatment with each treatment name listed in the second column. The third column presents the drawbacks of using these medical treatments that may or may not always be obvious to IBD sufferers using them, for instance, the long-term use of

steroids by women with IBD that may impair fertility. The majority of drawbacks involve the negative effects of drugs but Table 2.6 also describes the complications of having a stoma bag after surgery for example, the ulceration of the skin where the stoma bag is attached. Although there is reference to the 'cosmetic ramifications' of having a stoma bag, this table does not present the lived experience of such 'ramifications' involving much more than technical and health-related issues, for example, views on sexuality and body image in having to live with a stoma bag for the rest of one's life.

In taking the drawbacks of medical treatments into consideration, a secondary research study by Lloyd et al. (2002) looking at data on hospital admissions of IBD patients from the English Hospital Episode Statistics (HES) system, presented major changes in medical treatment of IBD since the 1980's. In examining the data from 1989/90 to 1999/2000, they found *"there was a significant increase in the percentage [40%] of admissions involving surgery"* for UC patients. They emphasised the value of their research by saying that data derived from hospital admissions provided information on *"changes in medical practice"* highlighting that *"[i]t is unlikely that this increase is due to a marked increase in the severity of ulcerative colitis necessitating surgery"* but *"probably reflects a change in medical management practice in England, leading towards a lower threshold for colectomy."* (ibid: 22, 23)

**Table 2-6: Drawbacks of Main Medical Treatments for IBD**

Type of treatment	Drug Name	Drawbacks
Steroids	Prednisolone	Women with high-dose steroid therapy often have anovulatory menstrual cycles, secondary amenorrhoea which temporarily impairs fertility. According to Bennett & Plum (1996: 713) in UC maintenance therapy is indicated because 80% of patients who improve will experience an exacerbation of their disease within a year after cessation of active therapy. This indicates that addiction due to physical need of this as well as other drugs is also a negative effect of drug therapy.
	Budesonide	
	Hydrocortisone	Hydrocortisone should be replaced by prednisolone after patients respond to IV treatment in severe disease.
Aminosalicylates	Olsalazine	Commonly causes watery diarrhoea in 10-15% of patients at therapeutic doses and may be severe enough to stop therapy in 6% of patients, therefore is used less frequently. It is only absorbed in the small intestine, may be nephrotoxic and is considerably more expensive than Sulfasalazine.
	Sulfasalazine	Has a wider negative effects profile than other Aminosalicylates, which includes occasionally exacerbating bloody diarrhoea, nausea, vomiting, malaise, headaches, myalgias, folate malabsorption, skin rashes, fever, anorexia, arthritis, toxic pancreatitis, hepatitis, haemolysis, cholestasis, granulomas, fibrosing alveolitis, eosinophilic pneumonitis, toxic epidermal necrolysis, alopecia, Stevens-Johnson syndrome, tachycardia, methemoglobinemia, sulfhemoglobinemia, neutropenia, cytopenias, lupus-like syndrome complications and reversible male infertility (80% of males). According to Bennett & Plum (1996: 713) this drug is another example where many patients develop negative effects before achieving therapeutic doses consequently reducing patient compliance.
	Mesalazine	Entero-coated preparations should be avoided as they may pass through into the faeces intact due to rapid transit in some patients. Some cases of proctitis are resistant to this treatment. Mesalazine medication is considerably more expensive than Sulfasalazine.
Immunosuppressive drugs	Azathioprine	Azathioprine is reserved for patients whose remissions have not been maintained with anti-inflammatories. Its mean response time for clinical improvement is slow (three months) and it can cause bone marrow suppression, cytopenias, infertility, teratogenicity and pancreatitis.
	Mercaptopurine	
	Cyclosporine	Cyclosporine is a controversial drug, which is recommended only for short-term use due to its toxicity as well as having a narrow therapeutic window.

Surgery	Colectomy	Efflux into the colostomy bag must not come into contact with the skin due to ulceration from digestive enzymes in the gut. Ostomy bags can cause loss of fluid therefore a high fluid intake is needed to prevent dehydration.
	Ileostomy	A 'standard' ileostomy requires an ostomy bag and a 'continent' ileostomy nipple, which commonly malfunctions and obstructs. Both have cosmetic ramifications and require self-care of ileostomy. Both can cause dehydration leading to uric acid kidney stones. Efflux into the colostomy bag must not come into contact with the skin due to ulceration from digestive enzymes in the gut. Ostomy bags can cause loss of fluid therefore a high fluid intake is needed to prevent dehydration.
	Ileo-anal anastomosis	Treatment is not always satisfactory and results in numerous complications including: diarrhoea, leakage and incontinence. One third of patients will develop pouchitis including: diarrhoea, bleeding, fever and exacerbation of extracolonic manifestations.

#### **2.1.4 Summary of Medical Approaches to IBD**

This section set out to provide an overview of the allopathic/medical approaches to the diagnosis and treatment of IBD. In doing so it has illustrated both the benefits and risks in the diagnostic procedures and possible medical treatments that might be applied. It is important to look overall and to consider these processes of diagnosis and treatment within the individual's wider life and world context. Through experiencing these processes, after their initial diagnosis, during which IBD sufferers will have gone through the experience of invasive diagnostic procedures, many IBD sufferers may begin a process of adapting to and finding additional or alternative ways of managing to live with this long-term illness. In addition to these life-changing events, IBD sufferers must also live with the medical treatments they use and find ways to cope with any negative effects or limitations on their life. For example, all the drugs prescribed for IBD have negative effects and if a sufferer has had to have surgery then living with a stoma bag will have involved the trade-off of having parted with the diseased bowel. These drawbacks often contribute to other physical problems, not to mention the psycho-social trauma of changes in body image and other perspectives of Self and identity.

#### **2.2 Perspectives of IBD in Chinese Medicine**

People with IBD may use a range of alternative healing practices. As a contrast to the bio-medical perspective presented in Section 2.1, another healing practice treating IBD, Chinese Medicine (CM), has been selected. Chinese Medicine was described as an alternative (healing) discipline within the House of Lords (2000: 2) report on CAM. As this report comments, CM is long-established and is a traditional system of healthcare. It thus provides a fitting contrast to the healing practice of Allopathic Medicine. The format of this part of the chapter purposely mirrors that followed in the first part, to enable contrasts to be exposed. The following text also includes insight into the form and nature of CM practice. However, it does not aim to provide a comprehensive or detailed exploration of CM itself. The explanations and illustrations of the foundations of CM represent simplification of the complexities and dynamic intricacies CM comprises.

The process of clinically investigating IBD in CM considers the following parts in the management and treatment of this illness:

- *Symptoms, signs and manifestations* – usually assessed during a consultation from interviewing and physical examination.

- *Applying methods of diagnosis* – for the identification of patterns of disharmony that lead to illness.
- *Identifying principles of treatment* – to preserve good health, defend attack of pathogenic factors and restoring balance of yin and yang in the body.

This overview as a healing practice for IBD draws upon an assortment of literature of textbooks on the foundations of CM including translated classical texts (some for students of CM education in the UK), the practice of CM with clinical cases as examples (aimed at practitioners of CM as well as students) as well as other sources contextualising the diverse practice of CM and how it views illness and healing of sufferers living with IBD.

### **2.2.1 Foundations of CM**

In order to understand the basic gist of perspectives of IBD in CM, one needs to comprehend its essential ontological tenets and functionalities. The principles of CM, as for each healing practice, have their origins in culture, that is, in (cultural) understandings of ways of life, illness and healing. The Taoist beliefs which individuals in Chinese communities practised are the foundations of CM theory. As Maciocia put it, *“the basis of all is Qi”*. (1998: 35). Qi (pronounced ‘chee’) is a difficult concept to define; but is commonly taken to mean ‘life energy’. It is described as *“the basis of all phenomena in the universe and provides a continuity between coarse, material forms and tenuous, rarefied, non-material energies”* (ibid: 36). According to Maciocia’s interpretation of the Chinese philosopher, Zhang Zai’s (1020-1077 CE), meanings of the concept of Qi relate to its transformations: *“Human life, too, is nothing but a condensation of Qi and death is a dispersal of Qi”*. (ibid: 37). Within CM and associated healing disciplines such as traditional, non-medical acupuncture, in the human body, Qi travels in ‘meridians’ or ‘channels’ which are ‘passages’ that usually run along blood vessels, although there is no tangible (bio-medical or physiological) evidence to show their existence. In illness, Qi can sink, stagnate, be rebellious (flow in an unnatural direction) or be deficient.

### ***Yin and Yang***

Qi is a self-moving force that is ever-changing and flows into two patterns of activity known as Yin and Yang that exist from the macrocosm of the universe to the microcosm of the meta-physical. The first references to yin and yang date back to the Zhou dynasty (about 1000-770 B.C.) (ibid: 16). The symbol below (Figure 2.2)

represents the perpetual, morphing inter-relationship between these two life forces, which when in balance basically mean a healthier state of being and when in disharmony lead to ill health.

**Figure 2.2: Symbol Representing the Inter-Relationship between Yin and Yang**



In Figure 2.2 the black part represents Yin with the seed of Yang (white dot) in it and vice versa, which means that there is never total Yin or Yang but a constant flux of these balancing each other out. There are basic qualities describing the opposing characteristics of Yin and Yang that can be applied to the human body and health in CM. Examples of these are displayed in Table 2.7 below (ibid: 9).

**Table 2-7: Qualities Representing Yin and Yang in Relation to Human Health**

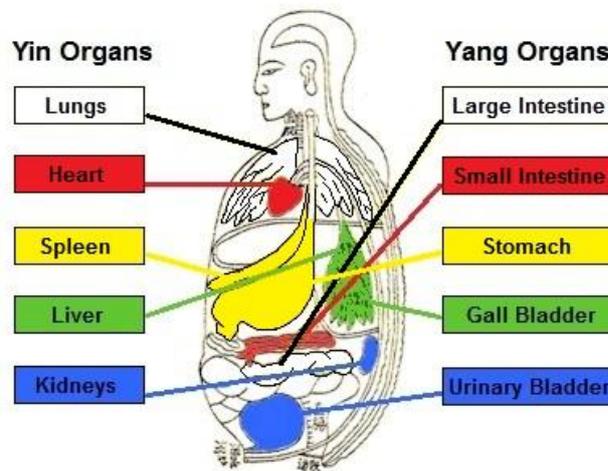
Yin	Yang
Fire	Water
Hot	Cold
Restless	Quiet
Dry	Wet
Hard	Soft
Excitement	Inhibition
Rapidity	Slowness
Non-substantial	Substantial
Transformation & Change	Conservation & storage sustainment

With these basic concepts in mind, one can better understand the link in CM between ill health and the environment in which IBD sufferers live both spatially as well as with regard to making life changes linked with illness experience.

***Yin Yang organ pairs***

On the level of the human body and its organs, Figure 2.3 below is a Song Dynasty (960-1279 CE) depiction of the organ pairs with corresponding colour representations. (Beijing Digital Museum of TCM: 2011). Unlike the anatomical and physiological perspectives of organs in Medicine, *“Chinese Medicine sees each organ as a complex*

system encompassing its anatomical entity and its corresponding emotion, tissue, sense organ, mental faculty, colour, climate and more.” (Maciocia, 1998: 67).



**Figure 2.3: Yin and Yang Organ Pairs and Their Corresponding Colours<sup>3</sup>**

Within the context of IBD, the Spleen is seen as the main organ in disharmony and therefore will be most often considered when treating an imbalance (illness). This is because *“the Spleen is the central organ in the digestive process”* (ibid: 89). For the sake of understanding the link between the foundations of CM and the way that it perceives IBD, the Spleen will serve as an example linking the impairment of its functions to disharmony, displayed in Table 2.8. (ibid: 89-92). The first two columns list the normal functions of the Spleen with regard to Qi, Blood and Body Fluids, which are three of four Vital Substances

<sup>4</sup> This illustrates a more holistic view of the Self where in CM *“the body and mind are not seen as a mechanism (however complex) but as a vortex of energy and vital substances interacting with each other to form an organism”*. (ibid: 35). The last column of the table shows what tends to happen when the Spleen function is impaired, with the resulting ill health manifestations highlighted in red.

<sup>3</sup> The Kidneys and Urinary Bladder are sometimes also linked to the colour black.

<sup>4</sup> The fourth Vital Substance is Essence, which is *“a rather precious substance to be cherished and guarded”*. (Maciocia, 1998: 38)

**Table 2-8: Normal and Impaired Function of the Spleen**

Normal Function		Impaired Function
Governs transportation & transformation	Transforms ingested food and drink to extract Qi called Food Qi, which is the basis for the production of Qi and Blood. The 'clean' Body Fluids are sent up to the Lungs. The 'dirty' Body Fluids are sent to the Small then the Large Intestine to be excreted.	Leads to poor appetite, bad digestion, abdominal distension and loose stools.
Controls the Blood	Keeps the Blood in the blood vessels.	Causes the Blood to 'spill' out of the vessels causing <b>haemorrhages</b> .
Controls the muscles and the four limbs	Nourishes all the tissues of the body, in particular the muscles of the limbs and keeps the tone and strength healthy.	Means the refined Qi from digestion cannot be transported to the muscles and the person will <b>feel weary or tired</b> , have <b>weak muscles</b> and in severe cases there may be <b>atrophy</b> .
Opens into the mouth and manifests in the lips	The mouth has a functional relationship with the Spleen from the action of chewing food for digestion. When the Spleen is normal, the sense of taste is good and the lips are moist and rosy.	Leads to <b>impairment of the sense of taste</b> (as 'flat' or 'sticky'); there will be a <b>lack of appetite</b> as well as <b>pale and dry lips</b> .
Controls the raising of Qi	Produces a 'lifting' effect that makes sure the internal organs are in their proper place.	Causes <b>prolapse</b> of various organs: uterus, stomach, kidney, bladder or <b>anus</b> .
Houses thought	Influences our capacity for thinking, studying, concentrating, focusing and memorising. If the Spleen Qi is flourishing, we will think clearly and be able to concentrate and memorise easily.	Causes thinking to be dull, there may be lack of concentration and poor memory.

***Body linked to environment***

Through this CM lens exploring the body as linked to the environment, CM perceives illness as manifestations of an excess or deficiency of Yin or Yang in link with the 'Five Elements', which "symbolise five different inherent qualities and states of natural phenomena". (ibid: 17). However, as Maciocia (1998) observes, "the theory of the Five Elements was not applied to Chinese Medicine throughout its historical development but its popularity waxed and waned through the centuries." (ibid: 16). The first recorded reference to the Five Elements dates back to the Warring States Period

(476-221 BCE). CM is thus not only concerned with the 'body, mind and spirit' phenomena; the theory of the Five Elements demonstrates the perspective of how humans, nature and the universe are all directly related. Therefore understanding the dynamics of the Five Elements theory and its effect on the Yin Yang (known as Zang-Fu) organ system will help in comprehending the complexity and diversity of CM's more holistic perspectives of illness and healing.

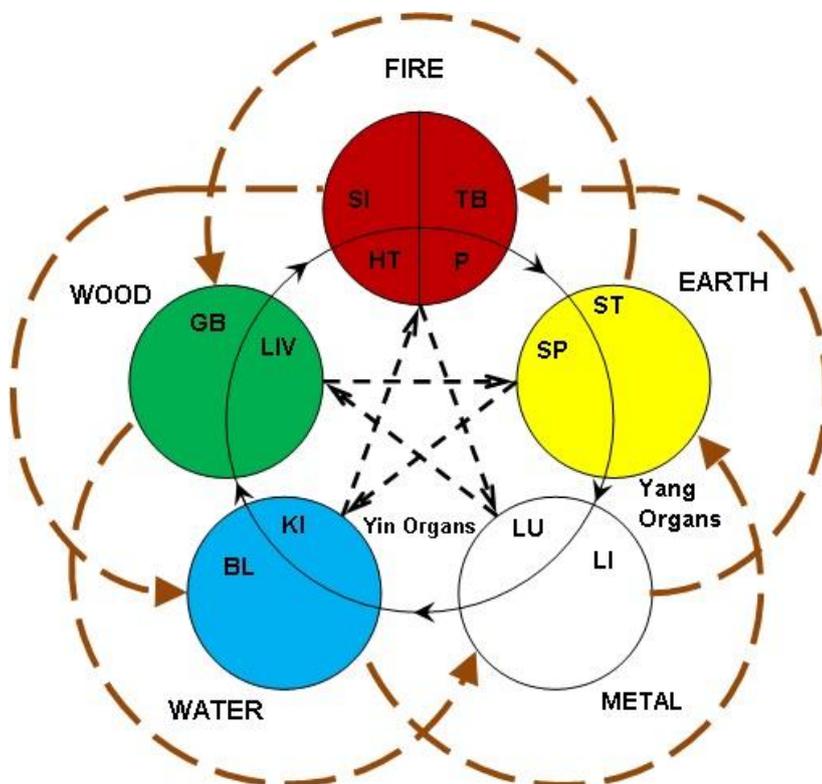
The Five Elements of Water, Fire, Wood, Metal and Earth each pertain to a significant, flavour, colour, stage of development, climate, direction, season, organ, tissue, emotion, sound even a planet as well as many other attributions to yin and yang.

Examples of attributes of the five elements in nature and the human body can be seen in Table 2.9 (ibid: 21). According to CM, the mentioned Yin and Yang, Five Element phenomena and attributes connected to the universe have a direct effect on a person's health. In an ideal state of health, the organs and their relative elements are in balance.

**Table 2-9: Attributes of the Five Elements in Nature and the Human Body**

Aspects & Phenomena	Five Elements				
	Wood	Fire	Earth	Metal	Water
Nature					
Flavour	Sour	Bitter	Sweet	Pungent	Salty
Colour	Green	Red	Yellow	White	Black/ Blue
Stage of Development	Birth	Growth	Transformation	Harvest	Storage
Climate	Wind	Summer-Heat	Dampness	Dryness	Cold
Direction	East	South	Centre	West	North
Season	Spring	Summer	Late Summer	Autumn	Winter
Planet	Jupiter	Mars	Saturn	Venus	Mercury
Human Body					
Zang organs (yin)	Liver	Heart	Spleen	Lungs	Kidneys
Fu organs (yang)	Gall-Bladder	Small Intestine	Stomach	Large Intestine	Urinary Bladder
Sense organs	Eyes	Tongue	Mouth	Nose	Ears
Tissues	Sinews	Vessels	Muscles	Skin & Hair	Bones
Emotion	Anger	Joy	Pensiveness	Sadness	Fear
Sound	Shouting	Laughing	Singing	Crying	Groaning

In CM there are five pathways or 'Sequences' which demonstrate the dynamics between each organ and their relevant element. Four out of five of these are shown in Figure 2.4 with the five elements corresponding to their organ pairs, for example the Spleen (Yin) and its pair the Stomach (Yang) in the yellow circle are linked to the 'Earth' element etc. The four sequences are represented as: the five-point star-shaped sequence in the centre of the figure (the **Controlling** and **Over-acting** Sequence), the circle connecting all the coloured circles together moving in a clockwise direction (the **Generating** Sequence) and lastly the brown dashed lines and arrows on the outer part of the figure moving in an anti-clockwise direction (the **Insulting** Sequence). (ibid: 1998).



**Figure 2.4: The Yin and Yang Organ Pairs and their Related Elements**

The Generating and Controlling Sequences demonstrate the 'normal', balanced (health) inter-relationships and flow of Vital Substances including Qi, whereas the Over-acting and Insulting Sequences represent the 'abnormal', imbalanced (illness) influence of organs on each other. The disharmony manifesting between organs and their corresponding meridians will make the Self susceptible to illness by pathogenic factors: Wind, Cold, Dampness, Heat, Dryness, Fire and Phlegm. These originate either inside or outside of the body. (Maciocia, 1998: 293).

### 2.2.2 Symptoms, Signs and Manifestations of IBD

Although IBD sufferers need to get a definitive diagnosis from a medical professional in order to say they have UC or CD, a CM practitioner will perceive their illness very differently. A particular point to note is that from the CM viewpoint *“many of the clinical manifestations contributing to form a picture of an underlying disharmony would not be considered as ‘symptoms’ or ‘signs’ in Western Medicine [,] for example, absence of thirst [or] inability to make decisions”*. (Maciocia, 1998: 175). Similarly to Maciocia, the meaning of ‘symptoms’ and ‘signs’ used in this section of the thesis, *“should be interpreted in [a] broad[er] way”*. (ibid).

During a consultation, the symptoms and signs experienced by an IBD sufferer are not only enquired about regarding intensity and frequency but also with reference to their particular characteristics. For example, in CM there are six types of diarrhoea patterns of illness (syndromes) related to IBD. These types have been displayed in Table 2.10, based on a variety of literature sources for CM (Hou & Zhao, 1995; Mitchell, Ye & Wiseman, 1999; Peng et al, 2000; Maciocia, 2000) along with other main symptoms and signs experienced in IBD.

Illness is usually seen as an excess or a deficiency then further sorted into Heat or Cold syndromes with most cases linked to the seven pathogenic factors listed previously following an assessment of symptoms and signs. Table 2.10 presents the link in CM between the seven pathogenic factors (originating internally and externally) and main symptoms and signs seen in IBD with their particular characteristics. It displays four excess and two deficiency types of diarrhoea syndromes with their relevant symptom characteristics with regard to stools, abdominal problems, symptoms related to the stomach and a final column presenting any other symptoms and signs listed under the ‘miscellaneous’ section. As mentioned in section 3.1 of this chapter, the main symptoms of IBD presented by sufferers are: diarrhoea, with or without blood in the stools (with or without pus and/or mucus), abdominal pain and tiredness. It is important to mention that the symptoms and signs presented in Table 2.10 do not necessarily have to present in every IBD sufferer but have been provided to illustrate the particular differences between types of symptoms etc. in order to differentiate illness and later treatment.

**Table 2-10: Symptoms, Signs & Manifestations Presenting in Four Excess and Two Deficiency Types of Diarrhoea**

Syndromes	Symptoms, Signs & Manifestations			
	Stools	Abdomen	Stomach	Miscellaneous
Retention of <b>Cold-Dampness</b> blocking the Spleen	- <b>thin</b> and/or <b>watery</b> stools	- abdominal <b>pain</b> - <b>fullness</b> sensation over the epigastrium - rumbling 'tummy' ( <b>borborygmi</b> )	- poor appetite	- aversion to <b>cold</b> - aching pain and <b>heaviness</b> of the limbs
Accumulation and retention of <b>Damp-Heat</b>	- hurried discharge of stools - <b>yellow-brown</b> loose stools - <b>fetid smell</b> of stools - <b>burning</b> sensation of the <b>anus</b>	- abdominal <b>pain</b>	- thirst	- feeling of heat - moodiness - scanty-dark urine
<b>Retention of food</b> in the Stomach and Intestines	- loose stools with <b>undigested food</b> - stools smell of rotten eggs	- abdominal <b>pain relieved after</b> passing stools - <b>fullness</b> sensation and <b>pressure</b> over the epigastrium and abdomen - rumbling 'tummy' ( <b>borborygmi</b> )	- loss of appetite - belching with sour regurgitation and a fetid smell - foul breath	
Hyperactive or Stagnant Liver Qi attacking the Spleen	- alternating diarrhoea and constipation - loose stools usually <b>after emotional changes</b> (anger, sadness, stress)	- abdominal <b>pain</b> usually <b>after emotional</b> changes (anger, sadness, stress) - abdominal <b>distension</b> and <b>pressure</b> in the chest and hypochondriac regions	- poor appetite - belching	- mental <b>depression</b> - moodiness - nervous <b>tension</b> - irritability

Excess

Deficiency	Insufficiency of the Spleen and Stomach	<ul style="list-style-type: none"> <li>- alternating loose and watery stools with undigested food and mucus</li> <li>- passing stools <b>more frequently</b> after eating greasy food</li> </ul>	<ul style="list-style-type: none"> <li>- feeling <b>discomfort</b> and <b>fullness</b> in the epigastrium and abdomen</li> </ul>	<ul style="list-style-type: none"> <li>- poor appetite</li> </ul>	<ul style="list-style-type: none"> <li>- lassitude</li> <li>- tiredness</li> <li>- <b>sallow</b> complexion</li> </ul>
	Deficiency of Kidney Yang	<ul style="list-style-type: none"> <li>- watery stools <b>following</b> a rumbling 'tummy' (<b>borborygmi</b>)</li> <li>- watery stools commonly <b>occurring</b> before dawn</li> </ul>	<ul style="list-style-type: none"> <li>- abdominal <b>pain</b> relieved <b>after</b> passing stools</li> </ul>		<ul style="list-style-type: none"> <li>- feeling cold or aversion to cold</li> <li>- <b>weakness</b> of the loins, knees and back</li> </ul>

### ***CM perspectives of symptoms, signs and manifestations***

Table 2.10 provided descriptive examples of types of diarrhoea and accompanying symptoms and signs that IBD sufferers experience as perceived by CM. From this it can be inferred that this CM way of perceiving illness and health as a whole in living with IBD includes the consideration of the following parts:

- *Aspects of an environment* – on a broader scale, this includes the weather as well as the surroundings a sufferer is living in, but more specifically is tied to the Five Elements and their relation to the internal organ pairs as seen in Figure 2.4
- The strength of a person's constitution (Essence) – “deduced from the patient's past: a history of serious childhood diseases would indicate a weak constitution”. (Maciocia, 1998: 41).
- *Features of physical signs* – the differing smells and consistency of stools indicating particular conditions.
- *Characteristics of symptoms felt* – expressed by the sufferer like stabbing, aching or throbbing abdominal pain.

The points listed above demonstrate that CM's perspective is more holistic than mechanistic with a heavy emphasis on the connection between individuals and their environment.

### ***Contextualising CM perspectives of IBD symptoms, signs and manifestations***

After considering the terminology and ideological perspectives that CM has of diarrhoea (Table 2.10), the following points arise when thinking about how these would translate and be used in the context of a consultation with an IBD sufferer:

- *Embarrassing detailed descriptions* – the detailed descriptions, for example, with regard to stool smell and consistency, might be considered somewhat embarrassing and too elaborate for some IBD sufferers in the UK, which perhaps in other countries and cultures might be considered normal. On the other hand, sufferers may find the attention to detail a fascinating and attentive thing.
- *Unfamiliar language* – to a practitioner, talking about retention of Damp-Heat in the body is a clarification of an illness condition, whereas, to an IBD sufferer, this terminology may not make any sense, making it difficult to understand what is going on inside them and understanding where their 'imbalance' is. This may either confuse or enthuse sufferers who use CM.

- *Making surprising links* – after going to a CM practitioner to get help chiefly for diarrhoea, it might seem surprising that an IBD sufferer is asked about whether they need to pass stools after they have an emotional experience (for example, see Table 2.12 which presents Hyperactive or Stagnant Liver Qi attacking the Spleen diarrhoea). Making this kind of connection between symptoms and signs which might be thought of as unrelated could leave an IBD sufferer puzzled or it could give them clarity as to why they are having a flare up.

These points demonstrate how theory translated into CM practice can lead to differences in interpretation between the practitioner and the IBD sufferer. This is likely to arise for a sufferer who may not be familiar with CM theory and its foundations, leading on to their not understanding the CM practitioner's depth of interest in such symptoms and signs or the way these are being perceived by the CM practitioner.

### **2.2.3 CM Diagnosis of IBD Sufferers**

This section is drawn from a variety of literature sources, in particular one of the 'bibles' of CM: The Yellow Emperor's Classic of Chinese Medicine (Huang Di Nei Jing). This work is composed of two texts: the 'Su Wen' (Plain Questions) and the 'Ling Shu' (Spiritual Pivot). When people refer to the Huang Di Nei Jing they usually mean the Su Wen part of this compiled work. The Su Wen covers the theoretical foundation of Chinese Medicine, diagnostics and treatment methods. (Ni, 1995: xii) As Maciocia outlines, there are two main principles to keep in mind in CM diagnosis:

- *“signs and symptoms reflect the condition of the Internal Organs”*
- *“a part reflects the whole”* (1998:143)

According to the CM literature reviewed (Hou and Zaho, 1995; Ni, 1995; Maciocia, 1998, 2000; Peng, 2000; Unschuld, 2003), a practitioner will gather as much detailed information as possible about a sufferer's illness and healing history before enquiring about the present visit's complaints. Then information, firstly, about the sufferer's main complaint (known as the 'chief complaint') is noted and, secondly, any other symptoms and signs accompanying the chief complaint at the time of consultation are recorded. In CM, the system of diagnosis includes two main processes: Four Diagnostic Methods and Syndrome Differentiation.

### ***The Four Diagnostic Methods***

In general, CM theory of diagnosis demonstrates that symptoms and signs of imbalance (illness) within the body show dysfunctions of one or more organs and their meridians. The practitioner will use the four diagnostic methods (1. looking; 2. hearing and smelling; 3. asking; and 4. feeling) to collect information on the symptoms and signs the sufferers present with. Table 2.11 displays the Four Diagnostic Methods used during a CM consultation according to several literature sources on CM diagnostics. (Hou and Zaho, 1995; Maciocia, 1998, 2000; Peng, 2000) The information presented in Table 2.11 reflects the complexity of what a CM practitioner needs as information from a sufferer in order to start the process of finding patterns in Syndrome differentiation. As this table provides only an overview of what and how a CM practitioner needs to assess disharmony, only some examples are given in cases where a concept might need a clarification of meaning.

Table 2.11 is divided into three columns: the first displays the diagnostic method title, the second lists the points of interest related to the method of diagnosis (what the practitioner is interested in examining) and the third presents brief examples of the points of interest in order to present commonly used terminology for disharmony. Explanations on some of the meanings behind terms presented in Table 2.11 are provided in the text following the table. These serve to demonstrate CM's perspectives of illness and healing as more to do with the sufferer (Self) as part of a 'bigger picture' (universe) living within a context (life experiences and environment).

**Table 2-11: The Four Diagnostic Methods in CM including brief descriptions or examples**

Methods	Points of Interest	Brief Descriptions and/or Examples
Looking (at the)	Spirit	to assess <b>vitality</b> and <b>mental state</b> of emotions
	Body	to examine <b>physical appearance</b> including <b>constitutional types</b> ( Wood, Fire , Metal, Earth and Water types)
	Demeanour	including the way a person moves
	Head and Face	for premature greying of the hair or whether the skin is shiny or dull
	Eyes	reflecting the <b>state of the Mind and the Essence</b> from clarity or dullness
	Nose	a greenish/bluish nose tip indicates <b>abdominal pain</b>
	Ears	a long and full lobe is indicative of strong Kidneys and a <b>good constitution</b>
	Mouth	very pale lips indicate Emptiness of Blood or Yang
	Teeth and Gums	very pale gums indicate deficiency of Blood
	Throat	redness and itchiness indicate <b>invasion of exterior Wind-Heat</b> (common cold)
	Limbs	Including nails with a bluish colour indicate Liver Blood Stagnation
	Skin	dryness can indicate Kidney Yin deficiency
	Tongue	as <i>“a pillar of diagnosis”</i> (Maciocia, 1998:149) and a <b>‘window’ into the internal organs state of health</b> (teeth marks along the sides of the tongue indicate Spleen Qi deficiency)
Channels	for <b>physical manifestations</b> (a greenish colour indicates retention of Cold in the channel) occurring <b>along the channels</b> indicating disharmony in relation to the Channels’ organs	
Hearing & Smelling (the)	Sound and pitch	of the: voice, cough, breathing, vomiting, hiccups, belching, borborygmi, groaning or other sounds from the sufferer
	Odours	of the body, breath, sweat, stools, urine or other parts presenting disharmony (for example <b>rancid smells</b> are associated with the <b>Liver</b> )
Asking (about)	Chills and Fever	aversion to cold and feeling chilly is an indication of Wind Cold or Heat invasion (common cold)
	Sweating	sweating only on the head indicates Heat in the Stomach or Damp-Heat
	Head and Body	headache in the forehead indicates Stomach-Heat or Blood deficiency

	Thorax and Abdomen	a feeling of fullness in the epigastrium is due to either Spleen deficiency or Dampness
	Food and Taste	being always hungry indicates Heat in the Stomach
	Vomit	a bitter taste with vomiting indicates involvement of Liver and Gall Bladder Heat
	Stools and Urine	constipation with stools like <b>goat's stools</b> indicates <b>stagnation of Liver Qi</b> and Heat in the Intestines
	Sleep	waking up early in the morning and <b>failing to fall asleep</b> again indicates <b>deficiency of the Gall Bladder</b>
	Ears and Eyes	a <b>low-pitch ringing</b> in the ears indicates Kidney deficiency
	Pain	sharp, stabbing pain indicates stagnation of Qi and Blood
	Women's health issues	if the menstrual blood has lots of clots this indicates stagnation of Blood or Cold
	Children's health	weaning early can lead to retention of food and some skin diseases
Feeling (the)	Pulse	because 1) it can give very <b>detailed information on the state of the internal organs</b> and 2) it reflects the whole complex of Qi and Blood. There are <b>twenty eight types of pulse</b> in CM.

### ***Holistic perspectives in diagnosing IBD***

To assist in clarifying the terminology used in Table 2.11 and rationale of the diagnostic approach, the following points have been drawn from the table to simplify the complexity of points of interest needed to be examined by the CM practitioner and thus to gain deeper insight into and understanding of the CM perspective of IBD.

- *Common terms with different meaning* – in Western culture and language, the term Spirit is commonly connected to an ethereal soul. In CM and thus in Table 2.11, it represents vitality as well as mental state of health. An IBD sufferer with many years of experiencing loss of body fluids and energy may manifest with a lack of lustre in the eyes and skin and be tired a lot of the time or depressed indicating a lack of Spirit from a CM perspective.
- *Making peculiar connections* – in allopathic Western Medicine and culture, there is no association between the nose and abdominal pain, yet in CM (as seen in Table 2.11) a bluish/greenish colour at the tip of the nose may indicate abdominal pain. Perhaps this is one sign that a CM practitioner would be observing during a consultation with an IBD sufferer without the sufferer seeing any connection between the two.
- *Linking the Self to the macrocosm* – When talking about looking at the Body one thinks about the physical body perhaps more in an anatomical way. In contrast, the CM practitioner is looking at a Body ‘type’ directly related to the Five Elements in nature. For example, “*a Wood type has a tall and slender body. A Fire type has a small pointed head and small hands.*” (Maciocia, 1998:144). Any person including an IBD sufferer could be a combination of body types whose features might be taken into account during a diagnosis in CM.
- *CM perspectives of pathogens* – in Western Medicine, pathogens in IBD usually involve microbiological agents like viruses and bacteria. In contrast, in CM pathogenic factors like Wind-Heat or Dampness are perceived “*as patterns of disharmony [more] than as causes of disease*” (ibid: 293) that take on the properties of some climatic influences occurring in nature, which may or may not attack the body. For example, in an IBD sufferer, accumulation of Dampness in the body does not necessarily mean the individual was exposed to a damp environment although sometimes this type of climate can affect a sufferer and make their condition worse.

In the same way as there are risks and benefits associated with medical diagnosis, one must examine the possible risks and benefits of CM methods. Two main observations can be made:

- *Lack of biotechnology* – If one considers CM practitioners in the UK as clinicians who may not have the medical knowledge (in contrast to the situation in China) to interpret medical tests done on an IBD sufferer or who do not have access to biotechnology, the question that arises when considering medical prognosis of IBD sufferers is: how does a CM practitioner know if a sufferer has bowel cancer? If it is not possible to ‘see’ inside the physical body, there is a reliance on medical diagnostics to know whether an IBD sufferer has abnormal tissue changes that can lead to serious conditions including perforation of the bowel.
- *Non-invasiveness on a physical level* – On the other hand, a CM practitioner needs to constantly exercise and fine-tune their sensory abilities, such as touch for feeling the pulse or smell to determine which organs are imbalanced. These skills are admirably acute when considering the non-invasiveness of a long-standing condition that could be diagnosed and ultimately treated with CM in a more holistic way.

After considering symptoms, signs and manifestations an IBD sufferer might present with during a CM consultation as well as having an overview of the complex nature of the use of diagnostic methods in CM, the next section will look at Syndrome Differentiation.

### ***Making sense of illness in CM: syndrome differentiation***

In CM, there are various ways to identifying patterns of disharmony according to the:

4. Eight Principles
5. Qi, Blood and Body Fluids
6. Internal Organs
7. Pathogenic Factors
8. Five Elements
9. Channels
10. Six Stages
11. Four Levels
12. Three Burners

The first way of identifying patterns of disharmony is the Eight Principles, *“the foundation for all the other methods of pattern formulation”* listed above. (Maciocia, 1998: 179). As these processes are quite complex the list above has been provided only to present an overview of the types of pattern identification being determined by the CM practitioner. The main point to emphasise about how CM and the CM practitioner perceive an illness such as IBD is that there is a connection between the Self (Body, Mind and Spirit) with the environment in which the person lives, the climate and energetically (in terms of Yin, Yang and Qi), the universe. Moreover, as indicated above, all the Yin Yang organs are *“bound in an exterior-interior relationship connected by related meridians forming an organic whole”*. (Cai et al., 1995: 182). The application of Syndrome Differentiation is illustrated below for a hypothetical person presenting to the CM practitioner with IBD.

### ***A hypothetical case***

With these points in mind, it is valuable to use a hypothetical example (a case named as Melissa) to illustrate and make more evident the process of diagnosis. Melissa's illness experience is summarised and presented below.

Melissa is twenty six years old and has been experiencing bouts of diarrhoea with a bloated and painful feeling in her abdomen for three and a half weeks. She also says she has been belching a lot which did not used to happen before and sometimes creates much embarrassment when this occurs in public. After having been asked how her general mood is, she explains that she has been feeling depressed about things that have been going on in her life over the last month. She has been crying a lot due to her grandmother having recently passed away and has been finding it particularly difficult to concentrate on her studies. She occasionally has bouts of dizziness especially right after crying. Due to her depressed mood and lack of concentration, she is becoming increasingly stressed about her ability to do well in her studies, compounded by the fact that she has been given a scholarship to do her studies. This 'pressure' causes her to sometimes feel tightness in her chest with palpitations and restlessness when thinking about her problems. She sometimes wakes up in the morning with a bitter taste in her mouth with the sides of her abdomen feeling sore and tense. Finally, the CM practitioner observes that her tongue diagnosis shows a red tongue with no coating and her pulse is wiry.

The following steps are ones, which may be taken into consideration when diagnosing Melissa's unique syndrome.

1. Diarrhoea is the main complaint with no apparent blood, pus or mucus in the stools.
2. Most symptoms show Heat and Excess.
3. Most symptoms 'fit' into the 'pathology' of Hyperactive Liver Yang attacking the Spleen due to sadness and frustration (Table 2.10).
4. Other symptoms show Heart Fire due to yin deficiency from prolonged crying, sadness and prolonged diarrhoea.

This example has reinforced that fact that in CM "each symptom and sign has a meaning only in relation to all the others: one symptom can mean different things in different situations". (Maciocia, 1998: 175, 176). For Melissa, the Syndrome Differentiation process would conclude that she has Hyperactive Liver Yang attacking the Spleen with Heart Fire from Yin deficiency. In this way, CM diagnosis "involves a synthesis of all symptoms and signs into a meaningful pattern of disharmony". (ibid: 144).

### ***Putting CM practice in context***

In the UK, although the principles and theory of CM are similar from one academic institute to another, the practice that materialises will most likely vary. This may, for example, arise because in the underlying theory of CM there are many techniques to gather information during diagnosis and ways to go through Syndrome Differentiation. In practice one practitioner may use the 'facial diagnostic method' (observational method) more than another who might base their diagnosis more on the 'pulse diagnostic method' (palpation method). Both these ways are considered as CM but the diagnostic method the practitioner uses will make their practice sometimes quite different to another practitioner. In consequence, although CM practice is generally similar, the sufferer's consultation and, in some cases, treatment experience will vary from one CM practitioner to another. It is as if all CM practitioners were 'speaking the same language but using different dialects'. Such practice variability in CM at one level contrasts with expectations for Medicine, especially given the likelihood of protocol- or guideline-led diagnostic process and treatment. However, in both healing practice systems and, as indicated above, embodied in a different way within CM, variation may occur depending on levels of experience, heuristic learning over what 'works best for me' and expertise and, appropriately in both CM and Medicine, because of the tailoring of treatment and care to the individual patient.

#### **2.2.4 Treatment of IBD in CM**

As noted above, there is likely to be much variation in the practice of CM in the UK due to different applications of diagnostic methods and often treatment. It is difficult to know how many actual CM health provider practices there are in the UK; many practices are not officially acknowledged and most are not regulated by law. There are associations and a few institutional bodies which offer guidelines on 'safe', 'effective' and 'acceptable' practice for their members and to some extent for non-members and the public.

In the UK, the main treatment options in CM are usually: Acupuncture, Chinese Herbal Medicine, Moxibustion, Cupping, Tui Na Massage Therapy, Qi Gong Healing Therapy, Chinese Nutritional Therapy and Tai Chi Exercise instruction. These may or may not be given together. According to the CM literature (Bensky and Barolet, 1990; Cai et al. 1995; Hou and Zaho, 1995; Peng et al., 2000) a variety of these combinations of treatments may be suggested and practised for a person presenting with symptoms and signs seen in IBD.

To illustrate possible treatment combinations, it is valuable to return to the hypothetical case of Melissa. For her situation, the most commonly used treatments for chronic symptoms and signs manifesting from Spleen impairment would be Chinese Herbal Medicine, Acupuncture, Moxibustion, Chinese Nutritional advice and/or therapy and in some cases Cupping and Tui Na Massage.

Melissa's CM practitioner would most probably recommend, at first, taking a CM herbal decoction and if Melissa has pain at the time of consultation and is not afraid of needles, then Acupuncture would be performed for forty-five minutes. She would also get nutritional and general advice on her food and drink intake as well as be provided help with her emotional state. She would probably be prescribed CM herbs to make into a decoction and consume warm twice daily for at least two weeks before re-assessing her situation and seeing if there has been some progress from the last prescription. Figure 2.5 displays the individualistic nature of prescribing dried Chinese herbs for decocting according to the symptom presentation and Syndrome Differentiation determined by the CM practitioner.

With regard to the herbal formula displayed in Figure 2.5, the general syndrome of Hyperactive Liver Qi attacking the Spleen causing her chief complaint – diarrhoea - is treated with a herbal formula called Tong Xie Yao Fang (Important Formula for Painful Diarrhoea). This formula dates back to as early as the fifteenth century and is famous for treating diarrhoea especially due to the Liver attacking the Spleen. (Bensky and

Barolet, 1990: 150). Due to the fact that Melissa also presents with palpitations due to Heart Fire from Yin deficiency, herbs have been added into Tong Xie Yao Fang from the general syndrome formula for these types of palpitations, Tian Wang Bu Xin Dan (Emperor of Heaven's Special Pill to Tonify the Heart). One cautionary recommendation made in Bensky and Barolet's (1990) book on herbal formulas is that Tong Xie Yao Fang's formula's chief herb, Bai Zhu, should be used with caution or replaced in cases of Yin deficiency.

**Figure 2.5: Deciding Herbs to Include in the CM Herbal Formula**

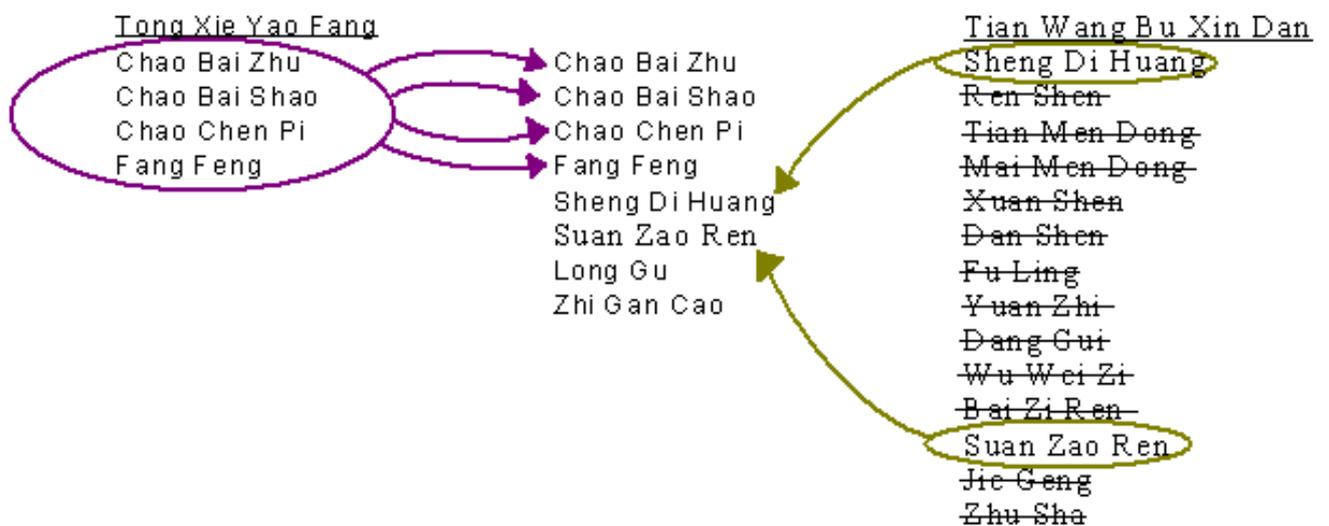


Figure 2.5 including Acupuncture and/or Moxibustion (mugwort herb heated over the skin) treatment in the set of treatments decided by the CM practitioner also serves to demonstrate that, as CM theory and principles indicate, not only diagnosis but also the treatment is unique to an individual sufferer at the time of consultation. In this case the main medical strategies would be to 1) Spread Liver Qi and 2) to Tonify the Spleen.

### ***Living with CM treatments***

Even though the treatment options listed seem perhaps more natural and less invasive than medical treatments, there are still drawbacks to using CM treatments. Table 2.12 presents some of these by looking at the main types of CM treatments recommended in treating IBD. The first column of Table 2.12 lists the types of CM treatments, the second mentions the drawbacks and the third column provides a more detailed

description of these when using CM treatments. As is briefly described in Table 2.12, the unpleasant and inconvenient circumstances that can be experienced in taking CMs make it sometimes difficult to comply with regular doses as well as tolerate a pain threshold (depending on the person and practitioner involved in treatment with Acupuncture) that one may not be accustomed to.

**Table 2-12: Drawbacks of Main CM treatments for IBD**

List of Main Treatments	Drawbacks	
Chinese herbal decoctions	Inconvenient preparations	Having to soak a two-day packet of dried herbs for around thirty minutes, then simmering it for another thirty minutes then extracting the herbal liquid, adding water and re-simmering the herbs for another thirty minutes seems a very long-winded process to have to do every two days for as long as the herbal decoction is needed.
	Unsavory taste	Unfortunately most Chinese herbal decoctions taste very unpleasant and are difficult to consume twice daily.
Acupuncture	Requires the practitioner	This means the sufferer is traveling to the clinic to get treated making it sometimes inconvenient.
	Long sessions	A standard Acupuncture session takes forty-five minutes when the needles have been inserted plus consultation time, making the treatment quite time consuming.
	Can be painful	This point depends on the practitioner's skill but demonstrates that some treatments can be very painful. This applies also to getting treatment from Chinese CM practitioners who might have a different concept of pain (if it hurts, it's healing).
	Needle phobia	In some cases Acupuncture is highly recommended for pain relief but some people have needle phobia making this treatment uncomfortable to quite traumatic.
Moxibustion	Unpleasant smell	The dried herb (Moxa) that is being burned during this treatment can be considered a very unpleasant smell by some people.
	Having a smoky environment	Similarly most Moxa burnt gives off smoke which can accumulate over the person during treatment which can be uncomfortable. Some practitioners use smokeless Moxa.

### 2.2.5 Summary on CM Approach to IBD

This section set out to provide an overview of the CM approach to the diagnosis and treatment of IBD. Following a short overview of some of key ontological tenets and functionalities of CM, the text aimed to mirror material presented on Medicine in section 2.1. It has thus illustrated both the nature and features of the diagnostic procedures and possible CM treatments, and possible drawbacks in the latter. One central difference between the CM and medical healing practices was emphasised. That is, within CM, focus lies on a perspective of the individual as part of the wider universe and living within a context (life experiences and environment). As expressed earlier, for an illness such as IBD there is a connection between the Self (Body, Mind and Spirit) with the environment in which the person lives, the climate and energetically (in terms of Yin, Yang and Qi), the universe.

### 2.3 Comparing the Medicine and CM Practice for IBD

This final section presents a short comparison of the major differences between the medical and the CM approach to the diagnosis and treatment of IBD. These are presented in summary form in Table 2.13 to enable easier comparison. The first column lists the aspects of perspectives of IBD with the second and third column presenting a brief summary on these aspects of perceiving IBD including its treatment using Medicine and CM respectively. In looking at Table 2.13 one can see the more mechanistic underpinnings of Medicine and more holistic approaches of CM with regard to treating IBD.

**Table 2-13: Characteristic Differences between Two Healing Practices: Medicine & CM**

Characteristics	Medicine	Chinese Medicine
General perspective of IBD	Anatomical, microbiological, pathological	Organ structure and system based on the Five Elements, Yin Yang and Qi, pathogenic factors manifest with properties associated with the Five Elements
Diagnostic techniques	Analysis of tests from biotechnological use and measurement	Analysing symptoms expressed using the Four Diagnostic Methods and Syndrome Differentiation
Treatment options	Long-term use of medication and frequent use of surgery	Long-term use of Chinese herbal decoction, frequent use of Acupuncture and sometimes Moxibustion

## **2.4 Conclusion**

This chapter has explored and compared perspectives of IBD, illness and healing as viewed by mainstream medical practice and Chinese Medicine. It outlined benefits and drawbacks of either practice and looked at a mechanistic (medical) versus a more holistic (CM) approach to interpretation of symptoms, diagnosis and treatment of IBD albeit from the perspective of healing practices not individual sufferers. The chapter has also drawn attention to the fact that there remain few qualitative studies on treatment of IBD with TCAMs and that the few that exist are limited in scope, especially with regard to taking the sufferers' point of view in living with IBD. These as well as other aspects of living with long-standing illness, in particular, to do with suffering in the context of life events, where IBD sufferers need to consider their likes and dislikes, how others influence their choice of treatments and how they use many healing practices together are examined in the following Chapter Three.

## **CHAPTER THREE: Cultural Construction of Illness and Healing**

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This chapter presents the conceptual framework that underpins the thesis. The adopted lens is drawn from medical and cultural anthropology. In essence, given interest in finding out *how* and *why* Inflammatory Bowel Disease (IBD) sufferers treat themselves (self-care) or are being treated (by someone including professionals) with particular healing practices, that is, to understand the meanings behind how and why, it is necessary to comprehend the sufferers' cultural construction of illness and healing. It is recognised that an alternative approach to exploring the meaning of how and why could have been to draw on psychological concepts behind IBD sufferers' behaviour and thoughts. This is however not the approach adopted here, as interest lies in the role of culture and thus in exploring and illustrating how aspects of culture (cultural influences) in the lives of IBD sufferers influence how they understand illness, healing and IBD and make use of a variety of healing practices.

There are four parts that make up the cultural construction of illness and healing: 1) cultural influences; 2) perspectives of the Self; 3) perspectives of illness and healing; and 4) healing practice pluralism. Healing practice pluralism is the use of many healing practices either simultaneously or intermittently combined to restore health and includes lay as well as professional healing practices, such as home-made remedies, resting, Panadol or Chinese Herbal Medicine. These four concepts, which are core to the conceptual framework, are paramount in understanding how and why IBD sufferers use healing practices within the context of the way they live (culture) and cope with this long-standing illness. Concepts concerned with the cultural construction of illness and healing will be explored through a discussion of the literature.

This chapter has three main sections. The first section outlines and explains the way literature was located to inform the construction and finalisation of the conceptual framework. The framework itself is heavily based on the writing of two major medical anthropologists, Professor Cecil Helmand and Professor Arthur Kleinman. To illustrate the framework, other literature on IBD, self-care and self-management was also explored. The second section examines and refines the meaning of the core concepts in the framework. The third part presents the components of the conceptual framework of the cultural construction of illness and healing.

### **3.1 Literature Search**

#### **3.1.1 Identifying Core ‘Cultural’ Concepts**

Core inspirations and sources for the conceptual framework lie in Professor Cecil Helman and Professor Arthur Kleinman’s work. Publications from these two authors provide insight into concepts to do with perspectives of illness and healing, perspectives of the Self and descriptions of healing practice pluralism within the context of culture. To add to these two sources, other literature drawing on their perspectives and examining perspectives on self-care and self-management for IBD sufferers was located.

Both Helman’s and Kleinman’s work explored the role of culture in the treatment and care of sufferers of illness. For example, Helman (2007) outlined a perspective of culture and expounded on its role in affecting behaviour in general as well as people’s health care practices in particular. In contrast, although Kleinman’s work dissected the meanings of these perspectives of healing practices in a more psycho-social context, he consistently applied these as one part of culture.

The literature by Helman (1985, 1995, 2001, 2007) and Kleinman (1981, 1995, 1997) has been monumental in providing a network of ideas on illness experience, perspectives of the Self, illness and healing in connection to cultural influences. The key concepts emerging from literature sources centred on the point that an individual’s construction of the Self and ultimately illness and healing included a number of factors (cultural influences) influencing their reality of suffering as well as the care received in treating their ailments. Although these factors can be looked at separately, it is important to recognise that they are not mutually exclusive. Moreover, each needs to be interpreted within a cultural context in order for their meanings to be understood.

#### **3.1.2 Gathering Information**

Building on the exploration in Chapter Two of perspectives of IBD according to medical points of view, it was appropriate to use the gaps emerging from medical perspectives of symptoms, diagnosis and treatment of IBD as a springboard to starting to gather information and gain insight into the experiences of IBD sufferers. This would then provide valuable illustrative material to locate within different parts of the emerging conceptual framework.

The approach involved identifying medical terminology and explanations of IBD as a disease from a microbiological point of view, searching for definitions and experiences of IBD and its treatment with Medicine from the vantage point of clinicians as well as

patients. Three phases of searching were undertaken. Firstly, keyword searches for literature included the medical symptoms, methods of diagnosis and treatments such as: diarrhoea, blood in the stools, bloody stools, faecal blood, mucus; barium x-ray, sigmoidoscopy, colonoscopy, CT scans, MRI, steroids, NSAIDs, immunosuppressive drugs, surgery etc. Secondly, other keywords were used directly in relation to the gaps identified on medical perspectives of IBD such as: side effects, toxic megacolon, Ulcerative Colitis, Inflammatory Bowel Disease, Crohn's Disease, etc. Thirdly, the keywords were expanded to focus on IBD sufferers and their points of view, using words such as: self-help, self-management, self-support, self-care, quality of life, patient, patient-centred, patient management, patient self-care/help, DIPEX, illness behaviour, illness experience, etc.

Altogether twelve literature sources were searched and provided the main material for this chapter. These included: four books, seven articles and one PhD thesis. Information on these sources was acquired from searching the University of Leeds' library catalogue, five databases, Google UK as well as following up on reference lists. Keyword searches were carried out on the following databases: OVID/AMED; OVID/CINHAL; ABI Global (Proquest Direct)/ Dissertations and Theses, ProQuest Dissertations and Theses; Anthropology Plus and International Bibliography of the Social Sciences 1951 to June Week 01 2006; PsycINFO 1967 to October Week 2 2007.

### **3.1.3 Cultural rather than psychological focus**

Thus far, the literature reviewed had revealed a limited number of sources directly concerning how and why IBD sufferers treat themselves (self-care) in coping with this long-standing illness as well as their opinions on Traditional Complementary and/or Alternative Medicine (TCAM) healing practices they received or would have liked to receive. Much of the published literature reported more on health-related quality of life (HRQoL), rather than illness experience of IBD sufferers per se nor did it illustrate deep meaning of living within a cultural context or perspective. Although this helped to illustrate general views and similarities between what Crohn's Disease (CD) and Ulcerative Colitis (UC) sufferers experienced, most of these types of studies and outcomes did not illustrate the reason behind how and why sufferers used or received certain types of healing practices.

Accordingly, a wider search was conducted within literature drawing on other concepts within illness and healing. Searches focused on literature relating to IBD using the following concepts: illness experience, illness behaviour, perspectives of illness and

healing, medical pluralism. These encompassed more the sense of a guiding framework located *primarily* within the anthropological context of culture.

Such searches lead in two key pieces of work. The first was that of Soivio (1999), a useful and informative source of literature, as his research focussed on anthropological concepts in the context of culture, as well as illustrating IBD sufferers' illness experience. He also used narratives as his data collection approach, similar to my emerging methodological ideas of how to conduct this study. Many of the Kleinman literature publications searched for were as a result of having followed up on some of Soivio's references. The second was the PhD thesis of Sevcik (2005). Her work delved into the meaning behind cognitive processes of IBD sufferers and people around them to find out, to some extent, how they perceived living with IBD. Although her research was both highly relevant (she used more meaningful terms to label concepts) and illustrated some depth into the perspectives of IBD sufferers, her methods of data collection, theoretical framework and to a certain extent, results were more based on psychological as opposed to cultural issues influencing the lives of IBD sufferers.

In considering the research interest as well as the identified gaps in literature on living with IBD and using healing practices including TCAMs within the context of culture, the main focus of this PhD research looked at cultural aspects, for example, ways of coping, language and behaviour in their particular context. This lay in contrast to exploring healing practices from psychological aspects such as cognitive mechanisms and the psychology behind behaviour with regard to living with IBD and caring for sufferers. Nevertheless, the psycho-social aspects of individuals' characters, for example, emotions, feelings, thoughts, attitudes, opinions and behaviour, all arose but were considered part of culture in this study. Viewing these issues in this way intended to illustrate how and why cultural influences affect healing practice treatments that IBD sufferers used as well as their perspectives of Self, illness and healing.

## **3.2 Refining Concepts and Constructing a Framework**

Having identified concepts in the literature reviewed, the next step was to refine the meaning behind concepts as they were to be used in this research by analysing and defining their characteristics.

### **3.2.1 What is 'Culture'?**

Culture is a dynamic concept with numerous definitions. Helman's (2007) descriptions of culture encompassed most facets of the meaning of culture applied to this research.

He described culture as: “*a set of guidelines (both explicit and implicit) that individuals inherit as members of a particular society, and that tell them how to view the world, how to experience it emotionally, and how to behave in it in relation to other people, to supernatural forces or gods, and to the natural environment.*” He added that these guidelines are transmitted to next generations by the use of “*symbols, language, art and ritual*” and that individuals have their own distinctive cultures. To explain this he used the example that “*adults, children and the elderly are subject to different rules of behaviour and different views of the world*” within a society, implying that there are ever-changing cultures within cultures. (2007: 2, 3)

Naturally, individuals will acculture other cultures within their existing culture/s, in time and space. “Acculturation is a concept used to refer to those phenomena which result when groups of individuals having different cultures come into continuous first-hand contact, with subsequent changes in the original culture patterns of either or both groups.” (Redfield, Linton and Herskovits, 1936: 149) One could therefore understand culture simply as someone’s ‘way of life’ whatever the influences which changed it may be labelled. Herzlich (1973) went into much detail in describing culture by also defining it as a ‘way of life’. In a study of Parisians’ perspectives of illness and healing, Herzlich (1973) pointed out two main characteristics of life in cities such as Paris, that is, their being both unhealthy and constraining. In this way, characteristics of a way of life are embodied and manifest into ill-health linking perspectives of illness and healing with culture.

The on-going interactions between individuals and culture within an ever-changing society emphasised the need to understand the *uniqueness* of perspectives of illness and healing of IBD sufferers as well as their perspectives of Self influenced by their way of life (culture). Living with IBD required many modifications to various aspects of sufferers’ lives, for example, how they perceived the loss of control of their physical bodies (anal incontinence) and that they needed to know where toilets were located in the vicinity of where they planned to be (coping with ‘safety nets’ in order to have a social life outside their residences). An intention in gathering and analysing this information was to assist healing practice providers in understanding what sufferers believed with regard to healing in order to improve treatment provision.

### **3.2.2 Overview of Cultural Construction of Illness and Healing**

An individual’s cultural construction of illness and healing is therefore an ever-changing creation of building blocks into a network of beliefs and perspectives about illness and healing adopted or discarded from the interaction with factors within the way of life in

which one lives. These building blocks are encultured and accultured within time and space and manifest into patterns of behaviour and expressions of identity that are unique to individual human beings.

As briefly noted in the chapter introduction, the parts that make up cultural construction of illness and healing are:

1. *Cultural Influences* – factors, which exist in culture/society/the environment (context) in which people live, that influence and in some ways shape our day-to-day lives.
2. *Perspectives of Self* – how people see themselves and express their identities.
3. *Perspectives of illness and healing* – what individuals believe their illness, state of health and/or healing process to be.
4. *Healing practice pluralism* – when individuals use more than one type of healing practice (received by themselves, people in their community or professional healing practitioners) to alleviate suffering from illness.

These parts are interrelating, overlapping and need each other to exist. The importance of understanding how these parts coexist and are constructed in the realities of individuals suffering from IBD may ultimately ameliorate treatment provision. As Henderson (2002: 199) put it “*beliefs about disease etiology and treatment are important determinants in how persons view the disease and how they respond to advice [and treatment] from health care providers*”.

Individuals with IBD have expressed many cultural constructions of IBD when describing their illness experience and suffering. The concepts interpreting these cultural constructions have been based on varying academic subjects such as psychology, anthropology, sociology. This research focussed on concepts primarily drawn from Medical Anthropology with regard to living with long-standing IBD and perspectives of illness and healing of individual sufferers within their ways of life (culture).

### **3.3 Components of Cultural Construction of Illness and Healing**

This section is divided into three sub-sections (cultural influences, perspectives of Self and healing practice pluralism), following the order of the four parts of the cultural construction of illness and healing listed above. Each includes examples, descriptions and aims to show how each came to become part of the conceptual framework.

‘Perspectives of illness and healing’ – the fourth part of the cultural construction - is interwoven into the exploration of the other three parts, to illustrate the experience of

living with IBD as a long-standing illness. However, when interpreting any person's cultural construction, it is important to remember that "*one cannot make generalisations about any human group without taking into account the fact that differences among the group's members may be just as marked as those between the members of different cultural groups*". (Helman, 2007: 4).

### 3.3.1 Cultural Influences

These are the 'factors', which influence people's day-to-day lives by shaping or guiding each individual's way of life within the context of living with a long-standing illness.

Helman (2007: 4) presented four categories of influencing factors in culture on health-related beliefs and behaviours:

1. "*Individual factors [– like] age, gender, size, appearance, personality, intelligence, experience, physical state and emotional state [.]*"
2. "*Educational factors [–] both formal and informal and including education into a religious, ethnic or professional subculture [.]*"
3. "*Socio-economic factors [– like] poverty, social class, economic status, occupation or unemployment, discrimination or racism, as well as the networks of social support from other people [.]*"
4. "*Environmental factors [– like] weather, population density, or pollution of the habitat, but also including types of infrastructure available, such as housing, roads, bridges, public transport and health facilities [.]*"

It is important to emphasise that it is difficult to name and categorise all cultural influences as all are mutually linked, coexist and sometimes overlap. Naming factors and categories serves only to facilitate comparative conceptual analysis and to enable deeper understanding of how they interact with and influence perspectives of the Self, illness and healing of individuals with IBD.

Whilst considering literature on the above four factors and issues with regard to caring for IBD suffering and treating illness, two others arose looking at how cultural influences affected the use of healing practices: 1) recommendations or suggestions from cultural influences; and/or 2) application of healing practices by cultural influences. This led to the identification of three main categories of cultural influences affecting IBD sufferers:

1. *The Self* – an IBD sufferer could actively or passively receive a recommendation of a healing practice from a cultural influence (like a TV documentary on Acupuncture for pain relief) or apply the healing practice to

him/herself from trial and error experience with what does or does not work for them (like lying down in particular positions to release trapped wind).

2. *The Community* – people whom the sufferer meets socially in their community like neighbours, family members, colleagues or strangers who are not receiving income from practising a healing practice and who making recommendations (for instance to get a reading from a particular medium for the sufferer to ‘connect’ with people who have passed away in order to ‘heal’).
3. *A Professional* – an individual who is paid to administer a healing practice to an IBD sufferer whether the healing practice is regulated/non-regulated by an associated and/or legal institution. For example, a doctor, shaman or practitioner (cultural influences) who recommends or applies a healing practice to IBD sufferers with the intention of restoring health or alleviating suffering.

Some cultural influences concerned with guiding the lives of IBD sufferers with regard to treatment options might be simply what they know to exist, for example, medication used at home (for example, Aspirin recommended by a mother to a child for pain). This use of self-care and other healing practices recommended by various cultural influences to alleviate symptoms are extremely relevant to coping with IBD. Therefore finding out what, how and why treatments are used by sufferers will prove beneficial to improving the contentment in living with IBD.

With this concept in mind, in the context of culture, IBD sufferers perceive their illness and healing differently depending on their enculturation and acculturation from cultural influences. Apart from the ones already listed, other cultural influences are likely to have an inevitable effect on choice of treatments including access to, availability and cost of healing practice treatments. For example, if an individual lives geographically far away (access to treatment) from the treatment option that they perceive might alleviate their suffering; they will most likely not receive that treatment as they cannot access it.

### **3.3.2 Perspectives of Self**

It is difficult to pinpoint exactly what the Self is as it varies depending on every individual and occurs within a particular cultural context. The Self can be depicted as something that encompasses an individual’s sense of identity within a community taking into consideration that individual’s characteristics and cultural influences. Examples include their religion, what and how they eat, how the weather and the news affect them, etc. Kagitcibasi (1996: 52, 53) provides a useful summary, in describing

the Self as “a social product in the sense that it emerges out of social interaction and is socially situated at any point in time”.

To try to illustrate the meaning and sense of the concept of the Self, a hypothetical example is used. The example relates to a person, named Aziz. This example has been created from a compilation of acquaintances in the UK with similar cultural backgrounds, over the span of ten years.

Aziz, a young man of twenty, whose mother is originally from Egypt and father is originally Lebanese, was born in North London. He has been raised in Great Britain, speaks fluent English with a North London accent, enjoys the occasional fish and chips but his favourite dish is the *molokhia* soup his mother makes, Egyptian style (*molokhia* is a home-made soup which contains mostly Egyptian spinach with spices of a gelatinous consistency). Although he is Muslim and fasts during Ramadan, he does not pray five times daily the rest of the year but believes in God, a soul and the *evil eye*. He is studying to become a yoga instructor and loves watching programmes like *ten years younger* (a reality show about aesthetic modification) because of the shocking yet fascinating ‘resculpturing’ surgery can perform on individuals who believe they need a make-over.

Aziz may consider the Self to be a combination of his physical body (influenced aesthetically by what *ten years younger* may consider beautiful), his soul (as a Muslim judged by God), his volatile personality (inspired by his parents’ diverse backgrounds, upbringing and behaviour) and his vital energy (a new concept he is learning in yoga class). This simple deconstruction is useful only to give examples of the variety of influences that are part of and surrounding Aziz’s life since before he was born, which have a major effect on who he thinks he is and how he perceives himself (the Self).

Uncovering Aziz’s perspectives of Self enables a better understanding of his cultural construction of illness and healing. His personal characteristics (inherited or encultured from family and friends), and educational factors (his religion, for example, Islam or going to yoga classes learning about concepts like vital energy) as well as other socio-economic and environmental factors will inevitably affect Aziz’s choice of treatment therapies.

For the sake of explanation, suppose that Aziz had a dry cough. Apart from the cough syrup his GP may prescribe, Aziz’s belief in the *evil eye* may influence him to burn incense (most probably *lubann* aka frankincense) in his residence mostly where he sleeps, for protection. This incense not only has a spiritual but an antibacterial effect on healing his illness. His mother or father may recommend reading ‘protection’ verses

from the holy Koran. He may also use a few yoga postures to get his 'energy' moving better and unblock his heart/lungs and throat chakras. Needless to say his mother's *molokhia* will most certainly play a big part in comforting him, giving him 'strength' as well as providing a gelatinous-like consistency which might help 'moisten his dry lungs'. These multiple healing practices used simultaneously are a good example of what I define as healing practice pluralism.

Similarly to Aziz, every individual constructs their own 'realities' from their culture and cultural influences. These factors will not only shape their perspectives of the Self but will also have an effect on how they perceive illness and healing. In order to understand this, we need to deconstruct parts of the Self to get a clearer picture of how individuals may construct their perspectives of illness and healing.

### **3.3.2.1 Constituent Parts of the Self**

Several literature sources have used categories representing parts, which make up the Self in order to explain and define it. Helman (2007: 23) described the human being as two symbolic bodies: *"an individual body-self (both physical and psychological), which is acquired at birth and a social body that is needed in order to live within a particular society and cultural group"*. This viewpoint helps to provide a general view of individuals existing within a society but clearly the Self can be divided further into sub-sections: the Body, the Mind, the Spirit, the Vitality, and Culture as Self. The 'Body' is usually used as a reference to the physical body on both an anatomical and physiological level. 'Mind' is understood here as the aspects of intellect and consciousness manifested as combinations of thought, perspective, memory, emotion, will and imagination including all of the brain's conscious processes. Again, 'Spirit' is understood as the material and/or immaterial, self-aware essence unique to a particular living being; the unification of one's sense of identity usually considered to be immortal and to exist prior to incarnation and sometimes has strong links with notions of an afterlife. Many traditional systems of healing centre on the idea of a vital power, associated with movement and breath, at the core of health and disease. Vitality has the meaning where the source of disease is not traced to a particular organ but to the disharmony of this vital power, circulating in the body. *"Vitality, efficacy, power - all capture the idea of a force of life that animates bodies/selves."* (Kleinman, 1995: 36).

It is recognised that, ultimately, one cannot separate the Body, Mind, Spirit, and Vitality of an individual or that individual's cultural influences within their way of life. Yet, even with this mutual co-existence, different healing practice philosophies, professionals and sufferers will vary on their perspectives of the Self as either: the Body, the Mind, the

Spirit or a combination of these. Vitality may or may not be shared within the meaning of the Spirit. Culture on the other hand is universal as a part of the Self which each individual identifies with either directly or indirectly as they are inevitably 'connected' to their environment whether they live within a community or in isolation like hermits.

Understanding what makes up the Self provides a base for comprehending cultural construction of illness and healing from the point of view of IBD sufferers. Different authors have provided diverse outcomes and concepts for discussion of possible cultural constructions of IBD but in this research the parts that make up the Self are represented as follows. Each 'aspect' of the Self is now considered in turn.

### ***The Body as the Self***

This section defines the Body as a living organism with tangible properties that 'responds' to sensory and motor stimuli of internal or external origin where manifestations of illness are expressed and experienced by individual human beings. There are many ways in which the Body is seen, it can be seen either more mechanistically whereas Kleinman (1995: 36) puts it, "*things are simply things: mechanisms that can be taken apart and put back together*", or more holistically, where it can be part of a system that involves not just mechanical reactions but also a sensitivity to intangible things such as vibrations.

When analysing the conceptual base of Medicine's perspectives of illness and healing, numerous authors have mentioned this healing practice's more mechanistic approach to healing. This was illustrated in Chapter Two in looking at the more mechanistic trajectory of perceiving IBD as the *disease* being the Body. Kleinman describes this view as being "*monotheist*" with the "*medicalization*" of sufferers' "*moral crises*" in their illness experiences. Medicalisation refers to the application of the expert's rational technical rules to deeply human experience (Kleinman, 1995: 34). The medical focus of sufferer's illness is on "*the solitary body*" due to Western society's emphasis on individual experience. (Kleinman, 1995: 36, 37).

Although medical professionals equate more severe symptoms in IBD as causing a poorer quality of life for their patients, they also consider the negative effects of medical treatments as part of living with this disease and contributing to the sufferer's perspectives of Body as Self. For example, Reddy and Wolf (2001) looked at this in their literature review on disease management for women with IBD. They examined the sufferer's perspectives of the Body as the Self in two ways with regard to:

1. Reduced bone density – from the long-standing loss of calcium as a complication of IBD due to loss of nutrients, but more controversially the

contribution to the development of osteoporosis from the use of steroids in the medical treatment of IBD. If these patients knew this, how would their perspectives of Body as Self and the healing practice of taking steroids change?

2. Sexuality vs. fertility – The authors pointed out that in order to increase sensitivity to ameliorate patient care, understanding the perspectives of body image by women suffering from IBD is important as it directly affects their sexuality and fertility. Alas, implementation of types of surgical ‘cures’ in women with IBD, are examples of ‘catch-twenty two’ scenarios, which appear to be a common consequence of medical treatment options for IBD. For instance, Reddy and Wolf (2001) explained that the most unpopular surgical options in ‘curing’ IBD are proctocolectomy and colectomy which increase fertility due to the eradication of active disease yet these drastically decrease sexuality, including sexual drive and perspectives of one’s sex appeal. Conversely, the most popular surgical option is ileo-anal anastomosis which means patients do not require a colostomy bag thereby increasing confidence in their body image (perspectives of the Body as the Self) resulting in increasing sexuality. They highlighted that unfortunately, this procedure increases the risk of infertility.

Helman (1995: 174) also mentioned the negative effects of medical treatments such as surgery on IBD sufferers’ sexuality due to “*fear of ridicule, incomprehension and stigma*” of stoma bags by their partners. Helman added that perspectives of body image changed after surgery because of a new ‘orifice’ being created (stoma) that became more ‘public’ with all sorts of other stigma attached to it. (1995: 169). Another example can be found in Black (1992: unpublished Masters dissertation, referred to in Helman). Black described how British Muslim colostomy patients preferred to have their stomas placed above their waists and on the left side of their bodies due to the fact that above the waist, waste products are still considered food not faeces and Muslims wash after defecation with their left hand, so would change their stomas with this hand. This example demonstrates a direct connection between this community’s religion and their perspectives of the Body as Self in modifying a healing practice to ‘suit’ the Self-image.

Sevcik’s (2004) PhD study provides further insight into the perspectives of the Body as part of the Self with regard to medical treatment, in particular when she emphasises the negative effects of medical drugs and colonoscopic diagnostic technique used in IBD. She highlighted the negative effects in order to explain the importance of measuring

*“illness intrusiveness”* and *“illness representation”* but did not then apply this as an *“obvious factor”* in her research. (2004: 35, 38). In particular, she did not explicitly include illness intrusiveness or representation as a factor in her questionnaires and thus did not explore how negative effects affect IBD sufferer’s perspectives of Body as Self. Sevcik’s (2004) medical perspective of IBD also expressed the fact that surgery is ‘curative’ but did not mention how post-surgery lifestyles affected the individuals. Again, it was paradoxical that this type of treatment was a very large part of IBD sufferers’ lives yet this was not taken into consideration in the measurement of illness intrusiveness and illness representation.

In contrast, one author who *did* bring out the subjective experience of living with IBD with regard to perceiving the Body as Self, including how medicine affects sufferers, is the Finnish anthropologist, Juha Soivio. He described how one IBD sufferer perceived the body as a *“pure object”* and described his colon like *“a little pipe which is not working properly [...] like the wheel of an old bike.”* (1999: 103). This perspective of IBD as a mechanical problem has partly been made possible due to the use of technology like colonoscopies in medical diagnosis of IBD, where patients can have a *live* view of their own colons.

### ***The Body & Mind as the Self***

According to Kleinman (1995: 26), in the past Medicine was also known as *“holistic medicine”*; a term he said was used by critics to encourage a less reductionist, mechanistic approach to human concerns of patients and families. The term ‘holistic’ nowadays is commonly used to refer to a more inclusive treatment approach (for example, looking beyond signs and symptom to what lies behind and treating the ‘whole’ person within the their socio-economic context); the term is also commonly used by TCAM, and other CAM, practitioners, to describe both their approach and wider TCAM healing practices.

Perhaps the general notion that Kleinman was trying to present is that Medicine is attempting to be more ‘humane’ in considering the Self as not just the body as a location for disease but also entails a wider consideration of emotions, feelings and behaviour (the Mind) as part of living with illness. This introduces Medicine’s second trajectory as a less mechanistic view, where the disease is perceived to be causing sickness to the Body as well as the Mind of IBD sufferers. As a result, support offered to sufferers is not only with medication and surgery but also with support groups assisting them in coping with their illness.

Aside from complications of surgery, an example of the Self as both Body and Mind can also be seen emerging from Reddy and Wolf's review (2001). The authors mentioned that many women with IBD experience discomfort or pain during intercourse perhaps due to abdominal pain, diarrhoea and fear of faecal incontinence. Subsequently, their bodies or rather loss of control of their bodies in connection with emotions such as fear becomes part of their perspective of IBD.

Many psychological complexes and phobias involved with living with IBD are studied by Sevcik in the context of how sufferers perceive their illness and the degree of "*illness intrusiveness*" and symptoms of IBD have on their day-to-day lives. Her work is based on concepts drawn from psychology, focusing on emotions, feelings and complexes experienced by IBD sufferers. She emphasises the unpredictability, humiliation and feelings of inadequacy of IBD sufferers as significantly intrusive aspects of coping with IBD. Although her research uses mostly quantitative methods to collect information from participants, she manages to call attention to the moral and psychological perspectives of illness and healing of students with IBD, their families, colleagues and friends with regard to a concept she calls "*familiarity*" (knowledge of living with IBD) (2004: 32).

Within Sevcik's (2004) psychology-based research, she also discusses and compares three socio-psychological models of illness behaviour (the Health Beliefs Model, Attribution Model and Self-Regulatory Model). According to Sevcik, one of the key ideas supported by these models and her research is that perspectives of illness experience may be influenced by "*familiarity*" with the illness (2005: 2). From her comparisons, she construed the use of a modified version of the Self-Regulatory Model as being the most favoured in her study to underpin perspectives of IBD. Although she argued that this model integrated environmental factors and was a more subjective framework to discovering the "*full illness experience*" of IBD sufferers (2005: 17), the many rigorously-structured questionnaires used to measure this outcome were quite paradoxical. Using a more mixed-methods approach to data collection like questionnaires and observation followed by interviews with sufferers to find out the meanings within contexts of the lives of people living with IBD may have been more effective.

A greater resonance with the perspective of Self as Body and Mind arises in Soivio's (1999) study. As previously noted, narratives are used within the data collection and analysis processes to interpret the meanings and illness construction of IBD sufferers. Soivio (1999) drew on Kleinman's (1981) notion of the Explanatory Model (EM) as a means of getting to understand IBD and how people made sense of it in their own lives.

Kleinman (1981: 105) defined an explanatory model as *“the notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process.”* He depicted an EM as having five components: aetiology of the condition; time and mode of onset of symptoms; patho-physiology; degree of severity and type of sick role; and treatment. These components are somewhat relatable to the components of the cultural construction of illness and healing included in this study. For instance, the onset of symptoms, and perceived aetiology (from the point of view of IBD sufferers) as part of the context of life events work together with living with suffering and coping with manifestations of the patho-physiology of the illness, all involving seeking advice on how to deal with manifestations with the help of cultural influences whilst considering the Self.

Soivio (1999) demonstrated from the narratives that people sufferers of IBD have more than one EM running parallel to each other in existence, which they use interchangeably depending on their current experience. He described this using the example of one narrative told by *“Marja”*. As he summarised (Soivio, 1999: 96), she *“is actively interpreting and explaining the subjective experience of colitis by drawing from the shared cultural knowledge of health and illness [...] around explanations concerning stress, a bug and a theory of cigarette smoking”*. Each perceived ‘trigger’ to her illness had a different EM to understand and describe what she thought might be rationalisations for her suffering. This ‘making sense of illness’ is relevant to this study in a similar way in seeking to understand sufferers’ perspectives of illness and healing.

While Soivio’s (1999) and Sevcik’s (2005) studies, from their different academic subject frameworks, discovered useful information from IBD sufferers, they both gathered these outcomes for only one type of healing practice, namely, Medicine. This material illustrated insight into only medical and/or ‘western’ thought patterns as the greatest influence in perceiving the Self, illness and healing. At the same time, this ‘single’ healing practice perspective and exploration highlights a significant gap in the literature and knowledge base in relation to other healing practices. This reinforces the potential significance, of this PhD and provides a particular justification for its focus of studies looking at perspectives of illness, healing and illness experience with regard to other healing practices, and here in particular TCAM treatments in healing IBD.

### ***The Body, Mind and Spirit as the Self***

As Kleinman (1995) and Helman (2007) described, certain types of healing practices encompass not just the Body and the Mind but also the Spirit. Some healing practices tend to see the Spirit as the soul of a being and will not necessarily consider an

individual's vitality as being part of their Spirit. For example, in many countries, religious or spiritual individuals provide healing from the source of their belief systems, for example, Jesus to heal ill people 'channelled' through practitioners in Christian hands-on healing. They may not consider this healing energy as vitality but more an extension of power coming directly from Jesus, that is, through the healer, out of the palms of their hands and into the person whom they are healing. Moreover, the cause of illness itself in many religions is considered to originate from God and who perceive the soul as the Spirit in combination with the Body and Mind as parts of the Self. Herzlich and Pierret (1984: 78) described this by writing: "*it is God, in the last analysis, who sends illness to mankind. This idea has been inherent in medical theory, in the whole of society, for many centuries in Western Christendom. One may of course seek various different 'causes' of illness, but God alone is the 'prime cause'*". These perspectives of parts of the Self can be easily included in the four components of the conceptual framework.

Another example of the cultural construction of illness and healing perceiving the Self as Body, Mind and Spirit is that of an American Indian tribe in Indian Territory, Oklahoma, USA. Here the Spirit involved the notion of the soul being directly involved in illness according to Henderson and Henderson's study (2002: 206), which presented the subjective experience of an American Indian tribe who describe their grandmother, Mrs. Maytubby's diagnosed dementia, as "*actual communications with the other side (the supernatural world), inhabited by the spirits of the dead'*".

In principle, the view of 'channelled healing is similar to how most TCAM healing practices perceive Vitality from the universe. Examples include Qi passing through channels/meridians in Chinese Medicine (CM) stimulated by acupuncture needles or a practitioner of Qi-Gong healing, through their hands into individuals seeking healing. Although many TCAMs may consider an individual's soul as part of their Spirit, each is considered almost exclusive to the identity of that person. In contrast, many of the healing practices, for example, in Indian Ayurvedic Medicine, consider a person's vitality to be a general source of life energy or breath of life, which exists in all *living* entities within the entire universe. Kleinman (1981: 91) described illness from a CM perspective as disharmony of "*vital essence (known as ch'i)*" in the body which may sometimes be unable to be understood by Western Medicine practitioners due to CM's completely different theoretical framework.

Vitality is not necessarily considered religiously spiritual even if its origins lie in the universe. For instance, Vitality in CM is present as 'life energy' within a physical body but it can be enhanced or reduced by the way individuals live (culture). Hence, when

food is eaten that does not agree with the body, an imbalance in the body's energy and vitality arises, which is to a certain extent healable but the source of that change originates outside the Body.

Many TCAM practitioners commonly use terms to suggest the energy and/or vitality's uniqueness within each individual. This can be seen when a person is ill and their practitioner considers their illness to be an imbalance of energy and/or vitality, using terms like: 'your energy is blocked' 'your vitality is weak'. It may then perhaps be more appropriate to say 'the energy in your body is blocked' or 'the vitality of/in your body is weak', if one considers its origins and especially as most TCAM healing practices believe every being is 'connected' to their environment and the universe. In this case, most TCAM healing practices consider the Self to be a combination of parts such as Body, Mind and Spirit including Vitality.

Helman (2007: 113) mentioned the Body, Mind and Spirit interrelationships when he described some similarities between "old-style" medical practice especially in rural areas, and consultations with TCAM practitioners who perceive the Self as Body, Mind and Spirit, as opposed to the present day "rushed" NHS medical consultation. He listed six points, two of which mentioned that TCAM consultations are more "holistic" and often have a "religious or mystical" element "in placing the individual's suffering in the wider social, psychological or spiritual context in their lives". (2007: 114)

Many healing practice philosophies, professionals and individuals within a culture possess similar views on illness and healing but still have their own *unique* cultural perspectives that determine the characteristics of the illness, healing process and healing practice constructed in individuals' realities. This is one of the core reasons why it is of utmost importance to understand the meanings behind how and why, people perceive the Self, illness and healing in using a diversity of healing practices within the context of their culture.

### ***The Body, Mind, Spirit and Culture as the Self***

This section explores the Body, Mind and Spirit embedded within culture as the Self. Healing practices as well as perspectives of the Self, illness and healing differ from country to country. Even within countries, professionals will perceive the cause and manifestations of illness in different ways. Most importantly, individual sufferers of illness will perceive themselves and their illness from different viewpoints and be influenced directly or indirectly by their culture/s when deciding on treatment options.

Kleinman compared the difference between Chinese and Western societies' healthcare systems by saying: "Chinese people seem to be much more concerned about questions of health, illness and health care than Americans; and health care systems in Chinese societies seem to possess many more elements and take up more time in the lives of people than do those in our own society." (1981: 40, 41) Another example is evident in Adams's (2002) work where he compared shiatsu as practised in Japan and Britain. He contrasted the culturally different notions of holism, its socio-centric connotation in Japan and its individualistic connotation in Britain. These perspectives of culture in both literature sources have to do with a sense of national identity connected to the perspectives of illness and healing. For instance, China, a country with a massive geographical space where public healthcare is available, affects individuals' perspectives of illness and healing due to the accessibility to basic healthcare.

Other writers' work has also demonstrated the Self and its cultural context. Herzlich illustrated how Parisians are affected by their city and referred to it as the source of their illness: "*in Paris I always have a feeling of heaviness, a feeling that my thinking is slowed down, that my blood is heavy [...] I feel my nerves tying themselves in knots [...] I live partly on my nerves, my nerves help me a lot, but with the pace in Paris, you can't leave it all to them*" (1973: 45). In this case, the culture of living in Paris was described as directly influencing the perspectives of illness and healing of its 'locals'.

Again, Krause (1989) described how a community of Punjabi people in Greater London had different diagnoses and treatments for the condition of the "*sinking heart*", which in Medicine might be easily linked to depression. It was, believed to be "*a state of illness which may be physical, emotional or both*" where the heart was "*decreasing*", "*shrinking*", "*becoming small*", "*sitting down*" and "*sinking*". (ibid: 566, 568). Here the heart was the most central part of the Self and was described as controlling distribution of food, blood and breath in the Body as well as being a reservoir of emotions and feelings, which were affected by individuals' personal characteristics. The study explained how the way people lived including how they coped with personal experiences in their lives affected their 'heart' possibly resulting in illness. Therefore, the heart was an important entity in influencing these Punjabi people's perspectives of illness and healing as part of their culture.

Krause reiterated the importance of culture in perspectives of illness and healing by explaining that illness is seen in its social, cultural, historical and individual context: "*these aspects are considered to be determining factors in the causation, expression, presentation and outcome of illness.*" (1989: 564). He emphasised that what mattered

was not so much the diagnosis of disease but the *meaning* of illness in connecting perspectives of illness and healing with individuals' ways of life (culture): "*the experience of 'sinking heart' and the need for this experience to be controlled and repressed is coherent with Punjabi culture as expressed by Punjabis in Bedford.*" (ibid: 564)

Krause (1989) commented more broadly about the Ayurvedic system of Medicine. He explained: "the Ayurvedic system of medicine provides a framework for the expression of Punjabi ideas about illness and treatment. In this system, the mode of thought is radically different from that of the Western scientific system of medicine." (1989: 565). Kleinman (1981) similarly described the influence of culture on perspectives of illness and healing for Chinese people in Taiwan with regard to the healing practice of Chinese Medicine (CM). These examinations are important in demonstrating the strong influence of encultured and accultured behaviour, language and beliefs from cultures in steering perspectives of illness and healing for sufferers and their carers within a society.

### **3.3.3 Healing Practice Pluralism**

Each type of healing practice emerges from culture. As Kleinman (1995) argued, the medical perspectives of illness and healing stem from the Western perspective of the 'solitary body' as the Self. In contrast, Traditional Chinese Medicine has ancient origins within China. The CM view that the Body, Mind, Spirit including Vitality are interconnectedly affected by the universe and the elements (Earth, Fire, Wood, Water and Metal) in nature reflects perspectives of Self, community, the environment and the universe from years of encultured history according to CM classical texts, like the 'Neijing Suwen' (Yellow Emperor's Classic of Chinese Medicine). The Su Wen is a compilation of fragmentary texts written, collected and edited by an unknown number of individuals in a period lasting from about the second century B.C.E. to the second century C.E. (Unschuld, 2003). The knowledge recorded in this as well as other Chinese classics is based on a Daoist way of life (culture) that may not be practised in the same way in present-day China but retains elements of ways of life in the past that are integrated into modern society and thinking with regard to perspectives of Self, illness and healing.

Healing practice pluralism is frequently referred to in the literature as 'medical pluralism'. It was described by Cant and Sharma (1999: 4) as "*the multiplicity of healing practices existing alongside each other and interacting with each other as well as the ways in which sick people and their kin make decisions about what kind of*

*healers to use*". Helman (2007: 81) on the other hand used the term "*health care pluralism*" to describe a similar concept. One point that Cant and Sharma (1999) made in their analysis to define 'pluralism' was that this term implied an equality and non-competition between healing practices. Notwithstanding, Medicine continues to be the most predominant healing practice within most industrialised societies and, within the context of this thesis, as the mainstream approach to treating IBD.

The term 'healing practice pluralism' is used in this thesis, to emphasise a shift in perspective. Terms such as 'health care' and 'medical' spring from a medical and systems of care provision background. This lies in contrast to the notion of 'healing', which has wider roots and focus. Thus, 'healing practice pluralism' involves healing practices where in principle each practice has similar degrees of credibility or value stemming from their diverse roots and diverse schools of thought and experimentation. The degree of credibility or value is only relative to the individuals who practise or are being treated with that healing practice in *their* experience of illness and its treatment according to their cultural beliefs and influences. It is thus evident that healing practices may vary widely between cultures or individuals.

Moreover, individuals may receive and use more than one type of healing practice simultaneously in searching for healing or in living with a long-term condition. Perhaps the most classic example relates to individuals treating themselves with different forms of healing, or, in common parlance, through 'self-care'. Apart from healing practices established through historical texts, philosophies and practices, self-care presents another form of healing practice, which may vary depending on culture within a society, community, household or other social group.

Self-care has been defined in several ways by other authors. Kennedy et al. (2003: 64) demonstrated the impact a guidebook, constructed from patient experiences of living with IBD, had on IBD sufferers in relation to how well they "*self-manage[d]*" their ailments "*in the community*" based on health-related quality of life (HRQoL) perspectives. Although the initial data used to compile the guidebook was based on patient experiences arising from their follow up of medical advice given, these were centred on a medical perspective of disease management, where the intention was to influence self-care amongst patients, outside of a clinical environment. Therefore self-care in their account meant patient experiences in using Medicine to alleviate IBD sufferers' ailments when a professional clinician was not present.

More generally, self-care can be perceived in the wider literature as being care undertaken by the individual to either cope with the particular illness or to adopt

healthier ways of living. Most commonly, this is centred on advice-giving by healthcare professionals. For example, Robinson et al. (2001) gave a similar meaning to what they defined as 'self-management' where IBD sufferers involved in a randomised controlled trial (RCT) demonstrated their understanding of how to use their medical drugs correctly outside a clinical environment, like at home. Similarly, Smith et al. (2002), while focusing more on the psychological characteristics of living with IBD, demonstrated again the active way of re-educating patients in how to cope with IBD; knowledge which they would use at home in self-care when counselling services were not accessible.

A wide interpretation of self-care is adopted in this thesis. Self-care is understood as arising both from trial and error, and use of medical or other approaches. Most importantly, it also arises from inherited methods of care and healing between generations. It describes ways that individuals use to treat themselves using a combination of home-made remedies and ways of coping. This may or may not include medical forms of treatments. This provides yet further justification for the need to conduct research on the way IBD sufferers use self-care as a healing practice whether it be influenced by Medicine or other types of healing practices and ways of coping passed down through familial relationships.

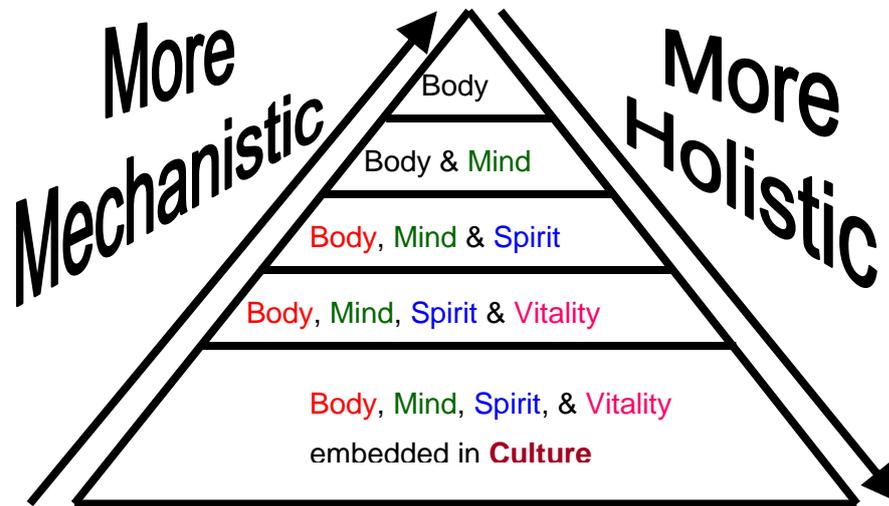
Building on the above, healing practice pluralism is defined in this PhD thesis as the application or practice (including self-care) of more than one healing practice by or on individuals suffering from illness in caring for suffering with the intention of restoring health and/or easing suffering. Medicine, CM and 'hot toddies' are all examples of healing practices (either systems, for example, Medicine, or particular treatments, for example, hot toddies).

### **3.4 Summary**

This chapter explored different perspectives and concepts of the Self as Body, Mind, Spirit, Vitality or a combination of these in the context of culture. A triangular, diagrammatic overview of the constituents of the Self with this perspective, as one of the four components of the cultural construction of illness and healing, is presented in Figure 3.1. At its apex is the depiction of the Self as the Body. This is perceived as the most mechanistic perspective of the Self. In contrast, at the base of the triangle, is the depiction of the Self as Body, Mind, Spirit and Vitality, embedded in culture. This portrays the most holistic perspective of the Self. This diagram serves only as an example to emphasise the varying perspectives of Self in relation to perspectives of

illness and healing that individuals take into consideration when choosing healing practices including TCAMs.

**Figure 3.1: Overall of the Constituent Parts of the Self**



The chapter also expounded the basis and elements of the conceptual framework, entitled '*Cultural Construction of Illness and Healing*', adopted within this PhD thesis. In summary, it encompasses four main areas.

1. *Cultural Influences*: anything that influences/guides/controls an individual to use a healing practice, for example: watching a TV documentary on Acupuncture, hearing about Reiki from a masseur, getting a personal recommendation to try Chinese Herbal Medicine.
2. *Perspectives of the Self*: where individuals perceive the Self as “a social product in the sense that it emerges out of social interaction and is socially situated at any point in time” (Kagitcibasi: 1996: 52, 53), encompassing an individual’s sense of identity within a community and considering their preferences and influencing factors.
3. *Perspectives of Illness and Healing*: where sufferers, practitioners and different types of healing practices perceive illness, its diagnosis and treatment in different ways.
4. *Healing Practice Pluralism*: where different healing practices are used together e.g. resting, burning scented candles, taking herbs or steroids.

This framework informs the way the thesis was conceptualised, designed and mode of analysis and interpretation of the narratives of the IBD sufferer participants. In particular, it is used as a way to help both organise the data collection and interpretation process and aid understanding of participants' use of multiple healing practice and differentiation of cultural influences. Thus, it is the perspectives of Self, illness and healing of these individuals as well as the cultural influences that exist in their lives, that need to be explored in order to understand how participants culturally construct illness and healing to ultimately choose healing practices.

The discussion in this chapter has brought perspectives of illness and healing to the surface to enable and promote understanding of how diverse and multi-faceted cultural construction of illness and healing can be, as well as its uniqueness relevant to individual sufferers. The chapter has shown how various types of cultural influences can affect how and why individuals view their illnesses and healing as well as express their suffering. With these cultural influences in mind, one can see that the treatment options for healing IBD may vary according to the culture of an individual sufferer's perspectives of the Self, illness and healing. In particular, it has been argued that it is the recommendations and application of healing practices by/on individual sufferers by themselves, the people in their community and the professionals (cultural influences) in the service of providing healing that have an effect on the choices made on which healing practices to receive.

Until recently, as argued in Chapter Two, the majority of IBD sufferers have been mostly provided with medical treatments as these have been advised to be the most effective, efficient, inexpensive and available options for treating IBD. As Medicine is the healing practice that determines diagnosis of IBD, physicians will provide the sufferer with a prognosis, which will necessarily require medication and, more often than not, surgery as a treatment and sometimes a 'cure' for the 'disease'. Medicine also but not always informs IBD sufferers of mortality risks in advanced or severe stages of inflammation and that treatment with surgery may in those cases be lifesaving. Nevertheless, surgery is also frequently recommended as a preventive treatment option to avoid IBD developing into a possibly dangerous stage of disease or causing serious complications such as perforation of the bowel, infection or cancer.

While situated against this medical healing practice dominance, this thesis aims to go beyond this and look at both the experiences and choices, in particular, the cultural influences on these choices, of a small set of sufferers of IBD. It purposively set out to explore the perspectives of individuals with IBD who had explicitly accessed an additional healing practice, here TCAM. The question driving this research is how and

why do IBD sufferers use healing practices including TCAMs to cope with living with illness? Focus now turns in Chapter Four to explore the methodology and methods adopted in this thesis to explore the research question located within the guiding conceptual '*Cultural Construction of Illness and Healing*' framework.

## ***CHAPTER FOUR: Methodology and Methods***

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This chapter explores and presents the methodology and methods adopted in this thesis in order to answer the research question of ‘how and why do IBD sufferers use healing practices including TCAMs to cope with living with illness?’ situated within the PhD’s guiding conceptual medical anthropological, conceptual framework. Rationales for the choice of approaches are explained, and insight into how the study is done. The chapter is divided into three sections. The first section examines the methodology underpinning the work; the second section presents the methods adopted and reasons for their choice; and the third section provides insight into the process of analysis and interpretation.

### **4.1 Methodology**

The outline and discussion in the first part of Chapter Two led to the conclusion that, for any potential sufferer of IBD, firstly, Medicine, with the use of biotechnology, is normally the healing practice able to diagnose IBD as accurately as possible and, secondly, because of this, IBD sufferers are expecting to be offered medical treatment options and prognosis. With this in mind, there were two motivating forces behind extending the focus onto the question ‘what other healing practices, particularly non-medical, are used by IBD sufferers living with long-standing illness?’: my own personal experience in using non-medical healing practices for IBD and interest in cultural factors that might influence the way sufferers from IBD use different healing practices.

Four specific objectives needed to be followed through:

1. To find out how individual sufferers perceive living with IBD relative to their cultural background.
2. To explore participants’ perspectives of healing practices they use, which ‘suit’ their perspectives of Self with regard to treating their ailments in the context of recommended treatments and their application.
3. To uncover the reasons why IBD sufferers use particular healing practices to manage their illness.
4. To gain insight into the TCAM healing practice settings in which IBD sufferers are situated.

To be able to realise these objectives, the following points of interest became the impetus behind refining this study's philosophical underpinnings, guiding conceptual framework (explored in Chapter Three) and research approach:

1. *Culture* – finding a field of research and methodology that focusses on examining various ways of life with regard to living with a long-standing illness like IBD.
2. *Context* – using a research approach that emphasises examining context in order to understand how recommendations from cultural influences are adopted by IBD sufferers during different life events.
3. *Life stories* – using tools that spring from a field of research that historically collects and examines narratives and observation of language, ways of coping and behaviour of individuals and groups.

Following this thought process, and to identify an appropriate research approach, literature was explored in the following areas: qualitative research, social anthropology, medical anthropology, ethnographic fieldwork, narratives, diaries, observation, inductive analysis, ethics, rigour in research, researcher roles and reflexivity. This reaffirmed the appropriateness of a research approach based within a qualitative frame, use of an inductive analytical process and the importance of maximising rigour and ethical practice in research. Each area is explored in turn.

#### **4.1.1 Doing Qualitative Research**

After considering the conceptual framework and research interest, a qualitative research frame seemed eminently suitable. The intention was to use this approach “as a starting point for scrutiny rather than for application” as Charmaz (2004: 985) advised, in order to “illuminate the worlds we visit and generate new theoretical insights”.

Reading and reflections thereon pointed towards a naturalistic approach to collecting and interpreting information in a context similar to Good and Good (1993: 103) who applied qualitative research “to analyse the emergence of the life world of medicine as the grounds of experienced reality for students during their first year of medical school”. In this way, this study used qualitative methodology and research methods to analyse emerging themes in IBD sufferers' ways of life by exploring and examining their ‘experienced reality’ of suffering when using healing practices in living with long-standing illness.

Qualitative research characteristically examines the nuances presented by participants in a study whilst inductively interpreting feelings, understandings, processes and actions expressed through social interaction in order to discover meaning and develop concepts about their ever-changing ways of life. Thus, use of qualitative as opposed to quantitative research would make it possible to examine perspectives of IBD sufferers in dynamic and complex situations; alongside it would be necessary to consider the role of the researcher in interpreting meaning behind how and why sufferers used a variety of healing practices including TCAMs. Quantitative research would have been inappropriate in answering the research question and interests. This research style tends to focus on collecting information usually expressed in numbers or standardised measuring instruments in order to generate data that can relate to a general population. Such tools, on the lived experience of IBD and cultural influences, also do not exist. Moreover, it was important to explore participants' meanings and perspectives within their own life context, again not possible within a quantitative approach.

In doing qualitative research in this study, the following points were kept in mind:

1. *Focus on meaning* – this way of conducting a research study made it possible to refine enquiry and discover depth of meaning behind the feelings, understandings and perspectives of IBD sufferers using various healing practices.
2. *Emphasis on individual experiences* – unlike quantitative research, qualitative research offers an approach that places the life of the 'individual', here, IBD sufferers, at the centre of this study.
3. *'Capturing' nuances* – qualitative research provided a medium for flexible and dynamic variables to occur which made it possible to 'see' the subtle and obvious complexities of lived experiences. This was extremely useful when 'capturing' the nuances emerging in IBD sufferers' life stories.
4. *Studying ways of life* – this way of doing research documented the study of physical, sensory and symbolic aspects of individuals' ways of life such as ways of coping, language and behaviour of IBD sufferers within the context of life events.
5. *Fieldwork through social interaction* – gathering and analysing information informed by a qualitative research methodology was conducive to a less structured form of enquiry where the researcher and participant interacted in a

natural conversation; within which there was an opportunity to reflect back to the participant and check back on the understanding of information expressed.

6. *Roles of the researcher* – qualitative research methodology and methods enabled the researcher to cultivate listening skills amassing as much detail, whilst being self-aware of the impact she had on the interpretation of data recorded. Researching in this way highlighted the importance of maximising rigour by being honest and explicit in expressing interpretations of data as well as being meticulous in recording and organising information on IBD sufferers' lives. The researcher needed to acknowledge that information gathered and processed represented only snapshots in time and space and therefore was vigilant to avoid making generalisations about ever-changing life events as well as making biases and intentions behind interpretations explicit.

In summary, the research methodology adopted a qualitative approach and was grounded within a medical anthropological perspective and conceptual framework (as explored in Chapter Three). This approach supported the research endeavour to explore the meaning behind behaviour and the lived experiences of individuals with IBD, embedded within their culture.

#### **4.1.2 Using a Qualitative Approach**

The interest in studying the context of IBD sufferers in living with long-standing illness by documenting the influence of culture, relationship networks, value and belief systems had a strong implication for the use of a qualitative approach to the research question. A cultural perspective includes looking at individuals' emotions, feelings, thoughts, attitudes, opinions and behaviour as a part of their culture.

Ethnography, with roots in anthropology, involves a dynamic exploration of how and why participants perceive, organise and make sense of the world they live in (Soivio, 1999). As Wolcott (1999) explained, ethnography is a '*way of seeing*' an experience immersed in culture; as a methodology, it influences what is seen as data, the way in which data are collected and interpreted including approaches to ensuring rigour.

Particular philosophical/theoretical commitments of ethnography relate to an emphasis on understanding (participants and their actions, for example, kinship networks), capturing the process of interaction (for example, inherited methods of care), in natural life settings, multiple perspectives and holism (actions in relation to their life world and culture) (Helman, 2007). These philosophical commitments translate into methodological commitments, for example, to explore not just what is said but also how this is followed through in action or behaviour, and to explore the perspectives of the

many different actors in a situation. As Wolcott (1999: 68) argued: *“the underlying purpose of ethnographic research in this view is to describe what the people in some particular place or status ordinarily do, and the meanings they ascribe to what they do, under ordinary or particular circumstances, presenting that description in a manner that draws attention to regularities that implicate cultural process.”*

Other literature sources demonstrated the use of ethnography for different research interests. Bourgois (2003) used ethnography to build on the analytic framework of cultural production theory, drawing from feminism, in the hope of restoring *“the agency of culture, the autonomy of individuals, and the centrality of gender and the domestic sphere to a political economic understanding of the experience of persistent poverty and social marginalization in the urban United States”* (ibid: 12). His reason for using this methodological approach was because he felt that traditional social science research tools based on Census Bureau statistics or random sampling surveys would not be able to access survivors of underground economies (especially those involved in illegal drugs) with any degree of accuracy. Similarly, the use of structured questionnaires or recording patient-practitioner interaction would have done very little to enable gaining insight into the perspectives of individual IBD sufferers.

Doing an ethnography suggests the need to have *“sustain[ed] intimate contact”* (Charmaz, 2004: 981), suggesting a level of intensity and engagement with, and thus potential intrusion into, the daily lives of participants, that might be both difficult to undertake within the confines of a PhD project and from an ethical and personal (myself having IBD) perspective. Nevertheless, Charmaz (2004) argues that interviewers who do not have the sustained intimate contact expected of those doing an ethnography and undertaking participant observation in a ‘natural setting’, can adopt an ethnographic approach.

The approach adopted in this thesis has its roots in the philosophy and practice of ethnography (Young, 1979; Emerson, 1995; Wolcott, 1999) but because of limited resources and time does not involve participant observation. Multiple interviews with the same participants were undertaken over time in a natural setting of their choice, all key values contained within the philosophy of ethnography. The approach is best characterised as qualitative research informed by the philosophy or values of ethnography. Adopting this approach still enables the researcher, albeit to a more limited degree, to *“entering a phenomenon”* in order to *“sense, feel, and fathom what having this experience is like, although [these researchers] enter [their] participants’ lives much less than an ethnographer does”*. (Charmaz, 2004: 981)

In asking the questions 'how' and 'why' IBD sufferers use healing practices, a number of alternative approaches to qualitative research were also explored and then discarded: phenomenology, ethno-methodology and auto-ethnography. The first two options were quickly discarded. The framework and question put to one side the possibility of using a phenomenological approach where primary interest lies in the essence of the phenomenon under study (Maso, 2001); there the appropriate question would take the form of, 'what does it mean to be an IBD sufferer?' The conceptual framework and research question also ruled out the possibility of ethnomethodology (an exploration of the 'taken-for-granted' (Garfinkel, 1967) with its base in a radical critique of positivism within sociology; the research question asked about the perspectives and meanings that people brought to situations, and the inter-connections with culture, not an exploration of the tacit, implicit or 'taken-for-granted'.

The rationale for not following an auto-ethnography approach needs a more extensive explanation. Due to my personal experience in caring for IBD, this would be a possible option to use in this study. Auto-ethnography involves the researcher incorporating his/her personal narratives into their ethnographic texts. Ethnic autobiography is similar to auto-ethnography (or autobiographical ethnography) but it focuses on the ethnic or cultural identity of the researcher's life history. (Reed-Danahay, 2001) There were two of reasons why neither of these was considered an appropriate approach to adopt.

1. A '*wider than self*' perspective: ultimately the most important reason, the research question centred not on my-self as a participant in the research, but on the perspectives of other IBD sufferers, and cultural influences that they perceive as affecting their use of TCAMs and their self-care of IBD.
2. *Insight from others' research*: many ethnographers who have had personal links with the research they have undertaken did not opt for auto-ethnography even if their participants had similar personal affiliations. For example, Parker (1999) used ethnography to present the setting and everyday conditions in which Muslim Sudanese women living in a village in Northern Sudan practise female circumcision. Apart from these two aspects of using ethnography, her research interest included exploring cultural dimensions (sexuality) of the participants. She was not expected to talk about her sexuality but she did mention Western women's perspectives of female sexuality in contrast to sexuality as perceived by the participants of her research study with regard to female circumcision.

### 4.1.3 Understanding Inductive Analysis

One characteristic of qualitative research is the emergent inductive process of gathering, analysing and presenting data in a cyclical and sometimes simultaneous way with participants of a study in order to refine the knowledge interpreted from processing data. These processes are therefore not separate and merge during fieldwork. Literature on inductive analysis of data suggests the importance of three points: keeping research strategies constructed in the conceptual framework in mind; developing codes; and feeding back information to participants in a further interview when more depth of meaning was required. (Lofland and Lofland, 1995)

An inductive approach involves multiple stages, each of which was adopted in this research:

1. *Sorting data*: With large amounts of data presented in narratives, sorting the data was one of the first ways to start making sense of it. Miles and Huberman (1994) suggested constructing tables of data, one of which they called the *"time-ordered matrix"* (ibid: 119). This is because *"[q]ualitative researchers are always interested in events: what they are, when they happened, and what their connections to other events are (or were) – in order to preserve chronology and illuminate the processes occurring. A process, after all, is essentially a string of coherently related events."* (ibid: 111)
2. *Focussing and presenting data*: From the literature review, analysis of data presented in this research would appropriately consider the following points:
  - a) Asking questions of the data in order to organise it thereby facilitating the emergence of patterns to focus data. For example, what type of data is this? (descriptive, analytical etc.) Or, what is the frequency in which it occurs? (Lofland & Lofland, 1995).
  - b) Identifying patterns and themes using *"housekeeping"* (ibid: 189) as well as analytic coding by linking themes to concepts in Medical Anthropology. Keeping information presented in a chronological order facilitating feedback information to participants in subsequent interviews to achieve clarification and more depth of meaning. This task enabled the researcher to *"construct social science order from the open-ended process of emergent induction"*. (ibid: 185)
  - c) Keeping memos of initial and focused codes and categories by recording one's thoughts and ideas (such as, personal, methodological and

substantive), in order to achieve a deeper interpretation of data. Memo writing was a central strategy in this research in order to “*eventually emerge as an interrelated set of memos that form a coherent analysis*”. (ibid: 193)

- d) Constructing diagrams for the purpose of organising research memos, codes and strategies into a visual display to make data more easily understandable in analysis and presentation.
- e) Using flexible thinking by constantly comparing data to explore what is distinctive (Godfrey and Townsend, 2008) about IBD sufferers’ experiences and their understanding of illness and the use of TCAM treatments.

3. *Category Saturation*: When there is a large amount of instances of codes with the possibility that these can be elaborated on to identify subdivisions, which may lead to the conclusion that there is little relevance of a closer analysis important enough to be performed in the time available. In this PhD, the notion of saturation refers to the situation where categories have been explored in as much detail and depth as the researcher deems possible through the analytic process and the researcher being satisfied that the ‘findings’ have been identified.

#### **4.1.4 Implementing Ethics and Confidentiality**

It is important to be vigilantly aware of ethical and confidentiality issues and to ensure that any study is conducted rigorously during all phases to protect participants’ personal privacy, medical information, anonymity, confidentiality and right to leave the study throughout the duration of the research and beyond. Key ethical concerns in this PhD related to: accessing practitioners and patients; informed consent to participate; ethical handling of the data collection process; safe and confidential storage of data; and anonymised dissemination in all oral or written reports on the study. The ways each of these was addressed is explored in the Methods below (section 4.2.4).

#### **4.1.5 Maximising Rigour in Research**

Any study needs to be conducted in a rigorous manner. Rigour in qualitative research involves addressing the issues of transparency (of the decisions and procedures undertaken in the research, that is, from ‘who to talk to’ down to and including the analysis and interpretation of the data) and reflexivity (“*monitoring your own subjective*

states”). (Lofland and Lofland, 1995: 18) Although these two aspects of rigour are different, the practical undertakings in carrying out ‘transparent’ procedures and being reflexive sometimes overlap and are interconnected. In this section the concepts to assess rigour, issues of transparency and reflexivity including the roles of the researcher are explored.

#### **4.1.5.1 Concepts Used To Assess Rigour**

To judge a piece of qualitative research, one has to look at its rigour. A number of approaches are evident in the literature.

As Seale & Silverman (1997) observe, while reliability and validity are core concepts used to assess rigour in quantitative research, these have different meanings in qualitative research. For example, they state that: *“authenticity rather than reliability is often the issue in qualitative research. The aim is usually to gather an ‘authentic’ understanding of people’s experiences and it is believed that open-ended questions are the most effective route towards this end.”* (ibid: 379, 380)

Similarly, Lincoln and Guba (1985) propose four criteria for assessing rigour in qualitative research: credibility (internal validity), transferability (can the findings of this research be applied to similar settings or persons? – a question of external validity), confirmability (do we have enough information about the study to judge the adequacy of the process and assess whether the findings emerge from the data?) and dependability. Dependability is similar to Seale & Silverman’s (1997) use of the term ‘authenticity’. It is concerned with the quality of the methods affecting the findings and making them more or less credible.

Long and Godfrey (2004), coming from the perspective of evaluating the quality of qualitative research, argued that such evaluation should reflect the uniqueness of the associated paradigm. Core evaluation questions included: assessing adequacy/appropriateness (*“[...] were these informants and events appropriate to explore given the study’s aims?”* (Ibid: 184)); the plausibility of the findings; and the appropriateness of the study design in relation to its aims and outcomes within the context of the study. Their evaluation tool also summarises the need for the reader to have confidence in the validity and credibility of the benefits identified by reporting the study *“in a way which provided insight into the way the data were generated and why”*. (Ibid: 191).

These criteria were kept in mind throughout the process of data collection, analysis and interpretation, and are followed through most explicitly through the approach taken to

transparency (discussed in the next sub-section) and in relation to the heading of reflectivity (sub-section 5.2.3.3).

#### **4.1.5.2 Issues of Transparency**

Transparency in qualitative research (Wolcott, 1994; Lofland and Lofland, 1995) involves being 'transparent' in describing procedures:

1. Clarity and honesty in presenting the research interest to potential participants before being included in the study.
2. Clarity and openness in ethical considerations such as the assurances of confidentiality and anonymity with participants and the process of obtaining consent before involving them, including freedom to leave the study at any time.
3. Clarity and as much detail as possible of fieldnotes during data collection. This includes the setting of the research, the participants with their perspectives, the gatekeepers and their relationship with participants and researcher, and the general state of living with regard to financial, economic or communal issues.
4. Clarity and honesty in the writing up of the research including literature review and analysis of data collected with respect to the medical anthropological concepts representing the research framework. It is also important to keep in mind the 'raw' data (for example, fieldnotes and interview transcripts) as the 'true' data with the acknowledgement that "[...] *field notes are only mnemonic devices to prompt our memories for fuller details [...]*". (Wolcott, 1994: 156)
5. The raw data must be open to re-analysis by another observer through another analytical 'lens'.
6. There is a need to make explicit the role of the researcher within the research process, and in particular how she/he perceives themselves in relation to the research topic area.

In the writing up of this thesis, all these points have been kept in mind. Examples include the use of verbatim extracts from participants, ensuring that 'they' almost tell their own story (Chapters Five and Six), presentation of reflective fieldnotes (see Methods section, 4.2) and reflexive comments presented in Chapter Seven on the strengths and weaknesses of the research.

#### 4.1.5.3 Issues surrounding Reflexivity and Role of the Researcher

In a valuable article, Chesney (2001) explored her approach to being reflexive in her research (conducted in 1997) on the birth experiences of Pakistani women and how these experiences interplay with their private, personal, and social worlds. Chesney quotes Lofland and Lofland (1995) as well as Hammersley and Atkinson (1995) regularly, about the debate surrounding 'going native' in ethnography. In her study, she felt that “[i]f we as researchers hold back, then it can be expected that the researched will also hold back”. (ibid: 130). This did not mean that she 'went native'; it simply showed that she was subjectively looking at the research and admitted another dilemma; describing being a Westerner studying non-Westerners as “*the inescapable nature of dominance*”. (Ibid: 133).

Parker (1999) also raised this dilemma. She opposed this aspect of qualitative research in her study by seeing female circumcision from the Sudanese women's point of view. Parker was extremely interested in reviewing studies carried out on female circumcision by Western researchers, some in the fields of Medicine, and how their backgrounds affected interpretation of data in the research interest. Reactions to the topic of female circumcision also included abhorrence by some of Parker's English friends and colleagues: “*It was difficult not to resent the fact that very few people appreciated the importance of thinking about the issue of circumcision in terms other than physical mutilation and the denial of sexual pleasure. Their views became increasingly offensive and the confidence with which they espoused them was, it seemed to me, little short of racist.*” (Ibid: 205).

Parker's reflexive thoughts helped as guidance when looking at the role of the researcher as someone familiar with IBD suffering whilst recording the perspectives of other IBD sufferers. For instance, the constant use of a personal reminder that the researcher's experiences may not be shared by other IBD sufferers in this study as every person was unique in their cultural background, upbringing, education, personal experiences, etc.

This also raises the insider-outsider dilemma, faced across research styles. It is important for a researcher to be very aware of these two roles which occur simultaneously. Both have significance in the undertaking of this PhD: myself, as an insider (someone very familiar with IBD suffering) and as an outsider (a non-clinical practitioner despite education in CM) engaging in interviews with study participants.

There are advantages and disadvantages to having personal experience in caring for IBD, and thus 'being an insider' researcher. Three major points need to be considered:

- a) Adopting this role facilitates familiarity with the condition although there needs to be full awareness of the fact that the researcher's experience is her own and unique. This can be said for every other IBD sufferer and is an important point when listening to IBD sufferers' experiences with a sense of naivety; the researcher is not the participant being interviewed and could not literally feel what they feel.
- b) Being an insider (that is, having IBD) means awareness and familiarity with IBD. This may pose the risk that patterns and themes emerging from the participants' experiences would be interpreted using assumptions from the researcher's experiences. This is why it is important to keep reminding oneself of the uniqueness of narratives and that there would be differing perspectives of illness, healing and Self hence the need to constantly feed back material to participants and check these were the meanings that *they* expressed.
- c) Being an insider may assist participants in telling their stories. Soivio (1999) mentioned that, from the reactions of some participants in his study, knowing he was a sufferer helped them 'open up'. For others and in general, it made no difference declaring he was a fellow sufferer. The researcher must consider the consequences of declaring her knowledge about IBD and the challenges of living with IBD, or not. For example, in doing so, some participants might open up more but this may hinder detailed explanations of life events and perspectives as participants would assume the researcher knew what they were talking about. However, there is the risk that in declaring their knowledge of IBD participants might want to exchange experiences to an extent that would focus on their gathering information from the researcher about her experiences in caring for IBD instead of her exploring the participant's views. In not declaring personal experience in caring for IBD, this might make it difficult for some participants to feel comfortable speaking about some of the more embarrassing scenarios and symptoms experienced in living with the illness.

Issues surrounding being an outsider researcher also need to be considered. Although present during conversations with participants, this part of the researcher role was appropriately conceptualised as being an outsider. An outsider also has to keep in mind the language used in the interaction and the context in which fieldwork happens. For example, a researcher, for whom English is one of many languages she speaks, needs to be acutely aware that there might be some English expressions in language as well as some habitual or culturally influenced nuances or meaning that people from the UK perform that are unfamiliar to the researcher. This is particularly relevant when

considering the manner of expressing feelings, understandings and issues about talking about private parts and experiences.

In summary, the approach adopted by this researcher was to take heed and follow the advice arising from the literature. In particular, this would mean making explicit my 'insider' knowledge of IBD, while emphasising that interest lay in their story, and avoidance, as far as possible, from being drawn into exchanges centred on sharing the approaches taken by the researcher in living with IBD. This was further enabled by the data collection approach, explored in section 4.2.4, in particular, the use of two interviews with each participant.

#### **4.1.5.4 Reflexive Accounting**

This sub-section draws on Lofland and Lofland's (1995) specific recommendations when evaluating the researcher's as well as the participants' perspectives. In the text below, the original authors' labels (1 to 7 from Lofland and Lofland, 1995: 74, 75) and point 8 from Wolcott, 1994)) have been modified and applied to my research in order to inform my position and to follow through on doing reflexive accounting of the research process.

##### ***“Directness of the report”***

The expression of each IBD sufferer in this research is taken as a first-hand account of their perspectives and choice of treatments. In addition to assessing the recording of first-, second-hand etc. sources, the first of Wolcott's (1994) strategies to keep in mind in qualitative, in particular ethnographic, research is that one records everything. Since this is not literally possible, what the researcher does record becomes evident. It is therefore important to be aware that what a researcher selects from their records provides important clues about their observations. Wolcott (1994) also advises researchers to uncover observing and recording habits. This can be achieved by expanding their gaze as well as bringing *“events, things and people that seem especially to attract [the researcher's] attention”* into conscious awareness. (ibid: 161).

##### ***“Spatial location of the [participant]”***

This has both to do with the researcher's as well as the participant's location as having an influence on the account being described. In this study, interviews were to be conducted in a setting of choice of the participant. This could be their own home, a room in a clinic or at a University or another setting. Wherever conducted, it was important for the setting to be a quiet and private location. Alongside, the researcher's prior knowledge of CM and IBD could affect the gathering and interpretation of data

presented by participants. Therefore being honest and self-aware during the recording of information becomes paramount. Another point to keep in mind is the comfort of the participant in a spatial environment to enable their feeling relaxed and open in expressing their narratives.

### ***“Social locational skewing of reported opinion”***

This recommendation deals with looking at social relationships and how these influence participants' stories. This links back to the issues surrounding the researcher as an insider/outsider' and how these roles would affect gathering and interpreting information presented. Further aspects of the role of the researcher include gender, age, ethnicity, spiritual belief systems, language, physical appearance, personality and the fact that the researcher herself here was a research academic. In keeping these points in mind, Wolcott (1994) describes a strategy for fieldwork that the researcher should look for *“nothing in particular”* (1994: 162) which can be helpful in both too-familiar as well as too-complex settings (in which the researcher may be unfamiliar and overwhelmed with)? For example, this took the form of the researcher feeling emotional after interviews as she had somewhat 'embodied' their struggles and suffering from her familiarity with living with IBD.

### ***“Self-serving error and bias concerning reports”***

The concern in this recommendation is with announced biases, by both the researcher and the participants, which give reason to be critical of the analysis/interpretations of the information presented. An example might be whether themes and patterns emerging from the research data were 'fitting' too conveniently with what the researcher wanted to believe about perspectives of illness, healing and Self. Another example linking with what Seale and Silverman (1997) described below, is where participants assumed the researcher understood what their suffering might be like, having the illness herself, so held back on information. Seale & Silverman (1997) quote a study by Clavarino, Najman & Silverman (1995) in which *“deviant”* case analysis was used by using systematic coding schemes of the data collected (ibid: 381). This way of conducting their research made it very transparent, in such that they and others could be clear about the codes that they were looking for.

### ***“Previous plain errors in reports”***

It is important to acknowledge the need for accuracy of both the researcher and the participant from simple errors even though they are not self-serving. An example might be, during a conversation in an interview, a participant described something, which the

researcher misinterpreted due to the participant recurrently using a term in a different way than in which it is frequently used.

***“Internal consistency of the report”***

This recommendation asked the researcher to question the overall ‘picture’ of emerging patterns by looking for paradoxes, the time and space constraints of the study that may otherwise have allowed more depth to emerge and if participants contradicted themselves in their stories. Wolcott (1994) pointed out another strategy about looking out for obvious paradoxes but being aware of the subtle ones too.

***“External consistency; agreement among independent reports”***

Questions raised here include the following: Do themes and patterns emerging in the study compare with similar themes and patterns emerging in other studies done on the same and different illnesses? Are there enough independent accounts of IBD sufferers, which the researcher has ‘tested’ using recommendations 1 to 6 which now can be compared for similarities? In the case of differences, for instance, has the researcher developed explanations for differences that have been tested in the data and gone back to explore the identified differences with participants? These questions point towards an acknowledgment of another version of truth.

***“Identify[ing] the key problems confronting a group”***

This is a further aspect, arising from Wolcott’s (1994: 163) strategies, which does not seem to correspond to any particular one of Lofland and Lofland’s (1995) recommendations. Wolcott (1994) used the example of medical students who could not possibly have learnt everything they needed to know from their formal training to practice Medicine. The key problem confronting this group was to figure out what they absolutely had to learn first. In this study, the researcher needed to keep aware of bringing participants back onto their life stories if they went off onto a tangent.

Wolcott’s (1994) description of the *“trained observer”* (ibid: 157, 161) as being an experienced observer leave the reader with an enormously broad picture of what it is to be a ‘good’ observer. He debates that training students in qualitative research, in particular ethnography, does not depend on physical attributes, for example, what to look for when observing but more the strategies described above as well as other points (for example, using intuitive judgement looking for internal consistency or face validity and that in attempting to record ‘everything’ one needs to uncover one’s observing and recording habits) to keep in mind when taking fieldnotes.

In summary, as the literature strongly argues, the central issue is to make plain how the research was done: that is, transparency of procedures and rigour in its undertaking. The above explanations portray the need for an awareness of issues and the adoption of strategies to ensure rigour and transparency. At the same time, the researcher needs to be adaptive to situations that arise as it is difficult to write down everything about what to do in fieldwork before doing it. As Wolcott (1994: 159) argued, *“I do not experience that same uncertainty in actual field settings. When engaged in fieldwork, I find a strong, if largely intuitive, sense of purpose.”* In the end, whichever strategies are adopted, the important thing in data collection, analysis and writing up is to be explicit about these thoughts and processes. Finally, one must note that, as Becker (1967) and Hammersley (2001) comment, some bias is inevitable in qualitative research. As they argue, this should not encourage partisanship in using one’s perspective to create the reality; but rather it is important to acknowledge that the researcher’s and the participants’ perspectives are fragments of a very large picture and thus make the process of data collection, analysis and interpretation as transparent and open to others as possible. This is the position adopted in this thesis.

## **4.2. Methods**

Against this methodological background, this section presents the methods adopted in the study and reasons for their choice. It moves through the different steps in the research process, beginning with site selection, participant recruitment including inclusion and exclusion criteria, onto sampling strategy and ethical issues, and ending by exploring data collection methods. The process of analysis is explored in the third and final section of the chapter. Ethical approval for the study was provided by the School of Healthcare Research Ethics Committee (August 2008, see approval letter, Appendix A).

### **4.2.1 Finding Sites for the Research**

A number of reasons guided choice for undertaking the fieldwork in the UK.

1. *Doing research in English* – even though English is not the researcher’s mother tongue, she has a working knowledge of English to be able to understand and interpret meanings from in-depth conversations.
2. *Being familiar with British cultures* – having known friends, colleagues and acquaintances from various ethnic and social backgrounds in the UK, there is enough familiarity with colloquialisms, symbols and behaviour to be able to follow the flow of expressions and implicit meanings conveyed by locals.

3. *Availability of TCAMs* – compared with countries the researcher has previously lived in or is familiar with (Switzerland, Italy, Serbia, Germany, the United Arab Emirates and China), the UK seemed to offer a country setting with substantial TCAM diversity in terms of clinical practices available as well as people having a cultural curiosity to adopt other ethnic ways of life with a potential readiness to change and acculture other healing practices.
4. *Having access to potential gatekeepers* – after having studied five years of CM as well as doing an MRes in Social Anthropology, there seemed to be enough potential gatekeepers to get into contact with about assistance with recruitment.

#### **4.2.2 Recruiting Participants**

Initial contact with potential gatekeepers for recruitment started in July 2008 and recruitment of participants to the study ended in November 2009. Following ethics approval from the School of Healthcare Research Ethics Committee (SHREC), client and practitioner participant packs were created to be sent to TCAM clinics for recruitment.

After contacting TCAM practitioners to briefly introduce them to the research study, each practitioner was sent at least two client information packs as well as a practitioner information pack. One example of each type of pack is provided in Appendix B. Practitioner packs consisted of a practitioner letter officially introducing them to the study, a practitioner information sheet (3 pages) about the study and a practitioner consent form (2 pages). Client packs, given to practitioners to give/send to their clients, included a client letter (from practitioners) officially introducing them to the study, a client information sheet (3 pages) about the study and two client consent forms (2 pages), one of which was signed and returned to the researcher in a pre-paid envelope indicating their interest in taking part in the study.

The clients would then contact the researcher via telephone or email about recruitment to the study, thus minimising the chance of the practitioner knowing who was taking part in the study. Initially ex-colleagues, some friends (who are TCAM practitioners) and past lecturers from the researcher's time as a CM student were contacted about helping with recruitment but by the end of August 2008 there were unfortunately no participants available. The original trawl was then supplemented by following up on three TCAM practitioner contacts of one of the researcher's supervisors. Together, these approaches ultimately led to the recruitment of eight client and six practitioner participants to the study.

### ***Participant Inclusion Criteria***

Given the PhD focus on IBD sufferers' perspectives of illness and healing, participants were chosen from among those who met the following inclusion criteria:

1. *Sufferers who had been medically diagnosed with Ulcerative Colitis or Crohn's Disease:* Although IBD is considered an idiopathic disease and in some cases is difficult even for Medicine to diagnose definitively, there are many other illnesses, which present with similar symptoms and signs. Therefore given the interests of this study participants needed to be medically diagnosed with IBD.
2. IBD sufferers who were at any stage of illness, for example having just been diagnosed or twenty years after diagnosis, and at any stage of severity: Whichever state of ill-health participants might have been experiencing; this research was interested in understanding their behaviours due to cultural influences in using TCAM treatments and care. After initial medical diagnosis, sufferers needed time to adjust to their 'new' illness as well as develop a curiosity for treating themselves with TCAM. This could have arisen due to the invasiveness of medical treatments, negative effects of medication and/or surgery as well as the on-going life-limiting symptoms experienced. With regard to this long-standing illness, some participants using TCAM to treat their ailments might have been experiencing an acute phase of illness when they were bleeding quite badly from their back passage. Other sufferers might have been in a remission phase of this illness when their symptoms were centred on perhaps, the number of times they had to go to the toilet due to diarrhoea or loose stools. (Kumar and Clark, 2009).
3. *IBD sufferers attending TCAM clinics using more than one healing practice, including at least one TCAM healing practice:* The research interest lay in exploring the cultural influences on healing practice treatments and healthcare processes other than Medicine, which IBD sufferers used so it was not in the interest of this research to include sufferers only using one type of healing practice treatment and medication (Medicine or CM).
4. *IBD sufferers aged eighteen or over:* With the most common ages of onset of IBD symptoms between fifteen and thirty, and fifty and eighty years, any participants aged eighteen or over were welcome to take part in the study. Due to ethical issues concerning 'vulnerable groups', eighteen was the minimum age for inclusion into the study. Both genders were included in the

study since the literature review (Kumar & Clark, 2009) pointed out that gender was not a clear predictor of IBD.

### ***Participant Exclusion Criteria***

In the context of this exploratory study, the following exclusion criteria were applied.

1. Patients at TCAM clinics known by their practitioner/s to be suffering from mental illness, cognitive and/or sensory impairment or deemed too ill to take part in this study by their TCAM practitioners.
2. All patients unable to participate in an in-depth interview to be conducted in the English language.
3. If the practitioner felt that taking part in this study would be 'detrimental' to their patients' health: for example, in particular cases where patients were deemed too physically ill or emotionally unstable to take part, which might worsen their illness.
4. If the practitioner felt the patient was not suitable for what the study needed: for example, certain types and severity of mental, cognitive and/or sensory illness or impairment could prevent patients from adequately understanding the study requirements.

These last two criteria / scenarios came with the understanding that practitioners 'knew' their patients 'cases' and life situations and that the practitioners had their patients' best interests at heart. In order to ensure rigour, awareness of possible sampling bias and transferability of the study findings, practitioners were asked to keep a short note of their reasons for excluding particular possible participants, who met the inclusion criteria, but the practitioner felt unable to ask due to these last two scenarios. Although including IBD sufferers with first languages other than English would have been very informative, this PhD study unfortunately did not have the capacity for translation and interpretation of their life stories.

### **4.2.3 Sampling Strategy**

Two different sampling strategies were employed in the study, both aimed at achieving a diverse sample of participants: criterion-based and theory-based approaches (Crabtree & Miller, 1992). A criterion-based approach involves selecting potential participants purposively according to pre-determined features, for example, the structural characteristics of age and gender. A theory-based strategy involves purposeful selection of potential participants in order to ensure that they enable insight

into the *a priori* position or theory that guides a study, here, the conceptual framework (see Chapter Three) grounded in social anthropology and a research question centred on cultural influences. Within both approaches, the aim was maximum variation, primarily due to the exploratory and qualitative nature of this study. It also enabled flexibility in recruitment, because it remained open for anyone to be recruited who was willing to talk to the researcher as well as identifying “*important common patterns that cut across variations*”. (Patton, 1990: 182). This combinatory approach seemed the best way of identifying who to talk to first and who to talk to next paying regard to research interest. (Dey, 1999; Richards & Morse, 2007).

Criteria-based sampling was used, with structural categories ensuring recruitment of an older person, a male, someone receiving Homeopathy, etc. These provided a guide in recruiting the ‘next participant’. Both Dey (1999) and Charmaz (2006) stressed that it is not possible “*to know our categories in advance, much less have them contained in our beginning research questions*”. (ibid: 100). This approach was thus vital in order to avoid making conclusive statements or generalisations about cultural groups/ethnicity/cultural concepts when searching for ‘whom to talk to next’.

A theory-based strategy centred on seeking to recruit potential participants with a diagnosis of IBD who were known to have used TCAM practices. Since the information gathered from IBD sufferers for this research was ‘seen’ as being immersed in culture, which included different ethnic backgrounds with every individual having their own ‘cultures within cultures’ (Helman, 2007), it fundamentally did not matter from which ethnic background they came. The researcher acknowledged that there were similarities of ways of living within an ethnic group but other similarities may be seen in people of different ethnic backgrounds with similar belief systems (religion, spiritual experience). Therefore, diversity of ethnic and cultural backgrounds of participants for this study was in a way inevitable as diversity pertained to the backgrounds and perspectives of each individual’s way of living (beliefs, tendencies, habit patterns etc.) with IBD including their cultural influences.

Thus, while religion, age, gender and academic education are structural characteristics or descriptors of an individual in a criterion-based approach, in a theory-based approach – and here, with the focus on culture – their potential ‘cultural’ meaning achieves significance. For example, age becomes translated into maturity and life experience, gender into different ways that women and men may deal with illness, health practice pluralism and the role of healing, and academic education into interest and capability gathering information on healing practices and understanding and interpreting the jargon and implications of research studies. Also these provide

potential examples of cultural influences that may affect how and why individuals with IBD looked after themselves and 'chose' TCAMs and/or Medicine. While this study, these types of factors were interpreted as they emerged from life stories and/or observation, and were not used to guide selection of potential participants.

### ***Sample Size***

With these sampling strategies and the multiple forms of data collection (in essence, two in-depth, two-hour long interviews per participant and a participant-kept written diary for one month) it was important to be careful of the amount of data gathered and being processed due to limited resources available for a PhD study. Sample size was purposively to be limited, with the intention to provide depth and richness, rather than seeking representativeness of IBD sufferers' perspectives. (Ritchie and Lewis, 2003). Considering this was a single, short study it was estimated that it would be possible to recruit up to twenty client participants (forty interviews). However, as the reflective fieldnote in Box 4.1 outlines, the sample size target was revised to ten participants; in fact, only eight were able to be recruited.

#### **Box 4.1: Reflective Fieldnote on Sample Size**

Initially I thought I would aim to recruit twenty participants but after five months of searching I came across three major barriers to finding enough people for my study. The first was that I needed to broaden my search, with SHREC approval, from initially only Ulcerative Colitis (UC) sufferers to both UC and Crohn's Disease (CD) sufferers as two TCAM practitioners I was in correspondence with had mentioned having patients with CD who might be interested in taking part in the study. The second barrier came after I had interviewed my first participant, Isa, and recognised that interviews might last more than two hours. Considering each participant would have two interviews and keep written diaries for a month, I realised that I would have a lot of data to process and in the time I had, doing this for twenty participants seemed a little over-ambitious. The third barrier and the most telling in terms of research on IBD sufferers using TCAMs was that I, obviously naively, thought there would be more people using non-medical healing practices in coping with this type of illness. This was why in the end I aimed for only ten participants for my study yet still ended up with eight.

#### **4.2.4 Applying Ethical Issues**

Throughout good ethical practices were followed. The process for each of four areas (informed consent, ethical handling of interviews and data collection, data storage and anonymised dissemination) is explored below. These highlight the efforts made to conduct the research in an open, honest, legal, dignified and protective way for both the researcher and participants.

### ***Informed Consent***

Written informed consent was obtained from client participants by receiving returned consent forms provided in client participant packs given to them by their practitioners. An example of this consent form is provided as part of Appendix B. Participants' right to withdraw from the study at any time was reconfirmed at interviews; if they were to withdraw from the study, no further data on that client or practitioner would be collected, but their data up to that point would be included in the study. None of the eight participants did withdraw. All interviews were voice recorded with participants' consent in order to enable their subsequent transcription by the researcher.

### ***Ethical Handling of Interviews and Data Collection***

Both practitioners and clients were made aware of both the potential benefits of taking part in the research as well as the possibility of distress that may be caused in expressing life stories. If the client preferred to rearrange an interview for another time or cancel the interview completely, then these wishes were respected. Box 4.2 presents a brief illustrative fieldnote.

#### **Box 4.2: Illustrative Fieldnote about Feeling Distressed in the Interview**

During feedback questions at the end of interviews, several client participants mentioned feeling "*churned up*" either during or after narrating their life stories. This made me feel bad to some extent because reminding people about events in their lives that they might prefer not recalling, is not the most comfortable experience. I took the ethical issues concerning distress during narration of life stories seriously, for example, in several cases when some participants remembered some life events that made them cry or feel uncomfortable.

### ***Safe and Confidential Data Storage***

All data was stored in accordance with the Data Protection Act of 1998 and the Access to Health Records Act of 1990 protecting participants' information. Audio tapes/CDs were destroyed after verified data transcription and/or given to the patient / practitioner if this was their wish. The full interviews, once anonymised, were only shared with supervisors throughout the PhD experience.

### ***Anonymised Dissemination***

All data presented in oral and written reports or presentations on this study have been and will continue to be anonymised. No data will be shared with practitioners or clients

except in the form of anonymised material, for feedback on the research or as part of other research dissemination.

#### 4.2.5 Data Collection Methods

Researchers using a qualitative approach may adopt any of a range of data collection methods from participant observation and informal conversations to in-depth open-ended or semi-structured interviews and structured questionnaires. (Richards and Morse, 2007). According to Lofland and Lofland (1995), “[field]notes and interview write-ups are the most basic of these, but logging [data] may also include mapping, census taking, photographing, sound recording, document collection, and so forth.” (Ibid: 66).

This research study used two main types of data collection methods: informal/in-depth interviews and written diaries; each is discussed in turn below. Figure 4.1 presents an overview of the data collection process. Each client participant was met for their first interview during which sketches of and jotted notes about the interview settings were made followed by keeping hand-written or verbally-recording reflexive notes about the interviewer’s thoughts, feelings, reminders and observations of the interview experience. At the end of interviews, participants were politely reminded about the invitation to keep a written diary for the period of four weeks any time between their first and second interviews and to return it to the researcher. As illustrated in Figure 4.1, the same process of data collection for their first interview was repeated during and after their second interview.

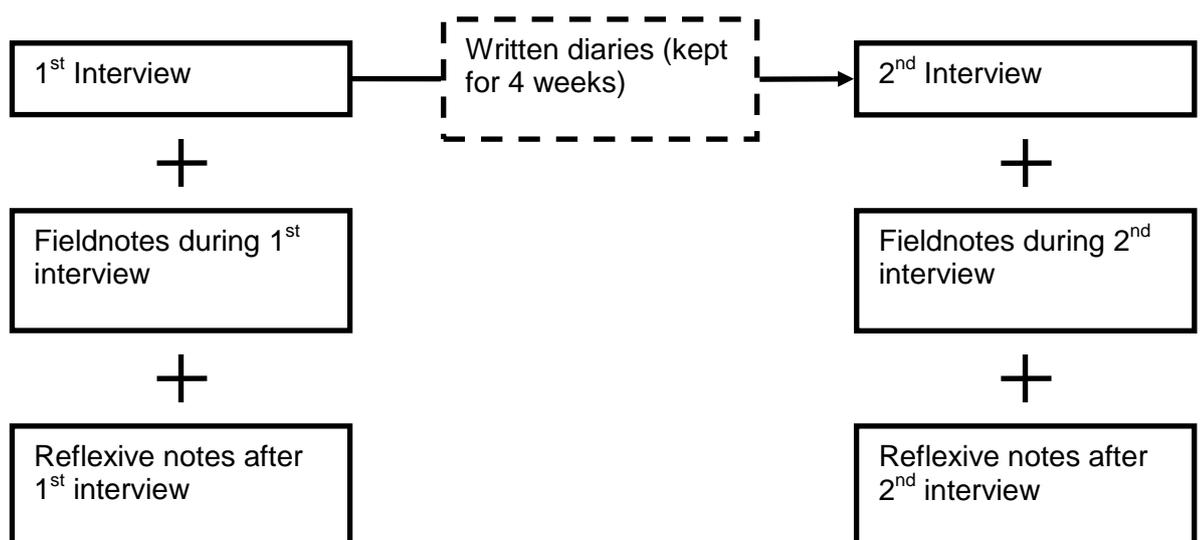


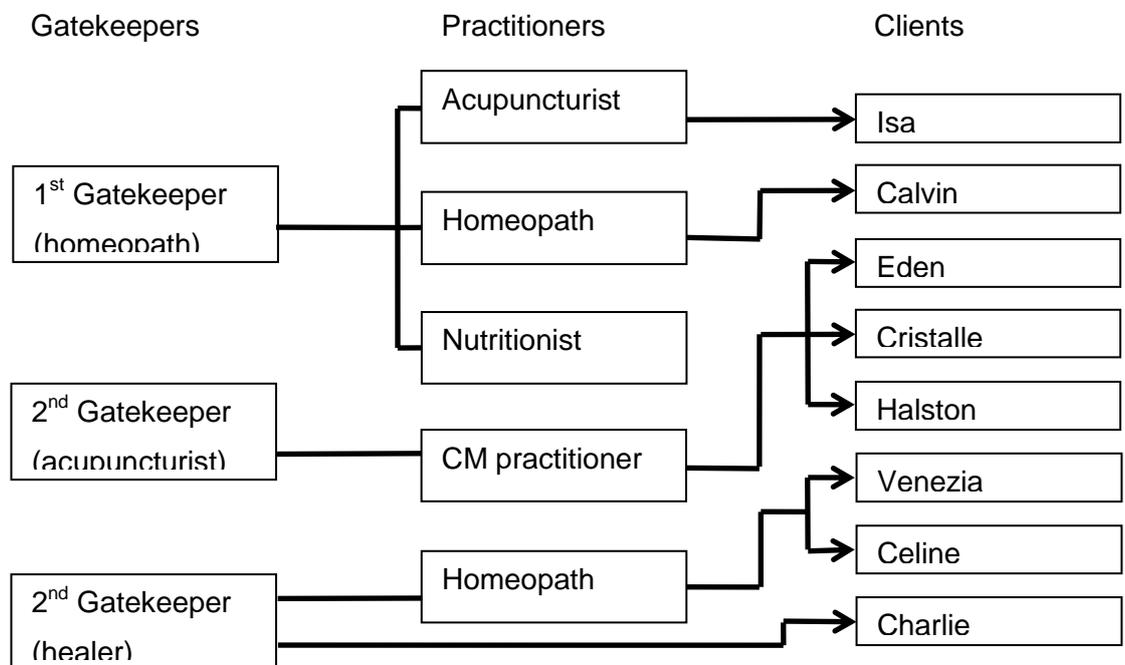
Figure 4.1: Data collection process for each client participant

#### 4.2.5.1 Using Informal Interviews

During five months of correspondence to recruit client participants, before ‘official’ interviews started, the researcher invited six people (friends, family and colleagues) to informal interviews (nine in total) in order to practise her skills and refine prompts and topic guides.

Figure 4.2 shows the links to enable access to the six practitioners and eight client participants recruited for the study. The first column displays the three gatekeepers, one of whom was one of the six practitioner participants interviewed. The second column shows the practitioners taking part in the study and the third column lists the eight client participants invited by practitioners to take part in the research.

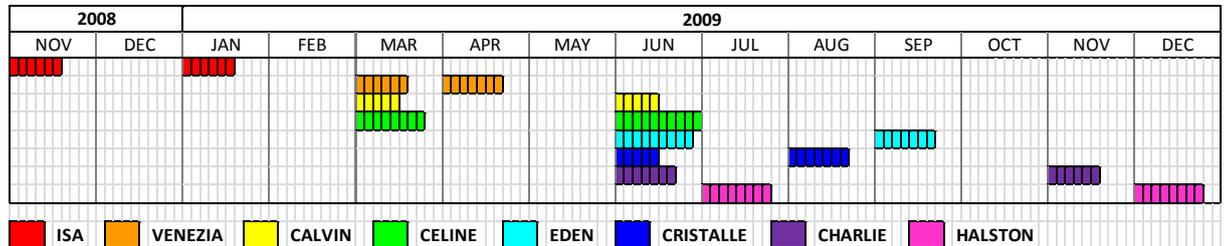
**Figure 4.2: Process of Access to Practitioner and Client Participants**



The data collection period for client participants including interviews, fieldnotes and written diaries started with Isa on 11 November 2008 and ended with Halston on 11 December 2009. Due to the nature of this type of qualitative research, meeting up for interviews was rather flexible so the participants would feel it was convenient and comfortable at a stage in their illness when they felt well enough to talk about their experiences. The pattern of when interviews took place as well as the length of time each interview took are displayed in Figure 4.3 in order to show the frequency of how interviews happened on a timeline of just over a year. This figure demonstrates the characteristic nature over time of using an qualitative approach in data collection

implementing flexibility, convenience in considering participants needs and time in between and during interviews to say what participants wanted to say. Each client participant is represented as a colour with the key displayed on the bottom line. One small square represents fifteen minutes of time during an interview.

**Figure 4.3: Data Collection Timeline of Client Interviews**



The process for each interview was similar. This consisted of arriving at the interview location, preparing for the interview itself including polite introductions followed by reminding the participant about anonymity and confidentiality and then adopting a listening mode during the interview to assist in developing rapport. Reflexive accounts about the interview as a method for data collection as well as notes on personal reflexive thoughts and feelings about the experience of interviewing were recorded just after interviews, mostly as verbal recollections into a voice recorder but sometimes also as fieldnotes. Box 4.3 presents one such reflective fieldnote, taken after the very first interview.

**Box 4.3: Illustrative Fieldnote on the Interview Process**

“I then said that I just needed to get organised and started pulling out the topic guide for the interview as well as my lined notepad, a black point pen and the digital voice recorder. Once everything was set up, I just checked there was enough battery in the voice recorder and then set it on the table pointing towards her. I asked her how she was doing and she said she was fine but that she was very curious about one particular thing and that was: why was I interested in this research, in particular, Ulcerative Colitis?”

Collecting life stories from IBD sufferers by using informal conversation in in-depth interviews as a data collection method was appropriate for this research, as it was a dynamic process leaving each sufferer free to express him/herself, as they like. Nevertheless, it was important to emphasise that the researcher adopted a listening mode, guiding the interviewee with open questions and prompts, in order to engage the participant in telling their story. Although a topic guide (see Appendix C) was used, by the time the researcher had conducted four interviews and gained confidence in her

aptitude in improvising according to what the participant was saying, the subsequent interviews were more loosely based on the topic guide and relied more on an improvised attitude towards getting information on life stories.

Even though participants were generally left to talk as long as they wanted, it was important that they were informed that the interview could take up to two hours. (Richards and Morse, 2007). Apart from the fact that some individuals had a lot to say, especially at first, participants needed time to get used to telling their stories and remembering life events with some needing to take time to coming to terms with what they were narrating regarding to unpleasant recollections.

While taking heed of the University's policy of risk assessment for the lone researcher during fieldwork, participants were offered a choice of where to have the interview. Interviews for each participant took place at the following locations:

- Isa – two interviews at a polyclinic (including acupuncture, counselling, homeopathy, massage, nutrition, osteopathy, psychotherapy etc.)
- Venezia – two interviews at her home
- Celine – two interviews in a lecture room at a University
- Cristalle – two interviews in a lecture room at a University
- Eden – two interviews over the telephone
- Calvin – the first interview at a business centre in a town near his hometown, the second interview at the college where he graduated in his hometown
- Charlie – two interviews at his community centre
- Halston – the first interview in a building within a University, the second interview at his home

In retrospect, a few of these locations may have been inappropriate; this was the case for Calvin and Halston. Calvin having been a young man in very casual clothing with a self-labelled “*shy*” personality did not seem comfortable during his first interview. The following extracts (Box 4.4) from the reflexive accounting notes about the process of preparing for his first interview demonstrate a possible reason why.

#### Box 4.4: Reflective Fieldnote on Calvin's First Interview

"[I] went to the toilets to make a braid and put some lipstick on. This is because of the 'business centre'. Don't think it looked appropriate to be casual; already I was in jeans and hiking boots. At that moment the receptionist walked into the toilets and mentioned that the interviewee was there at the reception."

"In general I think that he was not as open and comfortable as he could be. I think it has to do with being a young man and me the interviewer a lady. I don't think the red lipstick helped. His face flushed bright red several times during the interview. I understood this to be when he was nervous, uncomfortable or tense but I could be wrong."

In Calvin's case, the interview setting of being in an office-like environment at a business centre where people were walking around in suits and ties made the researcher feel out-of-place. This discomfort led her to attempt to fit into that environment by braiding her hair and putting lipstick on. Unfortunately this had the effect, on reflection, of her being less casual and relaxed during the interview. This seemed to have an effect on Calvin making him more uncomfortable.

After the first interview, participants were asked to keep a written diary for the period of one month and then an appointment was made for the second interview to be held preferably within six weeks from the first interview. The purpose of the second interview was to cover the 'complete' account of participants' reflections (if participants did not get to finish their story-telling), to gather more depth about information presented in their first interview and to ask any questions drawn from the diaries participants kept for one month.

All the interviews were subsequently transcribed. It was necessary to follow Wolcott's (1994) advice and uncover the researcher's "*observing and recording habits*" as well as selections in order to provide "*important clues about your own observing*" whilst voice recording, taking notes, transcribing interviews and keeping memos. (ibid: 161). The following extract (Box 4.5) presents a memo about when to transcribe interviews, justifying the need to transcribe interviews as soon as possible after interviews took place.

#### **Box 4.5: Memo on When to Transcribe**

“Do the documents very well at the beginning because when I look at the doc again I don’t see it in the same way as before. The good thing is that I see new things [later] but it seems to be easier to continue a train of thought if I do it from start to finish in one go. I think it’s a lot more concrete. (28 Dec 2009). It’s true that if I look at the doc a few months later or after a certain amount of time then I do see things differently from a different perspective but I think that the bulk of the work should be done in one go.”

This approach was adopted not only for the ‘fresh’ memories to be recorded as memos about the interview experience or method of organising data, but in order to draw up a bullet point list of life events narrated in each client participants’ first interview to be ready to present to them as ‘facts’ for verification at the second interview.

#### **4.2.5.2 Fieldnotes**

Fieldnotes made up data sets that were secondary to transcripts and memos from interviews yet nevertheless contributed a great deal to the context of interpreting meaning behind narratives. This section will describe the two types of fieldnotes gathered during data collection and analysis as well as explain how they contributed as a method tool for this research. “[E]xtracts or snippets of fieldnotes” (Sanjek, 1990: 187) will be provided as examples of the process of using this method as a tool to gaining insight into the lives of IBD sufferers using healing practices including TCAMs following Sanjek’s (1990) comments on the lack of evidence of fieldnotes in qualitative anthropological research writings.

In this research making verbal recordings, jotting notes, drawing sketches of surroundings or taking memos happened during and after the interviews. These made up different types of fieldnotes that contributed to the context of narratives of IBD sufferers by adding meaning to their life stories.

The main thing kept in mind throughout whilst using fieldnotes as a tool in data collection was, as Wolcott (1994, 1999) strongly advised, to ensure that fieldnotes were recorded ‘in situ’. If this was not possible, then they needed to be done as soon as possible after an event in order “*to minimize the potential influence of [...] interpretation or analysis that might [make the researcher remember and record] too selectively or [reinterpret] behaviour prior to recording it.*” (1994: 349)

### ***Fieldnotes during interviews***

These took the form of jotted notes, sketches and memos on the interview and settings. Jotted notes were made on the narratives of participants for the following reasons in order of importance of purpose:

1. Making sense of the narrative in terms of chronological sequence as well as emphasising something a participant expressed as significantly emotional or important to their life story.
2. As reminders of getting back to a point made during the interview in attempting to keep the flow of the narrative going as well as being sensitive to an emotional expression of a participant.
3. A method of demonstrating attentiveness towards the participant's unfolding narrative, which was continued or stopped depending on the response of the participant. If the participant looked like she/he felt this note-taking meant their being taken seriously and the researcher was being efficient in noting 'everything' about their story, then the note-taking continued. If she/he looked uncomfortable and that this jotting of notes seemed to take the researcher's attention away from their story, as if not being listened to properly, the note-taking ceased.

Sketches of the interview settings during interviews were made very briefly in the memos in order to remind the researcher of the surroundings in contributing to the comfort of the individual being interviewed, which facilitated or hindered the narrative generation process (for example, see above, and Calvin's discomfort with the interview setting during his first interview). These contributed to understanding the types of spatial environments and ambiance that contribute to client participants' healing experiences when receiving TCAMs.

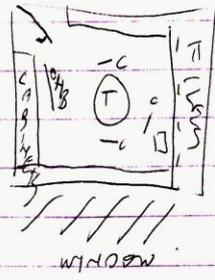
Memos were made during interviews not necessarily just about what was mentioned in a particular narrative but also about a similar topic, which the researcher wanted to ask the participant about in order to make sense of their life events or to 'cover' a point seen in other interviews. These memos also served as a reminder about feelings about the interviewing experience and process the researcher was having in the learning experience of doing qualitative research.

The following scanned fieldnote extract (Box 4.6) displays a combination of the above types of fieldnotes were made during the first interview with Calvin, the third participant interviewed. As the researcher had gained in experience and knowledge, the interview was a little easier to undertake. The researcher was more organised in jotting notes

during the interview; this was aided by the slower pace of his narrative, in contrast to the interviews with Isa and Venezia (who were the first two participants interviewed).

Looking closely at Box 4.6, one can see an example of the jotted notes about the life story narrative on all rows of the left page of fieldnotes except row eighteen, where there is a reflexive memo reminding the researcher about the 'confused' nature of story-telling and recollection by participants, jumping from one thing to another. On the first row of the right page of fieldnotes, there is a note about the date of the interview, participant name and age at the time of the interview. Following this a note made to emphasise how Calvin felt about 'getting' UC at his friend's grandmother's funeral and a list of all the healing practices mentioned up to that point as well as a chronological list of life events for the researcher to pick up on later on in the interview. Finally, the sketch very briefly made on the interview settings, shows the main objects present at the time of the interview (a 'T' table, 3 'C' chairs, 'Filing Cabinets' on opposite walls of the room, an open door at the top left-hand corner, 'windows' and an 'OHP' over-head projector).

**Box 4.6: Example of a Fieldnote relating to Calvin's First Interview**

1		
2	15 16 17 18 19 20 21 22 23	CALVIN
3	15 years old. <sup>allergy</sup> hospital	10 / March 2009. 23
4	Trigger alcohol friends' grand mother's funeral	
5	*diarrhoea + blood, massive weight loss.	anxiety d. - funeral.
6		hospital. - 2 wks.
7	went to GP a few days.	steroid drip - hydrocortisone.
8		anti-inflammatory tablets.
9	Mum worries more than he does.	steroid enema. -
10		Coping with UC.
11	1 week after <sup>Δ</sup> did something - Mum called	gran - recommended.
12	hospital. Reviewed 2 be in hospital - 10 times toilet	rest after hospital.
13	1 week to figure out what it was <sup>blood.</sup>	4 years - ignored it.
14		Candida Diet. <del>yeast</del> + yeast - avoid
15	steroid drip, blood thinner, anti-inflammatory	
16	tablets, steroid enema, iron, calcium	
17		2nd floor.
18	(2 weeks) 15 → hospital.	
19	[MS: confusing life events]	
20	grandfather's wife recommended homeopathy	
21	(■)	
22	3 months @ home by back 2 work.	
23	18/19	
24	15 - <del>had</del> sloppy stools, rotten smell, 5 times toilet 4 years	

In retrospect, these fieldnotes provided an excellent lesson on the way to conduct qualitative research. It was able to be used to improve on data collection skills and to indicate aspects to keep in mind regarding interview settings (for example, comfort) and familiarity for participants in the context of telling intimate life stories. Moreover, in retrospect and as long as researcher safety and fieldworker risk issues can be satisfactorily addressed, it would seem more appropriate to conduct life story interviews in people's own homes, rather than the low(er) fieldwork risk setting provided by more formal settings (such as a room in a University or TCAM clinic).

### ***Fieldnotes after interviews***

These were jotted notes that were made after interviews (mostly from researcher voice recordings). These were in the form of reflexive accounts on the data collection process, memos reminding the researcher about things to keep in mind in future for following interviews or data analysis and personal reflections about the content of narratives and interview experiences. The following extract (Box 4.7) presents typed notes on researcher voice recordings made immediately after Celine's first interview. These demonstrate, for example, how much emphasis Celine gave to the issue of stoma bags and their needing to be closer in colour to her skin colour, in help her living with the consequence of having had surgery as a healing practice.

#### **Box 4.7: Memo on Time to Transcribe**

“She also mentioned before we left the room that she thinks that it's important to do research on these kinds of illnesses. Mentioned the fact that it was important to have a different coloured stoma bag for people from different ethnic backgrounds and that she was wondering, she was aware that the literature for Crohn's disease for younger people is better, she was wondering if it still points towards younger people, the target audience is for a younger population. Needs to be improved to include/directed more at/ different ethnic backgrounds as well as age groups. This was something she found difficult to connect to when she was coping with her illness and body image changes from having surgery for Crohn's disease.”

#### **4.2.5.3 Written Diaries**

Participants were invited, after their first interview, to keep written recollections and/or their daily activities in a diary for the period of one month. (Richards and Morse, 2007). An example of a written diary can be seen in Appendix D. Diaries took the form of an introductory page on a guide to how participants might like to use the diary followed by a page for each day of a month including a space for the date and a sentence guiding the participant on what they might like to jot down on that day (*'things influencing the way I care for myself today'*), with some space to jot any comments, thoughts or feelings participants wanted to add. Participants were reminded after first interviews that this method of collecting information was very flexible and they could jot or draw whatever they wanted and whenever they wanted as well as having the possibility of keeping the diary electronically (as Halston did) or not doing the diary at all (as Charlie preferred). In total, seven of the eight participants provided some diary material.

Using written diaries facilitated remembering events, names or sequences of events as participants could see their stories unfolding on paper (or computer screen) and search back to bits they already described. Another reason for using written diaries is that participants would have more opportunities permitting them convenience, time, intimacy (privacy), appropriateness and comfort in their homes, work place, recreational areas etc. to record information. Information from the use of this method provided an insight into participants' every-day activities with regard to living with IBD, from which information was further probed in second interviews if it was deemed to potentially provide depth to narratives.

### **4.3 The Analysis Process: from Data to Interpretation**

The third part of this chapter explores the approach used to analyse the data arising from the participants within the context of the PhD's guiding conceptual framework. Focus lies on showing how the movement of data from an empirical source through a qualitative 'lens' was interpreted as rigorously as possible as addressing the research questions.

#### **4.3.1 The First Stages**

After transcribing the first client interviews, each transcript was reorganised into a chronological sequence of life events in order to understand what happened first and what happened next. A life events bullet points list (1-3 pages long) was constructed to verify with participants at the beginning of their second interviews. Participants had also been asked to return their written diaries before the date of the second interview, for the researcher to read in case there were further questions to ask at the second interview.

At the end of data collection for each client, the researcher ended up with three main data sets: transcripts from interviews one and two, written diaries and fieldnotes. Initial coding of first interviews mainly happened during the construction of the life events list; this was then followed by focussed coding following completion of data collection. Throughout the time frame of the data, the researcher identified and interpreted themes found in the data in an inductive process that fed back into modified prompts and topics to be revisited during second interviews with participants. These processes, seen through an anthropological 'lens' (Lofland and Lofland, 1995), are described and justified in the following sections of this part of the chapter. In reality, however, while indicated below as seemingly separate steps, organising, coding and analysing data

overlapped and happened in a messier way than depicted, but the order in which processes happened is more or less as presented below.

#### **4.3.2 Organising Data**

This involved the following processes, listed in the order in which they were carried out: listening to interview recordings, transcribing them, using descriptive codes to label life events, putting transcripts into chronological order and keeping memos and notes on these processes. Two are illustrated below.

##### ***Listening to interviews***

This occurred just before, during and after transcribing client interviews. This method of processing data was one of the most important as it enabled the researcher to re-live the interview experience to some extent, remember thoughts and feelings felt during the interview and get a 'feel' of the situation during narratives (for example, hesitations in narration, the sound of the client's voice choking up or becoming louder). On average recordings were replayed three times, sometimes more depending on whether there was a felt need to re-familiarise with the experience or verify factual information not properly understood.

##### ***Transcribing interviews***

This involved listening to recordings of client interviews at first in normal speaking frequency to hear and note the main life events that occurred in the client's narrative and then in triple slow speaking frequency in order to be able to type what people were saying at a steady flow. This was quite difficult because the slower the replay, the more warped the client's voice sounded, making it sometimes less clear what was being said. Moreover, transcribing in triple slow frequency was extremely effortful and tedious due to the monotone drone of voices, which to a large extent, took the natural gist of conversation away, reducing data to mechanical word understanding rather than capturing expression and natural feeling of meaning in verbal communication (see Box 4.8).

#### **Box 4.8: Fieldnote on Transcribing Process**

Transcribing was particularly difficult with regard to colloquialisms and local accents because in some cases I got the gist of what people were saying during interviews but when it came to transcribing them when data collection had already finished, it was really difficult to understand the use of expressions or metaphors, which informed data being interpreted, without being able to contact people again to verify my understanding of the language used.

#### **4.3.3 The Emerging Analysis: Experimenting with Initial Codes**

Most of the IBD sufferers told their narratives in a 'natural', non-chronological way, which made it important to listen to the recordings and start initial, descriptive coding of life events in keeping with the original sequence of narratives. This enabled the researcher to see what was mentioned first and what was mentioned next where participants sometimes emphasised particularly traumatic or uplifting life events during their narratives. The main concern was to avoid 'leading' the data according to the conceptual framework while keeping focused on the PhD research questions. As Wolcott (1994) advised, it might be better to keep a wider lens when looking at the data initially and not narrow one's view too soon when looking initially at a data set analytically.

Four ways or versions, presented below, of initial, descriptive coding of transcripts were undertaken in order to organise the data into understandable units of a coherent narrative. The first three versions were the result of trial and error on the first source of data gathered during research, namely the transcript of Isa's first interview (the first participant interviewed). The fourth version is the final method of organising data with the style of initial, descriptive codes settled upon and repeated for every client participant's first interview transcript. It is important to remember that data from the first interview made up the bulk of the participants' life stories; the second interviews provided an opportunity for participants to add anything they wanted and to go into more detail on things already mentioned in their first interview and/or follow up from their written diaries.

##### **1. Version 1 – Highlighting hard copies of data that 'stood out'**

Using highlight, coloured markers on a printed copy of Isa's first interview transcript, sections of data were marked and notes made about what the researcher thought was

being said. It was decided early on to try and code using terms and language expressed in participant narratives. There was uncertainty about where to start as well as what exactly codes were. Transcripts were looked at in their original form since this study was about perspectives; getting a sense of what people said first and said next was important in order to understand their narrative, with the emphases participants wanted to make about things that happened in their lives and how they remembered their stories at the time of data collection. At this point it seemed codes were more like summaries of what sections read. There was much indecision about what the researcher was looking for in the data in terms of creating labels as the main concern was trying to be as open and unassuming as possible. This process was attempted twice on a hardcopy of the interview.

## 2. Version 2 – Using Nvivo8 software and categorising according to the conceptual framework

After the first failed attempt at using Nvivo8 software and subsequent attendance at the Nvivo8 software training and learning to use it, a further attempt was made to make use of Nvivo8, as an aid to managing, retrieving and sorting the data. Data was marked as belonging to one or more of the four categories in the conceptual framework including reasons behind labelling data that way. Any data that did not necessarily fit in these categories would be sorted out later. This was an attempt to 'get the ball rolling', and was very helpful in giving a sense of how the data might be linked to the conceptual framework. Retrospectively, however, this way of categorising seemed to be making the data fit into the conceptual framework. This process was attempted twice on hardcopy.

## 3. Version 3 – Encountering limitations of Nvivo8 software whilst creating nodes

Finding a format to use in order to sort data and see it together with codes seemed to be a challenge. Another attempt at using Nvivo8 in the simplest way was made. After importing the transcripts of two clients' interviews, this vantage point made it possible to see the similarities and differences between stories more clearly. The obstacle was now that the nodes (described as coded in NVivo) for each individual were gathered in one list it was difficult to see the nodes for each participant separately. A decision was made to create separate Nvivo8 projects for each participant and then import them into a combined 'project' so the data for each could be compared or likened with others. There was an attempt to use Tree Nodes (a way of grouping codes) but this seemed to make things more confusing and not help to get a handle on the data. The fear remained of using labels that might pigeonhole participants as well as the added worry

that the researcher was distancing herself from the data. This process was done twice in Nvivo8.

#### 4. Version 4 – Using simple tables in Microsoft Word and Charmaz’s initial coding strategies

Wider reading was undertaken, including La Pelle’s (2004) useful paper, suggesting use of Word tables to sort data, and advice about coding within Miles and Huberman (1994), Lofland and Lofland (1995), Strauss and Corbin (1990) and finally Charmaz (2006). Particular heed was paid to La Pelle’s (2004) advice (use of Word tables) and explanations and examples from Charmaz (2006). The latter’s suggestions seemed to offer a valuable approach and to make it easier to start initial coding of the data. Particular note was paid to the use of action words ending in ‘ing’ as descriptive codes as well as the “*careful word-by-word, line-by-line, incident-by-incident coding*” (ibid: 54). This made it possible to be more open and less structured in the initial coding process of sorting data. Nevertheless, it was important to create a provisional list of words that pertained to the conceptual framework concepts in order to make any researcher’s biases obvious. Table 4.1 lists words and topics that the researcher was conscious of searching in the data even though she acknowledged a genuine effort to stick to creating descriptive codes whilst summarising adjacent text.

**Table 4-1: Words in Data Sources Related to Research Interest Categories**

Category	Words Related to the Category
Self	personality, likes and dislikes, experiences, feelings, emotions, symptoms, attitudes, opinions, impressions, reactions, behaviour, ways of coping
Work	attitude, way of doing things, responses, pattern in the day, hours, professionalism, achievement, purpose, motivation, understanding about illness by others, time-off, pass-times, responsibility to clients, boss, colleagues, dependent persons (children, husband etc.), ways of coping
Education	interest, innovation, motivation, initiative, self-development, controlling one’s future, attitude, purpose, experience
Relationships	age, attitude, similarities/differences, support, influence, advice, personal recommendation, motivation, conflict, difference in opinion, control, freedom, understanding, like-mindedness, sharing experience/information, indifference, care, comfort, kindness, willingness, fairness, interest in something/someone
Healing practices	things done at home, exercise, food and drink, resting patterns, TCAM, relaxation, keeping calm, being organised, pre-empting problems, dealing with emotion, coping mechanisms

#### 4.3.4 Doing Open Coding

Having found the format, that is, to use La Pelle's (2004) Word table approach, to sort the data and some tips on how to start coding, the following snippets illustrate how data was initially coded, sorted and analysed. Table 4.2 is an example of the way open coding was carried out on the first interview transcripts of all client participants.

**Table 4-2: An Extract of Celine's First Interview Transcript with Adjacent Descriptive Codes**

C N	Life Events	Transcript	S N
13	2 <sup>nd</sup> surgery	Uhm so I had my 2 <sup>nd</sup> operation in 2004, which removed my, the last bit of my lower bowel and made my ileostomy permanent. And so really from 2004 till now I've just been living with that really.	17
12	Medicating with Homeopathy	And then heavily, basically just medicating myself with Homeopathy.	18
10	Taking steroids	[Ok. So you're not taking any more steroids?] No, no, I stopped taking steroids uhm, 2004. I had t-, t-, uhm between 2000 and 2004 when uhm my rectum and my anus uhm developed the Crohn's; started flaring up again, I took steroids then. I found that really painful and, and that's really what led me to bel(ieve)-, I-, I couldn't keep it, it had to go. And so, but from 2004 I haven't been on anything.	19

Each first interview transcript was read line-by-line and incident-by-incident in order to separate text into boxes. The first column of Table 4.2 shows the Code Numbers (CN) that numbered rows according to life event chronology. The second column is the 'Life Events' column that usually contained words that were used by clients in the adjacent text from transcripts in order to stay close to the original language used. In this column, descriptive codes usually commence with an 'action' word as advised by Charmaz (2006), for example, under CN 12 ('medicating'). This use of action words helps to keep the flow of movement in reading and organising descriptive codes and life events in making sense of the narrative chronology. The third column contains the actual transcribed text from client participant first interview including questions posed by the researcher in '[' ]' brackets. This made it easier to understand the connection between what was being said by the participant and the line of thought of the researcher. The last column lists the Sequence Numbers (SN) of rows in the original flow of the narrative. This number served as a reminder of what was said first and what was said next that helped identify an emphasised life event that was particularly memorable to a participant.

### 4.3.5 Sorting Life Events Chronologically

The original thought behind sorting transcripts in order of chronological life events was to make a brief list of bullet points of the entire narrative in terms of factual information about time, location, the start and end of life events. As noted above, the life events list was presented to the participant at the beginning of the second interview, for verification or modification. An example of the life events list drawn up in preparation for Isa's second interview is included in Appendix E. It is important to remember that words used to describe life events in the list were mostly taken from participants in order to keep with the way they expressed themselves therefore making it more identifiable to them when they read it back to themselves during their second interviews. Questions to participants were also included in the list in the form of notes in parentheses in addition to questions asked by the researcher during the second interview whilst taking the first interview data into consideration.

Another reason behind wanting to sort the data in chronological order was the intention of the research to be empirically epistemological in how and why IBD sufferers made sense of their illness and used healing practices (for example, deciding on which to choose from). By sorting the lists into what happened first and what happened next, the researcher was able to understand the connections between life events and what they meant to participants guiding them towards making decisions about which healing practices to use. After having done open coding on first interview transcripts according to the original flow of participant narratives, the table rows were rearranged according to the chronology of life events. This can be seen in Figure 4.4 below.

**Figure 4.4: An Extract of Halston's First Interview Transcript by Life Event**

CN	Age	Life Events	Transcript	SN
52	50	Taking control back – looking for an alternative	But it was a – I didn't want just to be stuck in uh taking conventional medicine for the rest of my days. I wanted to take some control back. And it was – it was that really that that cause it something like that I found it hit me quite hard at the time. And so I wanted something that that uh was back with me rather than with a third party.	46
53	50	Deciding to try other things	It was at that point that I sort of fairly soon decided well I'll try other things than, rather than sort of just passively take drugs effectively for the rest of my days.	7
54	50	Going into Acupuncture and Homeopathy	So I at that point I tried, I went into acupuncture and um also homeopathy.	8

This table has an added column for 'age' of the client participant. This made it easier to see life events according to a time line and consider the impact suffering had on the lives of participants. The first column of Code Numbers (CN) list the rows of life events to show what happened first and what happened next with life events described in the 'transcript' column and the descriptive codes summarising the transcript text in the third column. The last column showing Sequence Numbers (SN) demonstrates the original order of the narrative with the participant narrating the second, third and first rows in that order yet after being rearranged according to life event chronology, are listed as they appear in the above table. With these different time columns (columns 1, 2 and 5) it was possible to see three different things: 1) when something happened in actual life sequence; 2) roughly how old the participant was when it happened; and 3) when it was mentioned by the participant in their narrative. Sorting the data in these ways made it possible to see the information from different vantage points and therefore gain a depth of meaning that would otherwise seem lacking in perspective in the task to understanding the nuances of suffering lived within the context of life events.

### ***Creating biographical summaries***

After each second interview, the researcher created biographical summaries of each client's narrative to highlight particularly important life events as described by participants. Rearranging transcripts into chronological order and creating bio-summaries made it possible to see the impact IBD had on the lives of these participants. For all of the participants, their illness experience and life circumstances escalated to crisis points where, as Bury (1982) put "*the structures of everyday life and the forms of knowledge which underpin them are disrupted*". (ibid: 169)

### **4.3.6 Developing Outline Analytic Strategies**

Faced with an enormous quantity of data, there was a need to create an outline of the PhD analytic strategies including explanations on how and why particular data was selected for focussed coding. Table 4.3 below includes descriptions and thoughts on the research question, the 'lens' through which data was interpreted, the focus of analysis in terms of strategy, questions that were asked about the data as it was analysed, the overall approach to analysis (case analysis) and the data sources accumulated.

The following points elaborate the sections seen in Table 4.3.

1. *Research Question* – the researcher acknowledged that the research question was perhaps a bit too abstract and needed to be refined as well as the need for a selective approach to doing analysis (Box 4.9).

#### **Box 4.9: Fieldnote on the Analytic Outline**

I decided to look back, as I have done in the past, at my mind map and inspiration description at the start of my PhD. Within these I was able to see that Perspectives of the Self was the major section that I would focus on in my analysis and then any Perspectives of Illness and Healing and Current Healing Strategies would be based on Perspectives of the Self. The idea behind it is that people need to know themselves and what they want and dislike, to be able to identify gaps in their Current Healing Strategies in order to search for healing practices that would fill those gaps.

2. *'Lens'* – With Lofland and Lofland's (1995) descriptions in mind regarding using interpretive 'lenses' whilst looking through data, this section briefly describes the underlying 'tone' of the research with an interest in cultural influences in guiding treatment options within the context of life events.
3. *Analysis focus* – Here the focus lies on selecting data chunks for focussed coding with two strategies in mind: finding two decision points made by participants about treatment options (the first a medical treatment, the second a non-medical treatment/ TCAM); and, identifying healing practices currently used by participants including why. The intention was to link illness behaviour with experience in different contexts in constructing illness and healing as described by Kleinman (1981, 1988, 1995), Frank (1995, 1998) and Helman (1985, 1995, 2007). Moreover the relation between cultural influences in shaping health-related behaviours was the main aim of selecting decision points related to healing practice choice/management.
4. *Some questions to ask of the data* – Table 4.3 lists some single as well as linking questions kept in mind during interpretation and coding of data.

**Table 4-3: Outline of Analytic Strategies in Selecting Data for Focussed Coding**

	Research Question	Given the inevitable medical management of their condition - What made it possible for this group of patients to access TCAMs / engage in therapeutic pluralism for their IBD?		Relationship between analysis focus and data sources	Decision points a. First interview b. Second interview	Current strategies a. Both interviews b. Diaries c. Context
	'Lens'	Cultural influences on behaviour and context, especially (but not exclusively) their (developing) concepts of Self, illness and healing expressed in terms of mind/body/spirit conceptualisations and mechanistic vs. holistic dualism in treatment choices.		Likely outputs	<p>1. Descriptive case studies (brief chronological bio + brief description of key decision points + summary of current strategies).</p> <p>2. Cross-case findings of cultural influences at key historical decision points, including barriers and facilitators. Looking for similarities and differences between participants within an over-arching explanatory framework.</p> <p>3. Cross-case findings relating to cultural influences on current behaviours re 'managing integration' and current strategies for coping with IBD using therapeutic pluralism. Looking at similarities and differences between participants within an over-arching explanatory framework.</p>	
	Analysis focus	<p>a. <i>Key historical decision points</i> in patient stories – identified from narrative accounts of illness behaviours and experiences over time and the attempt to access accounts of cultural influences relating to / shaping health-related behaviours and beliefs.</p> <p>b. <i>Current strategies</i> for managing IBD and personal health. What makes these possible? Also their current management of integration/therapeutic pluralism at the individual level. What does this look like, and what makes it work for them/ what makes it possible?</p>				
	Some questions to ask of the data	i) What appears to have made it possible for this person to make this decision at this time? What appear to have been the barriers and facilitators?		Reflective methods 'meta-questions'	<p>i) How did different types and timings of data collected contribute to the analysis?</p> <p>ii) How did different data sources reflect, support or</p>	

		<p>ii) How do they talk about concepts of Self, and how might these relate to their decisions/ decision-making processes?</p> <p>iii) How does their current management strategy reflect cultural influences? How does it reflect their earlier decisions, and how far does it represent a wider integration strategy?</p> <p>iv) How does the context of care in which they access TCAMs appear to support or hinder these strategies?</p>		<p>challenge each other?</p> <p>iii) How did a chronological approach to initial data ordering/ charting help with the analysis?</p>
	Practical analysis approach	Analysis by case initially and then analysis across cases.	Substantive 'meta-questions'	<p>i) What, if anything, do participants appear to have gained (in their terms) from therapeutic pluralism?</p> <p>ii) What, if any, are the common culturally-related facilitators and barriers to engaging in therapeutic pluralism for this group of patients?</p> <p>iii) How far might any of these findings be transferable? (for example, to other IBD patients or to other patient groups). This would include reflections on the UK cultural context of this study.</p> <p>iv) How do my findings relate to the wider literature?</p>
	Data sources	<p>I) First interview</p> <p>II) Second interview</p> <p>III) Diaries</p> <p>IV) Observation of interview settings</p>		

5. *Practical analysis approach* – The aim was to ensure that the richness of meaning within narratives as well as the uniqueness of these participants with the rarity of their illness behaviours and strategies came across. This provides a justification of why the analysis and representation of participants' narratives should be structured and displayed by using an individual case analysis approach.
6. *Data sources* – This lists in priority the data sources available for analysis
7. *Relationship between analysis focus and data sources* – This lists which data sources will be used to extract information in relation to the structure of the analysis: decision points or current healing practices.
8. *Likely outputs* – This briefly describes how the data was displayed and represented as case analyses including barriers and facilitators.
9. *Research methods 'meta-questions'* – These questions pertain to the data collection methods used in relation to how they affected information gathered and analysis of data.
10. *Substantive 'meta-questions'* – These asked how this research sits in the wider scheme, in particular examining the potential impact of the PhD findings on people with chronic illness as well as healthcare process that may or may not be available to sufferers. It also looked at the transferability of findings towards people who suffer from chronic illnesses other than IBD and looks at the usefulness of these findings which many healing practice practitioners can relate to.

#### **4.3.7 Creating Individual Case Analyses**

After having created eight bio-summaries for participants, the outline presented in Table 4.3 made it possible to arrange data according to two strategies: finding two decision points in treatment options and examining healing practices used currently by participants. Following these sections, a Perspectives of Self section was also created to understand the links between life events, the Self and opting for different treatments. Explanatory models and tables listing current healing practices and healing strategies to avoid and treat symptoms, were also included in all eight individual cases.

##### ***Selecting and examining two decision points***

It was apparent from looking at all the life events described in the narratives that Medicine was the healing practice used and considered mainstream in terms of diagnosis and initial treatment after experiencing first symptoms of IBD. This is why the first decision point, which was usually linked to a critical phase of illness, was selected to represent the first major decision point reached and made by participants towards treating their illness. The context

of the first decision point usually revolved around being in hospital after having reached a point of no return and desperation to regain health. The second decision point was a purposeful decision to include a decision on the part of participants to use a non-medical healing practice (TCAM or home/self-made remedy/ ways of coping).

The process of selecting the two decision points was as follows. All the descriptive codes of each participants' first interview transcript were copied and pasted into a Word document, then all the transcript text removed to leave four remaining columns: Code Numbers (CN), Life Events (with the descriptive codes), Age and Sequence Numbers (SN). Then two rows were identified and highlighted in different colours representing Decision Point 1 (medical healing practice) and Decision Point 2 (non-medical healing practice). Afterwards, all rows that were more or less directly related to leading up to the decision points were highlighted in the relevant colours leaving a list of chronological life events with two decision points including points leading up to these as seen in Figure 4.5 below. Decision Point 1 and corresponding life events leading up to the point are coloured green and the same has been done for Decision Point 2 in blue.

**Figure 4.5: Two Highlighted Decision Points and Corresponding Life Events**

CN	Life Events	SN	Age
1	Receiving word of illness	1	48
2	Going to the GP - # visit	1	48
3	White matter - 1 <sup>st</sup> presentation	1	48
4	Going to the GP - 2 <sup>nd</sup> visit - referred to hospital	1	48
5	Being in hospital for 9 years	1	48
6	Receiving the label 'desperately ill' the morning	1	48
7	Receiving open-ended biomedics - feeling supported by biomedics	1	48
8	Being told herbs for IBD	1	48
9	Using self-administered herbs	1	48
10	Receiving biomedics - feeling supported over time	1	48
10a	Keeping a record of past procedures	47	25-72
10b	Understanding biomedics with regard to patients records doubling up tests over time	48	25-72
11	Having loose tests during attacks of IBD	49	25-72
12a	Describing having missed opportunities because of IBD	95	25-72
12b	Feeling (often) out having a good presentation with IBD - how others see people with IBD	96	25-72
13	Being viewed as people who have nothing significant to cope with	97	25-72 (mid-50s)
12c	Fighting resentment towards life with CD and trying not to be bitter in life	108	25-72
12d	Putting on a brave face	114	72
13	Giving birth to son	16	27
14	Being a mum with illness	16	27
15	Being in surgery - request of bowel & Crohn's Disease diagnosis	1	16
16	Describing open-ended biomedics	1	16
17	Having an anal fistula was a scary burden	1	16
18	Being referred (2 <sup>nd</sup> ) for a second opinion for anal fistula - production line experience, no progress	1	16
19	Having 2 <sup>nd</sup> surgery - getting an ileostomy & diagnosis	1	16
15c	Opting for sterilisation - Crohn's Disease and having children	19	35
15d	Being unpopular when coming out of the anaesthetic after her ileostomy	110	35
15e	Identifying the differences of surgery use with CD and UC	101	35-72
15a	Getting support from husband post-ileostomy at hospital - finding another stoma bag	21	35
15b	Getting support from husband - getting her confidence back - going out with her stoma bag	22	35
20a	Describing the fear of the stoma after ileostomy - connected with the Self - new you	111	35
20b	Describing the new self after surgery	112	35
20c	Having a momentous life-changing event - surgery	113	35
20d	Living with an ileostomy	83	35-72
20e	Describing the bowel as plumbing	85	35-72
20f	Keeping a well-managed stoma bag	23	35-48
20g	Having a new life after surgery	24	35-48
21a	Having debilitating upsets with no test results - flux post ileostomy	25	48
21b	Wishing for Angiotensin. Having periodical tests with no results. Trying Sando-K - flux post ileostomy	26	50
21c	Wanting an explanation - no results - flux post ileostomy	27	50
21d	Having an examination of stoma - flux post ileostomy	28	50
22	Using bulking agents	29	48-72
21e	Describing an attack of flux - post ileostomy	30	48-72
23	Going to bed - flux post ileostomy	31	48-72
24	Taking Proton-pump - flux post ileostomy	32	48-72
25a	Protecting her bones	33	48-72
21f	Having attacks of flux disrupting her life	34	50
21g	Feeling emotional about not being anything one can do to help - flux post ileostomy	35	48-72
26	Taking electrolytes - flux post ileostomy	36	45-72
27	Feeling alone in this situation (CD - flux post ileostomy)	37	48-72
27	Reading letters from sufferers of the ileostomy Association to boost morale - flux post ileostomy	38	48-72
21i	Having difficulty managing a stoma bag - flux post ileostomy	39	48-72
21j	Wanting to write about her living with CD - flux post ileostomy	40	48-72
28	Having debilitating migraines	41	57
29a	Having energy levels plummeting	42	63
29b	Having a bone marrow biopsy and diagnosed with anaemia of chronic disease	43	64
29c	Observing disagreement between biomedics	44	64-72
29d	Being the last to know	45	64-72
30a	Describing Cliona's daughter's eczema treatment with TCM herbs	46	64-72
30b	Being personally recommended TCM by Cliona	51	64-72
30c	Seeing a Chinese doctor	46	64-72
30	Having supportive biomedics	49	64-72
31	Visiting Dr. Ning for TCM	52	64-72
30d	Having monetary and travel problems to access TCM	53	64-72
30e	Changing TCM practitioner	54	64-72
30f	Having monetary problems	55	64-72
32	Using acupuncture for migraines	56	64-72
30g	Stopping TCM due to change in financial situation	57	64-72
30h	Stopping TCM herbs due to financial constraints	63	64-72
3c	Getting support from biomedics for TCM	66	64-72
30i	Being grateful for TCM and practitioners	58	64-72
30j	Advocating TCM against charlatans	59	64-72
30k	Defending the credibility of TCM practitioner	60	64-72
30l	Describing how TCM practitioners come to the UK from China	62	64-72
30m	Comparing healing with TCM herbs vs. Biomedication - manipulating formulas	64	mid-60's
30n	Comparing healing with TCM herbs vs. Biomedication - taste of the medicine	65	mid-60's
30o	Comparing healing with TCM herbs vs. Biomedication - Drugs are powerful	68	72
30p	Going back to TCM if available on the NHS	67	72
29e	Having Osteoporosis	71	65-72
34	Taking bisphosphonate to prevent Osteoporosis	72	65-72
35a	Describing her gastroenterologist	74	65-72
35b	Having a new gastroenterologist - apprehensive	91	65-72
35c	Having a new gastroenterologist	93	65-72
25c	Having hip problems - seeing an orthopaedic surgeon	76	65
25d	Describing peculiar hip problems	81	65
36a	Being diagnosed with 40% kidney function loss	82	65
36b	Being comforted by gradual rather than sudden kidney loss	86	65
36c	Describing departments working together	90	65
36d	Linking kidney function loss with CD	84	65-72
36e	Having regular tests influencing medication	88	65-72
37	Using Omeprazole during attacks of flux	89	72
38a	Treating gas with antibiotics	70	67
38b	Identifying the doctor - Metronidazole	92	67
38	Taking Paracetamol for back pains	73	71
39a	Describing how biomedics work together - medication	76	71
39b	Being referred to a rheumatologist - Paracetamol	77	71
40	Being recommended to use Physiotherapy by a Rheumatologist	78	71
41a	Needing a hip replacement	79	71

All data pertaining to the coloured rows was gathered and the data was developed into the text of individual cases for all eight participants under the sections presenting the two decision points. Along with this construction of individual cases, the data regarding both decision points was put into two tables. During the learning experience of constructing tables that might help understand the data better, tables examining cultural influences were developed into what ultimately became part of the analytical strategies for all participants.

Table 4.4 presents a snippet of one of these cultural influences tables constructed for Eden’s Decision Point 1 to having ileostomy surgery. Some of the data was highlighted in different colours in order to link these to the conceptual framework. Since decision points were closely related to cultural influences within life events, these tables were constructed to focus on this with the question seen in the second column. The third column presented the healing practices recommended by the cultural influence and the last column was a reminder of the location of what was said in the narrative. At a later time, cultural influences tables were re-examined and improved for focussed coding.

**Table 4-4: Cultural Influences Guiding/Controlling Use of Healing Practices up to Eden’s Decision Point 1, Ileostomy Surgery**

Cultural Influence	What made it possible to have an ileostomy?	Healing Practices	CN, Age	SN,
Locum GP	<ul style="list-style-type: none"> <li>- [after onset of symptoms] [went] to the GP and just mentioned about all the times [I had] to go to the loo.</li> <li>- unfortunately it was a locum place at the time, which was unfortunate because I had a very good GP and I found myself confronted by this rather be-whiskered gentlemen who told me he’d been in the war in the Far East and he was in the habit, out there, of having to go the toilet God knows how many times a day, as if that was what I was having in the same way, which wasn’t very helpful and</li> <li>- it was the old white mixture Codeine Morph or something like that I think it was called, which did absolutely nothing for me.</li> </ul>	The old white mixture, Codeine Morph	1+2,4+5,25	

(CN, SN, Age) = Code Number, Serial Number, approximate Age of participant. Highlights key = Cultural Influences, Healing Practices, Perspectives of Self (PoS), Perspectives of Illness and Healing (PoIH), condition being treated, healing practice strategies.

**Identifying and examining current healing practices: preventive and curative**

After revising transcripts of both the first and second interviews as well as looking over written diaries and any notes made from observation during data collection, a table was created for each of the eight participants displaying only the current healing practices they were using. After identifying which healing practices currently being used, any data linked to how and why participants described their use of the treatments was added to the figure. Although it was not completely definitive, treatments were divided into two sections: preventive and curative treatments. Preventive treatments were described as being generally applied before getting a ‘flare up’ in order to avoid getting to a point where medication needed to be taken. Curative treatments were described as being consumed or applied in order to eradicate or lessen symptoms after experiencing a flare up of illness. These tables can be seen in Chapter Five at the end of each individual case.

### ***Creating Perspectives of the Self***

This section was an important component of living with a long-standing illness in the context of life events including cultural influences whilst being guided towards using particular healing practices. At first, language used from the provisional code lists, for example, body, mind or spirit was used as keywords to enter searches of the transcripts and written diaries. During searching, any similar words found were researched for example, mental state. This section can be seen in each individual case analysed.

### ***Constructing Explanatory Models***

At this point, individual cases were beginning to take the general form of starting with a bio-summary followed by decision points 1 and 2 with relevant life events leading up to chosen treatments. Following further reading on explanatory models (Kleinman, 1981; Soivio, 1999), both having mentioned research participants using these in coping with living with a chronic illness, an explanatory model was drawn up for each participant. This was to link four aspects of participants' lives in order to simplify the complexity of understanding how different parts of living with illness interact: 1) life events (context); 2) cultural influences; 3) healing practices; and 4) perspectives of the Self. These explanatory models are presented later in Chapter Five, towards the end of each individual case analysis.

#### **4.3.8 Cross Case Analysis**

The following material explores how data was selected for focussed coding with the goal of understanding the differences and similarities between people's stories. Two comparison approaches were used: firstly, comparing Decision Point 2; and, secondly, comparing current healing strategies. Given the PhD's interest in exploring the participants' use of non-medical healing practices, this enabled selectively narrowing down the data for focussed coding

### ***Constructing Comparing Decision Point 2***

One of the main reasons for doing this research was to find people who suffer with IBD who do not use chiefly the mainstream treatments in Medicine to manage their illness; instead it was their use of treatments like TCAMs and home remedies/ ways of coping which separated them from the 'norm'. Selecting data and coding it in the following ways made it possible for the characteristics sought in diagnosis, treatment and service of restoring health to emerge including possible 'pre-requisites' to making it possible for sufferers to use non-medical healing practices.

With the Decision Points 2 printed for all eight participants, the next step was to put all information pertaining to each individual in a table with 3 rows. Each row represented the life events (first, second and in some cases third ones) leading up to Decision Point 2. This step

helped to group data, destined for focussed coding, neatly into one table, albeit being inconveniently large and difficult to handle efficiently. Accordingly, this large table was split into three separate tables, one for each life event, with adjacent cultural influences involved with the data presented for each individual. An example for the first life event is presented in Table 4.5. These tables made it possible to see the different types of cultural influences arising between cases.

To take the analysis a stage further, a table was formed for each of the emerging cultural influences leading up to Decision Point 2. These tables made it possible to see the different types of cultural influences arising between cases. Table 4.6 provides one example for the cultural influence, 'openness to change'. The leading question for these tables was: 'how does this cultural influence affect the participant?' For example, Isa's first experience with TCAM was when her consultant gastroenterologist told her he referred people with IBD to see a hypnotist.

The analysis became ever more detailed. Once all three tables were finished, the aspects/characteristics created were gathered together to determine differences within these categories. These main categories were labelled '*factors that contributed*' towards participants being more receptive to suggestions made by cultural influences. The aim was to extend understanding about each of the eight 'contributing' cultural factors.

Table 4.7 provides an example of this, for the emerged cultural influence, 'doing things differently'. It is based on a phrase by phrase analysis, to unpick and deepen insight into the meaning for the particular participants. The first column provides the 'semi-raw' data and the second an explanation for what this demonstrates or might mean. In this way, the six entries, labelled by participant, led to further clarification of one aspect of 'doing things differently'. One of these was 'negative perspectives of Medicine', itself have different meaning for each participant. For example, three of the participants (Venezia, Celine and Charlie, rows 3-4) had something unpleasant to say about their negative experiences using Medicine (services and support for Venezia, row 3; and medicinal drugs for Celine and Charlie, row 4). Another example is the negative perspective of Medicine portrayed, in a separate extract, for Venezia (row 5), her feelings against surgery. In total, the table demonstrates six shades of meaning within the particular cultural influence.

**Table 4-5: Example of a Table Comparing Life Events leading up to Decision Point 2 for the Participants**

Life Event	ISA	VENEZIA	CELINE	CALVIN	EDEN	CRISTALLE	HALSTON	CHARLIE
1	<ul style="list-style-type: none"> <li>- Consultant</li> <li>- “regularly used a hypnotist”</li> <li>- “help people with Irritable Bowel”</li> <li>- “referred people [with] Ulcerative Colitis or Crohn’s Disease”</li> <li>- “prepared to be guided by him”</li> <li>- “quite a big influence”</li> <li>- “liked him”</li> <li>- “slightly quirky personality”</li> <li>- “trusted him”</li> <li>- “knowledge of the</li> </ul>	<ul style="list-style-type: none"> <li>- her brother</li> <li>- “sent [her] a photocopy of a chapter from a book ‘When The Body Says No’”</li> <li>- “autoimmune disorders like Ulcerative Colitis”</li> <li>- “immune system is overacting and attacking itself”</li> <li>- “there is this emotional trigger”</li> <li>- “a deeper, psychological issue is at play”</li> <li>- “to get interest in</li> </ul>	<ul style="list-style-type: none"> <li>- Homeopathy was “something that, [I’d] watched on TV or the kind of programme that was looking at different therapies” and things she had heard from “other people”</li> <li>- “school friend”</li> <li>- “we both grew up together”</li> <li>- “we met at 9”</li> <li>- parents “hippies with money in the bank”</li> </ul>	<ul style="list-style-type: none"> <li>- “My mum was quite concerned, so upset and worried her more than it has done me”</li> <li>- “I’ve always, since I can remember, just had this ability to cope with problems without too much grief really which is weird.”</li> <li>- “just not being affected so emotionally by it</li> <li>- “just being able to get on with it”</li> <li>- “I did really</li> </ul>	<ul style="list-style-type: none"> <li>- her mother</li> <li>- my mum used to go to a herbalist</li> <li>- “a fascinating shop [that] had got the most gorgeous smells when you went in.</li> <li>- “It was a small shop and it seemed to be stacked from floor to ceiling with all these containers; beautiful little drawers with all these</li> </ul>	<ul style="list-style-type: none"> <li>- her father passed away</li> <li>- “I think emotions can trigger”</li> <li>- “I think that was a trigger for my condition of Ulcerative Colitis”</li> <li>- “if you grieve, you are breaking down, you are crying”</li> <li>- “just a shock” “how quickly [her] dad went; it was just unbelievable”</li> <li>- “didn’t grieve properly for [her] dad” “too busy worrying about her mother and “being strong for [her] girls cause they were very close to their</li> </ul>	<ul style="list-style-type: none"> <li>- “mid-thirties”</li> <li>- “start[ed] to think about [his] condition”</li> <li>- “how [he was doing] to how healthy [he was]”, “how fit [he was]”, “what impact that’s going to have an all that”.</li> <li>- “the marathon boom” “there was a big boom in running in the early eighties”</li> <li>- “went whumph [upwards]”.</li> <li>- “need to do something so I’ll see what’s running like”.</li> <li>- “done some big races but nothing much of consequence since [he’s] been poorly”.</li> <li>- “it took [him] quite a while to having</li> </ul>	<ul style="list-style-type: none"> <li>- left hospital “bec[oming] very depressed”</li> <li>- “divorce in ‘89”</li> <li>- losing his sister</li> <li>“was relieved that she wasn’t in any pain again”, “sad” “it all [brought him] a lot of trauma” “having to sort things afterwards”</li> <li>- “a disease” “a nervous reaction” “struggling” “finding himself” “sometimes finding an obstacle in [his] way” “if [he] hadn’t got anything to worry about [he] would find something to worry about”.</li> <li>- “used to have flare ups” “just catch [him] out” “have to wear pads sometimes in case [he] couldn’t hold it to go to the toilet”</li> <li>“it can just happen out of the blue” “it’s an urgency” “feel[s] [he’s] not emptied [him]self”.</li> <li>“as the Crohn’s went away, then became Colitis and [...]</li> </ul>

<p>disease”</p> <ul style="list-style-type: none"> <li>- “my family are quite conventional”</li> </ul>	<p>ideas”</p> <ul style="list-style-type: none"> <li>- “started to read all these other alternative health books”</li> </ul>	<ul style="list-style-type: none"> <li>- “were a bit alternative”</li> <li>friend’s family</li> <li>- “very middle class”, “wide circle of adult friends doing lots of alternative things”</li> <li>- “used to go to a commune in Scotland”</li> <li>- “bad thing is just medication”</li> <li>- “diseased bowel”</li> </ul>	<p>feel quite sorry for myself</p> <ul style="list-style-type: none"> <li>- “doesn’t do any good</li> <li>- “in that way it gives you the enthusiasm and compassion to do a bit more about it</li> <li>- “I think it would make it more worse</li> <li>- “it all depends on how you look at it really”</li> <li>- “letting it get you down and feeling sorry for yourself thinking</li> <li>- “I haven’t really thought like that, so that hasn’t really got ill from that.</li> </ul>	<p>labels on.”</p> <ul style="list-style-type: none"> <li>- “mum always used to buy [her] liquorice sticks, not the black liquorice stuff; it was like twigs.”</li> <li>- “it was [...] the ringing of the bell when you went in the door and this wonderful smell that greeted you.”</li> <li>- “was our equivalent of the Chinese herbs when you went to the Chinese doctor.”</li> </ul>	<p>granddad”.</p> <ul style="list-style-type: none"> <li>- had to deal with the coroner, [they] had to deal with arranging the funeral, letting family know and there just wasn’t any time when [she could sit] and let it all out”</li> <li>- “grief” “build[ing] up inside [her], like stress, instead of crying”, “shouting”, “screaming” or “getting upset”.</li> <li>- “maybe if [she] had broken down and been more emotional, cried more” and not “bottling it up” she “would’ve let it out that way instead of it coming out in the colon”.</li> <li>- “it’s stress-</li> </ul>	<p>knocked off for two or three years and it obviously [took him] a little while to get [his] fitness back”</p> <ul style="list-style-type: none"> <li>- “get[ing] older [which] does have an effect as well”.</li> <li>“muscles wasted away to some extent”</li> <li>“it wasn’t very good”.</li> <li>- “build up [his] muscles”</li> <li>- “start[ing] walking in to work and back to work rather than running” “a couple of miles” “gradually build[ing] up again” “about a year”</li> <li>- “feel as though [he’s] probably as fit now as [he] was but [he thought], by in part, [that] it is age as well”</li> <li>- “when [he was] younger, [he] could knock off for two or three weeks and go</li> </ul>	<p>now it’s sort of IBS” “still hav[ing] flare ups but not as frequent[ly]”.</p> <ul style="list-style-type: none"> <li>- “4 months” in hospital, “made [him] institutionalised” “didn’t want to come out because it was a safe house”.</li> <li>- “wanted to look at [his] flat because [he] didn’t know what was happening”. “living in a church”, “was very depressing in itself really” “renovated and was really small” “little windows” “[he] couldn’t see out”.</li> <li>“couldn’t work, [he] was reliant on benefits” “used to sit in [his] flat in the dark because [he] had no money”.</li> <li>“go[ing] for the rig marole of claiming” “tribunals” “all-work test[s]” “stressful”. “pressure” couldn’t take any[more] at all” “a little bit of stress” like “a household bill” “run to the toilet”.</li> <li>“accumulat[ed]” “[he] was told by a physician”, “when you get a chronic illness” “you get something else</li> </ul>
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				<p>- I think it has helped not thinking about it really and just getting on with it.</p>		<p>related but it, to me, it leans that way"</p>	<p>back and everything was fine" but "now [he] knock[s] off for two or three weeks and it takes [him] a while to get back and that's just an age thing".</p> <p>- "[he's] feeling happy about [his] running again now" and is "content".</p>	<p>chronic as well".</p> <p>"fe[eling] suicidal and decided in '96 to try and get out of where [he] was [living]". "another area where [he] had a few friends" "made [him] feel a lot better but [he] still was depressed".</p> <p>"to see a psychiatrist" "antidepressants" "at times [he] felt [he] was walking around like a zombie".</p>
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**Table 4-6: The Cultural Influence, Openness to Change, leading up to Decision Point 2 for the Participants**

TABLE 1	CULTURAL INFLUENCES FOR:							
How does this cultural influence affect you?	Isa	Venezia	Celine	Calvin	Eden	Cristalle	Charlie	Halston
Openness to TCAM								
"regularly used a hypnotist" to "help people with UC & CD"	Consultant							
sent a book 'When The <b>Body Says No</b> ' describing how "immune system is overacting and attacking itself" because of an "emotional trigger" where "a deeper, psychological issue is at play" "started to read all these other alternative health books"		Brother, Book						
"I watch on TV too programmes that come up about homeopathy and the big debate about science and non-science and proven and non proven."			TV					
"A bit hippy but more new age, like middle class hippies really. Hippies with money in the bank" "they were into alternative therapies"			Bohemian school friend & her parents					
"homeopathy sites and alternative medicines sites that can give you a bit of information on different herbs and stuff."			Alternative medicines sites					
my mum used to go to a herbalist "a fascinating shop" "gorgeous smells", "beautiful little drawers with all these labels on." ringing of the bell when you went in the door" "our equivalent of the Chinese herbs" "mum always used to buy [her] liquorice sticks, not the black liquorice stuff; it was like twigs."					Mother			

**Table 4-7: Deepening Understanding of the Meaning of the Cultural Influence, Doing Things Differently, across Participants**

Original List	Explanation
Doing things differently (15)	This category is one of the eight factors contributing to participants being receptive to suggestions made by cultural influences. The adjacent number '15' is how many different ways participants mentioned this factor.
Replaced	This is a subcategory of this factor, the second being 'Compensatory'. In other words people do things differently than what they were doing before by replacing an old pattern of behaviour with a new one or compensating one they already use with another.
1 = anti medicine – service and support (Venezia)	This demonstrates that an 'anti-medicine' comment was made about the service and support to patients was mentioned by Venezia.
1 = anti medication – drugs (Celine) 1 = anti medicine – drugs (Charlie)	Here, two people (Celine and Charlie) mentioned something 'anti-medicine' regarding medical drugs.
1 = anti medicine – surgery (Venezia)	Venezia also added how she felt about surgery (against)
1 = anti medicine – drugs for kids (Venezia)	Venezia mentioned not wanting her children taking medication
1 = anti medicine – surgery, acceptance of emotional component, mind over matter (Venezia)	Venezia mentioned the lack of emotional component in surgery adding that getting better in order not to have surgery was 'mind over matter'.
1 = medicine not working – drugs – Chinese medicine (Eden)	Eden expressed how she felt the medication was no longer effective enough, which is she was more receptive to her friend's suggestion she try Chinese Medicine.
1 = opposite to family idea – medicine (Isa)	Isa spoke 'against medicine' in relation to not continuing her family's inherited methods of care by not complying with medical treatments.

### ***Comparing Cultural Influences***

A further reason for conducting this research study was to find out what, how and why these IBD sufferers use healing practices including TCAMs. By comparing current healing practice strategies, it was possible to see the similarities and differences between the way people use healing practices, especially non-conventional ones. This analytical exercise / method was closely linked to what participants thought of the types of treatments they used, not only how and why they used them, but how they related to themselves in relation to likes and dislikes. The objective here was to see which descriptions led to categorising certain healing practices to treat particular parts of the Self (Body, Mind, the Social Body, etc.).

After printing out all the explanatory models and current healing practice strategies arising from the individual case analysis (see Chapter Five), focus lay on grouping preventive and curative healing practices. Tables were created, based on what participants said about the healing practices they currently used with regard to the Self. This involved reviewing and then comparing what each participant's perspectives of Self for all the participants using each of the different types of healing practices for particular parts of the Self. This led to the creation of two final tables, summarising the variety of types of healing practices used by participants either preventively or curatively. These are presented in Chapter Six. These tables enable a direct link between the conceptual framework and the use of healing practices by these IBD sufferers.

#### **4.3.9 A Reflective Note on the Process of Doing Inductive Analysis**

Since the beginning of the PhD, the knowledge gained about the various methods used in qualitative research to process and interpret data has been substantial. In the journey to understanding how to do research, this colourful menu of method choices at first seemed daunting and confusing, in particular with regard to labelling ones method of choice and way of doing research. This was very challenging with regard to the inductive approaches of the grounded theory strategies of qualitative enquiry.

Early on in the PhD study process, it became clear that there was already a 'hunch' and conceptual curiosity. This developed into the conceptual framework explored in Chapter Three. Having a more objective approach to qualitative enquiry as described by Glaser and Strauss's (1967) initial joint work did not seem a viable option. Looking back, it nevertheless seems that they are bits from a more Glaserian approach, others from a more Straussian approach, and yet others from the more constructivist

viewpoints from Charmaz (2006); all could be identified in the methods used in this research. For instance, although there were strong preconceptions before data collection had occurred, once the data had been initially prepared (chronological transcripts), the researcher made a great effort to look at the data in a way described by Glaser's open coding. However, one can also argue that the repeated links and reference back to the guiding conceptual framework for the PhD thesis would mean that the method was more intended on building up from a set of ideas or framework that already existed. This has similarities to Charmaz's (2006) viewpoint on using a constructivist approach to grounded theory.

In attempting to understand and use methods whilst being honest about what approach to take and has been taken, Braun and Clarke's (2006) observations seem fitting, in particular when observing the similarities between the inductive approaches in this research with their work regarding thematic analysis. If comparisons between inductive versus theoretical thematic analyses are made, it would seem difficult to exactly pinpoint which analytical method has been used in this research. The real answer would probably be both. Inductive analysis can be linked with the approach taken to the initial open coding of the data and onto the more focussed coding in the construction of the cultural influences tables in the cross-case analysis. The approach used in creating the current healing practice strategies tables could however be considered to take the form of a more theoretical thematic analysis. Within this, the categories used to group data were already determined before coding started. At the same time, the sub-categories seemed more to have sprung from an inductive thematic analysis of the raw data from the narratives (for example, participants' need to 'control' the bowel).

#### **4.4 Chapter Summary**

This chapter presented and provided the rationales for the methodology, methods and process of data analysis adopted in the empirical phase of this thesis in order to explore the perspectives of eight participants with IBD. In the spirit of qualitative enquiry, the researcher has tried to make the processing, analysis and interpretation of data phases open to external scrutiny, to enable the reader to come to an understanding of why things were done as they were and how they were done. Throughout, emphasis lay on ensuring that rigour was taken forward within each of the research phases. The approach was closely linked and informed by the guiding conceptual framework for the research. Its aim was to elucidate the way these IBD sufferers constructed their illness and healing in the context of living with a long-

standing illness and choosing healing practices including TCAMs. Again, it is important to remember that throughout, concepts linked with understanding behaviour, language and ways of coping were 'seen' from an anthropological point of view, including psycho-social aspects of different ways of life. The thesis now turns to exploring the resultant findings arising from the multiple data sources used in the study, beginning with the individual case analyses in Chapter Five.

## **CHAPTER FIVE: Living with IBD**

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### **5.1 Introduction**

This multi-sectioned chapter presents an analysis of each of the eight participants separately. Its purpose is twofold. Firstly, it aims to illuminate and demonstrate the uniqueness of the journeys and ways of coping with IBD of each of the participants. This is taken forward through careful and systematic analysis of the interview and diary data. Secondly, it aims to illustrate the application of the conceptual framework of Self as Body, Mind, Spirit and Vitality, expounded in Chapter Three. Throughout, multiple extracts are provided for each case with connected analytical links. The intention is to re-present the individual stories of the participants, in their own words as far as possible, and thus demonstrate the validity of the interpretations made.

Each of the individual case analyses has a common structure. Firstly, following a short overview of the participant, extracts from the data are used to provide insight into their journey with IBD through four phases (first symptoms, getting worse, critical phase and recovery) and exploration of the participant 'accepting their new Self', cultural influences, current healing strategies and elements of healing practice pluralism in their stories. Secondly, two decision points are selected, based on careful reading and analysis of the particular participant. The first relates to a critical, medical related decision that the participant had to make, and the second to a critical alternative treatment, generally TCAM, related decision point. Reasons underlying their decision making are explored. Thirdly, the participant's story is explored in relation the conceptual framework of Self as Body, Mind, Spirit and Vitality. Finally, each of the individual sections is brought together through provision of an overview of the explanatory model and current healing practices for the participant.

To provide a succinct overview of the eight participants, Table 5.1 presents a short summary overview of each participant. Participants have been listed in the first column of Table 5.1 in the order in which they were interviewed during data collection. The second and third columns show participants' gender and which IBD condition they described experiencing. The middle three columns show participants' approximate ages at the time of their first interview for this study, when they experienced their first symptoms and when they were diagnosed with IBD. The last column gives a brief description of the most currently used non-medical healing practices that participants used at the time of data collection.

**Table 5-1: Overview of Each of the Eight Participants**

Participant	Gender	Condition	Age (in years) of participant at:			Which non-medical practices did participants choose as their main treatment/s?
			1 <sup>st</sup> Interview	First Symptoms	Diagnosis	
1. Isa	F	UC	early 40s	21	21	Homeopathy after stopping 14 years of medication
2. Venezia	F	UC	36	19	22	Homeopathy after over 10 years of UC, wanting a 'drug free' system
3. Calvin	M	UC	23	15	19	Having a healthy diet and getting plenty of rest
4. Celine	F	CD	40	around 25	28	Homeopathy 4 years after diagnosis, wanting a more 'holistic way' of healing
5. Eden	F	UC-CD	72	25	27	Watching what she eats and drinks
6. Cristalle	F	UC	53	36	37	Watching her portions and drinking more water
7. Charlie	M	CD-UC-IBD	64	49	49	Watching what he eats and resting
8. Halston	M	CD	60	late 40s	50	Going running and making diet changes

## 5.2 Case Study One: ISA

*“What’s so nice about Complementary Therapy is that, when you see a therapist, a good one, they’re interested in the whole of you and you get an opportunity to express yourself in that way”*

### 5.2.1 Section One: Overview of Isa

#### **Who is Isa?**

Isa is a white woman in her early forties with a friendly, perky personality who was quite open and talkative about her illness. She has a son and a husband who is “quite supportive” of her. She described herself, in her youth, as “quite demanding of [her]self”, “quite focussed”, having “goals” and “quite a high achiever” with “high expectations of [her]self”. She attributed these personality traits to her father saying he was “quite pushy” when she was still at school because “he wanted [her] to be good academically” and this is why Isa said she “was always pushing [her]self that bit harder”. She described herself as “a bit too sensitive” and “easily upset by things” adding that this might have been because she was an “only child” and her “mum was

*quite soft with [her]*”; but this has been a “*real asset*” as she has a “*natural affinity with people*”. At fifteen years old, Isa’s parents “*separated acrimoniously*” and divorced when she was seventeen. She lived at home with her father for another year before she went to university. It was during her last school years that Isa was told at school that she “*shouldn’t have such high expectations of [her]self*” because of her parents separating but she said she was “*quite determined that [she] would achieve as well academically*” and that this “*wasn’t going to get in the way*”. She worked as a solicitor for ten years, but found this very stressful, and later trained as family mediator.

### ***First symptoms***

After her undergraduate studies, Isa took a year out to work in another city before commencing her postgraduate degree in law. It was during this year that she started experiencing symptoms of UC aged twenty one: “*passing blood*”, “*chronic diarrhoea*”, “*urgency for the loo*”, “*struggling to eat so gradually eating less*”, “*becoming thinner and thinner*”. She said she thought this was “*not coincidental*” as she “*didn’t deal with the emotion that was going [during her parents’ separation] very well*” and said she “*took it in and stored it*”. In particular, Isa said it was all the “*grief, anger and heartache*” that “*had gone into [her] gut*”.

### ***Getting a Diagnosis***

Isa was “*initially misdiagnosed*” with IBS by her GP at university and given Fibre Gel, which “*made it worse*”. She was “*referred to a consultant*”, which took three to four months. She indicated that it was in this “*phase*” when “*[she] declined pretty quickly and seemed to be extremely ill*”. Isa’s parents were “*very concerned*” and “*thought [she] was going to die*” as she “*was disappearing before their eyes*”. Admitted to hospital for two weeks for “*various tests*”, “*the diagnosis was quite easy....As soon as [the consultant] looked up [her] bum, the signs were all there*”. Isa described herself as “*so classically Ulcerative Colitis*”, adding that she was “*relieved*” as she thought she had bowel cancer. She was stabilised with steroids and prescribed Mesalazine. Though “*well managed*” in hospital and coming out “*a bit delicate*”, she “*recovered quite quickly*”.

Isa spent the next fourteen years on “*a maintenance dose of Mesalazine*” and considered herself “*very, very lucky with [her] disease*” because she had “*little relapses, little hiccups but not anything major*”. She commented that she “*went along with mainstream medical advice*” and had “*regular colonoscopies every two to three years*” because her “*family are quite conventional*”.

### ***Crisis Phase***

During the initial years of her illness, “everyone assumed [she] was an adult”; but she commented “[she] was given too much responsibility for sorting [her]self out”. This is why she was and still is “quite self-reliant”, “didn’t particularly discuss [UC] with anybody” or has not “been able to ask people for help or support”. This attitude of “coping [by] [her]self” was “how [she] was with the Ulcerative Colitis” and sometimes wondered “whether [it’s] been a stress in [her] life that [she’s] taken inside [her]self”. There was one person in particular who Isa met at university and considered to be a support for her, who was training to be an osteopath and was “naturally inclined to... ask often” about Isa’s health. Isa also started seeing a counsellor after she left hospital. After her grandfather died, Isa had another “relapse” and said she felt that “grief was a bit of a trigger to the disease” so she “went back on steroids for a while”. Following that Isa got “very, very depressed” and “didn’t cope very well at all” having to have “a period of time off work” and “lost a lot of self-esteem”. This was “a nagging thing” to Isa and she said she needed “to help [her]self and this disease in a different way”.

### ***Accepting the ‘new’ Self***

By the time she was thirty five years old, Isa explained she had “a watershed period”; she felt she needed to make some “big lifestyle changes” to get her life “how [she] wanted it to be; a bit more in harmony”. These included: changing the way she dealt with her UC because her self-reliance “wasn’t that helpful to [her]”. She changed from working as a “divorce lawyer” to becoming “a family mediator”, left the “long relationship [she’d] been in” and “embarked on a relationship with a much older man”. It was after having had “a couple of miscarriages” and “wanting to get pregnant” again that Isa said she “reached a point where [she] didn’t want to continue on the medication...[for my] system to be as free of drugs as possible”. As she was on “a very low dose of Mesalazine”, she reduced this and gradually stopped.

### ***Cultural influences***

Isa had a number of cultural influences guiding her way of life in living with UC and her transition from “managing” her first symptoms to “help[ing] [her]self”. Coming from a “conventional family”, she was “expect[ed]” to “take what medics advised and [her family] would follow that to the letter”. After fourteen years of “[going] along” with medical treatment, in particular medical drugs, Isa’s osteopath friend “who is very keen on Complementary Medicine generally and was very into Homeopathy” “discussed” it with her to see “whether [it] might be something that [she] would try”. This

subsequently became Isa's main healing practice. Her husband has also been a big influence in her life (*"learnt a lot from [him] in terms of how to be"*), describing how she has *"absorbed some stuff he has about him"* like understanding that *"life's a process and you've got to accept that it doesn't always go quite to plan and that's the way it is"*.

### ***Current healing strategies***

Out of all the therapies Isa tried, many are regularly used for either preventive and/or curative purposes. These include: resting, Homeopathy, counselling, Acupuncture, Swedish Massage, Reiki, Aromatherapy baths and scented candles and (medical) Mesalazine foam enemas.

### ***Healing practice pluralism***

Isa commented that some people think she is *"some sort of therapy junkie"*, in light of the wide variety of healing practices she had used during the course of her illness. Isa used both medical (steroids and Mesalazine, orally and as enemas) and alternative healing practices, as well as resting together to treat or prevent 'flare ups'.

## **5.2.2 Section Two: Exploration of Two Decision Points**

### ***Decision Point 1: Stopping taking Mesalazine***

This decision point has been selected as it stands out as one of the major turning points in Isa's narrative concerning the way she lives with and manages UC. It is evident that Isa's Perspective of Self is of great importance to her when assessing what she would like to use as a therapy for her illness. The action to stop her use of Mesalazine comes at the end of a process of change in many other areas of her life; what she refers to as a *"watershed period"*.

Isa experienced several life events leading up to her decision point to stop taking the only *"mainstream"* drug she had been taking for fourteen years, of which the main ones are discussed below. Isa explained that since her bowel was *"responding"* in the form of *"a relapse"* on the occasions that it did, it was *"telling [her] that several things weren't quite right in [her] life"*. The analytical descriptions below link to cultural influences in Isa's life as well as her Perspectives of the Self, illness and healing that changed in the course of these events.

- Changing her attitude towards UC

Isa felt she needed to change how she was towards her UC, following her connecting her attitudes and relapses, particularly regarding being self-reliant and having low self-esteem. Being self-reliant during most of her life led her to take this attitude *"with the*

*Ulcerative Colitis ... [so she] didn't particularly discuss it with anybody*". She explained how *"cop[ing] [by] [her]self"* affected her illness, saying she had *"a feeling in [her] that the disease comes from that part of [her] ... whether there's been a stress in [her] life that [she's] taken inside [her]self somehow"*. She added that *"as [she] got older, [she] felt that [being self-reliant] needed to change cause it actually wasn't helpful to [her]"*. Her self-esteem was severely affected by a set of events consequent on her grandfather's death; she experienced a relapse, returned to steroids for a while and became *"very, very depressed...[not] cop[ing] very well at all"* and needed *"a period of time off work"* and thus *"lost a lot of self-esteem"*. This loss of self-esteem was *"a nagging thing"* to her and led her to realise she needed *"to help [her]self and this disease in a different way"*.

The main cultural influences at this time were her husband and the professional help in seeing a counsellor. In contrast to her *"[growing] up with a much more black and white attitude about things, he can go with all the nuance and the grey bits"*. This helped her to learn *"how to be"* and *"not to polarise things so much"*. Through these two influences, Isa starts to perceive her Self and her illness differently by reflecting on how she previously managed her UC; she seemed to be in an initial stage of understanding what she wants and what she does not want as a treatment or way of life.

- Changing jobs

Talking of her working life, Isa indicated that being a *"matrimonial solicitor"* for ten years, and within *"[a] quite adversarial [legal system]"* there is *"quite a lot of conflict"*. This was having an effect on Isa's health; *"the pressures that came around that job were not suiting [her]"* and were *"causing aggravations with [her] bowel problem"*. Isa compared being a solicitor with her new job as a family mediator by saying *"it's a much more holistic approach"* and *"not adversarial"*. She affirmed that *"the fact that [she's] gone on to do this sort of work [means] [she] feel[s] more comfortable with it and [is] physically more well"*; she thinks that is *"an indicator"* that *"things are more in harmony for [her] and feel like the right way of doing things"*.

Isa's change of job seemed in itself almost to be a healing process, or at least necessary to improve her health. She implies that her initial start as a solicitor was most likely influenced by her experience of her parents' break-up; this, she says, was *"embodied"* into her guts. She shows a change of attitude towards her work context; resolving past issues and healing her bowels through this process helps her to find a 'comfort zone' to cope with her illness.

- Disliking medical treatments and being treated each time by someone different

After having taken a maintenance dose of Mesalazine for over fourteen years and occasionally used steroids during flare ups, Isa indicated having being '*slightly concerned*' about this long-term use. She elaborated by commenting, "*there weren't people out there who had started with Ulcerative Colitis in their twenties like [her] and were sixty or seventy and been taking maintenance doses of that medication for that length of time*". In addition, Isa expressed dislike of how she was treated by medical professionals, saying "*every single time [she] went, [she] saw somebody different and never really felt anyone had a kind of proper handle on where [she] was at*". Moreover, she "*never really developed any relationship with the GP over [her UC]*". At the same time, Isa indicated that she might be able to continue taking medication until "*forced to a crisis point*" ("*[she] had to change [because she] wasn't coping very well*").

- Changing relationships

Isa had "*always known*" she wanted to have children. Her earlier eight-year relationship she described as "*[having] difficulties*". At around thirty five years old, Isa met her husband and had "*got to that stage in [her] life [when having a baby] was 'number one' on the agenda*" and he was "*happy to go along with that*". She decided to stop taking the medication, as she "*want[ed] [her] system to be as free of drugs as possible*". After suffering two miscarriages which were "*really upsetting*", Isa had a successful pregnancy. A part of the Self wanting to be a mother seems to always have been present in Isa's life. Changing relationships meant she could pursue this need. She seemed to have connected having a baby with stopping medication after having identified that taking chemicals regularly was not something she identified with.

### ***Decision Point 2: Using Homeopathy***

Isa turned to using Homeopathy as her main healing practice, but used this in combination with eight other healing practices both preventively and curatively. In addition to her decision to stop taking Mesalazine, there are two main life events that led up to Isa starting to use Homeopathy as one of her main healing practices. These life events including the cultural influences are explored below.

- Open to using Hypnotherapy

At the age of twenty one, when first diagnosed with UC, her consultant at the hospital where she was admitted "*regularly used a hypnotist as part of his clinic... to help people with Irritable Bowel*", and he sometimes "*referred people [with] Ulcerative Colitis or Crohn's Disease*". Although Isa did not receive this treatment at this time (she had already left hospital), she indicated she "*would've been open to it*" and "*was prepared to be guided by him*" if he would have suggested it at that time. She explained that this

consultant had “quite a big influence”, as she both “liked him ... [his] slightly quirky personality” and “trusted him” and his knowledge of the disease. He thus introduced the idea of something ‘non-conventional’; to treat the condition with a complementary healing practice.

- Being friends with an osteopath

Although it was another friend who recommended Isa visit the TCAM clinic in which she was recruited into this study, it was Isa’s university friend, studying Osteopathy, who “guided [her] towards” Homeopathy. Isa explained that she would talk about her UC with her osteopath friend, “just because she was in that kind of caring profession and was into Complementary Therapy and would ask [about Isa’s health] quite often”. While others “tend[ed] to forget [she’s] got [UC]”, her osteopath friend was “naturally inclined to all of that” and “be concerned about it”. Having known her osteopath friend since university, as well as being able to talk about UC with her, seems to have made Isa more open to her suggestions to try Homeopathy. Homeopathy also seemed to be the opposite of what she had received until then, medical drugs.

### **5.2.3 Section Three: Exploration of Isa’s Perspectives of Self**

Isa expressed perspectives of Self interpreted as relating to concepts of a Self as a System including Body and Mind (in particular “intuition”) and being a Mother. The following analytical explanation illustrates this by extracting information from the data presented in her narrative.

#### ***The Self as a System***

It is difficult to know exactly what Isa means when she refers to her System but close analysis of the data support the interpretation of a physical body that is personified as reacting to the emotions and personality in the Mind. Isa refers to herself as a system when talking about the use of drugs in treating her illness both before and after her diagnosis of UC. For example, in commenting on her initial diagnosis with IBD, she remarked: “I was given Fibre Gel [and] things to really push stuff through my system, which actually made it worse.” Another occasion when she used “system” to express the Self is when she explained why she no longer wanted to use medical medication: “I just want my system to be as free of drugs as possible”. This data suggests more a physical emphasis on the System, while also implying there is more than just the material body.

### ***The Self as the Body***

Isa only directly refers to the Self as the Body on one occasion. This was when she talked about medical understanding of the Body, explaining why she did not have any “relapses” during her pregnancy: *“when you’re pregnant, in any case, your body produces natural steroid.”*

Isa’s main perspective of Self as the Body is most explicitly evident where she talks about the Body, when describing her “guts” or “bowels”. These were described as having three functions: as a storage device, as a measuring device and as a guiding entity. Firstly, her guts were seen as storing her stresses: *“the guts and the fact that this disease is there, is very much [her] weak spot”* and *“at times of stress [or] difficult times in [her] life, that’s where it’s gonna go....”* Secondly, she saw the bowels as a barometer: *“[where] there’s been a stress in [her] life that [she has] taken inside [her]self somehow”*. An example was the stress of her job as solicitor: *“the kind of pressures that came around that job, were not suiting [her] and were causing aggravations with [her] bowel problem.”* Thirdly, Isa talked about the ‘guiding’ gut, using phrases such as having “gut reactions”, “gut feelings”, her “gut guides [her] for something positive” and *“[having] good gut instincts about things which help [her]”* in her work and relationships.“ She herself links this perspective to *“perhaps [being] a bit more sensitive and ... guided not just by reason but by something more instinctive.”*

It is clear that these three functions are closely connected to the Mind part of the Self. The personification of the “guts” and “bowels” suggests an overlap between mechanistic functions and a more holistic view of the Self as a System.

### ***The Self as the Mind***

Isa seemed to express two parts of the Self as the Mind connected to UC: emotions and personality “features”. Both of these play a role in how she lives her life with UC and contribute to how she perceives the Self and what healing practices she uses.

- Emotions affecting UC

Isa mentioned that after her parents divorced it was *“not coincidental”* that after graduating from her undergraduate degree, *“in the year where [she was] not doing something academic”* is when the UC *“all comes out”*. She explained that *“all the emotion: grief, anger and heartache had gone into [her] gut.”* Another occasion when Isa said she had *“a relapse”* was shortly after her grandfather died adding that she felt *“like grief was a bit of a trigger to the disease”*.

- Linking personality with UC

Isa said she *“wonder[ed] whether people with Ulcerative Colitis are particular types and have some particular features to their personalities or certain skills”*. In particular, she used several terms to describe her personality; *“features”* that seemed to pertain to two main aspects of her life: how she was towards herself and how she was towards others. Her attitude to herself related to a perspective of being a *“high achiever”* (having *“high expectations of [her]self....always pushing [her]self that bit harder”*), being *“quite self-reliant”* and a recognition of a need to change as she got older (*“it actually wasn’t that helpful to [her]”*). Her attitude to others she described as *“always been quite a sensitive person, probably a bit too sensitive”* and *“easily upset by things.”* But, this was *“a real asset ... [being] quite sensitive”* and *“can understand where people are coming from and they recognise that in [her]”*. She elaborated by saying that her *“natural empathy with people”* means that they *“find [her] quite easy to talk to”*.

It is thus evident that Isa places emphasis on the Mind part of the Self. Although the Self as System, as the Body and as the Mind have been separated above, for Isa these are interrelated in a complex *“system”*. Even as Isa described her *“guts”* and *“bowels”* having the physical function of ‘storing’ emotions, *“pressures”* and *“stresses”*, their personification of ‘reacting’, ‘guiding’, ‘telling’ and ‘feeling’ in the context of life events shows a more holistic view of the Self. In this context, it thus seemed likely that Isa would try to find a combination of healing practices that treated the different parts of her System.

### ***The Self as a Mother***

For Isa, the role of being a mother forms, albeit a small, part of Isa’s perspective of the Self in living with UC as it shaped her attitude towards her relationships and choice of treatments. As explored in decision point one, Isa’s final turning point in stopping her general use of *“mainstream medication”* was because she wanted to have a child and was looking to have a *“system....free of drugs”*. Isa talked about feeling *“overtaken”* by the *“weight of responsibility”* to her parents’, in particular her mother’s, ill health and their demands, which ended up making her *“dysfunctional”*. She added that she was *“aware all the time of the conflict between [her] responsibility to [them] and where that responsibility has to end because [she] need[s] to look after [her]self and because of [her] responsibilities to other people to be able to fulfil [her] other roles as a mother, a wife and a working person.”*

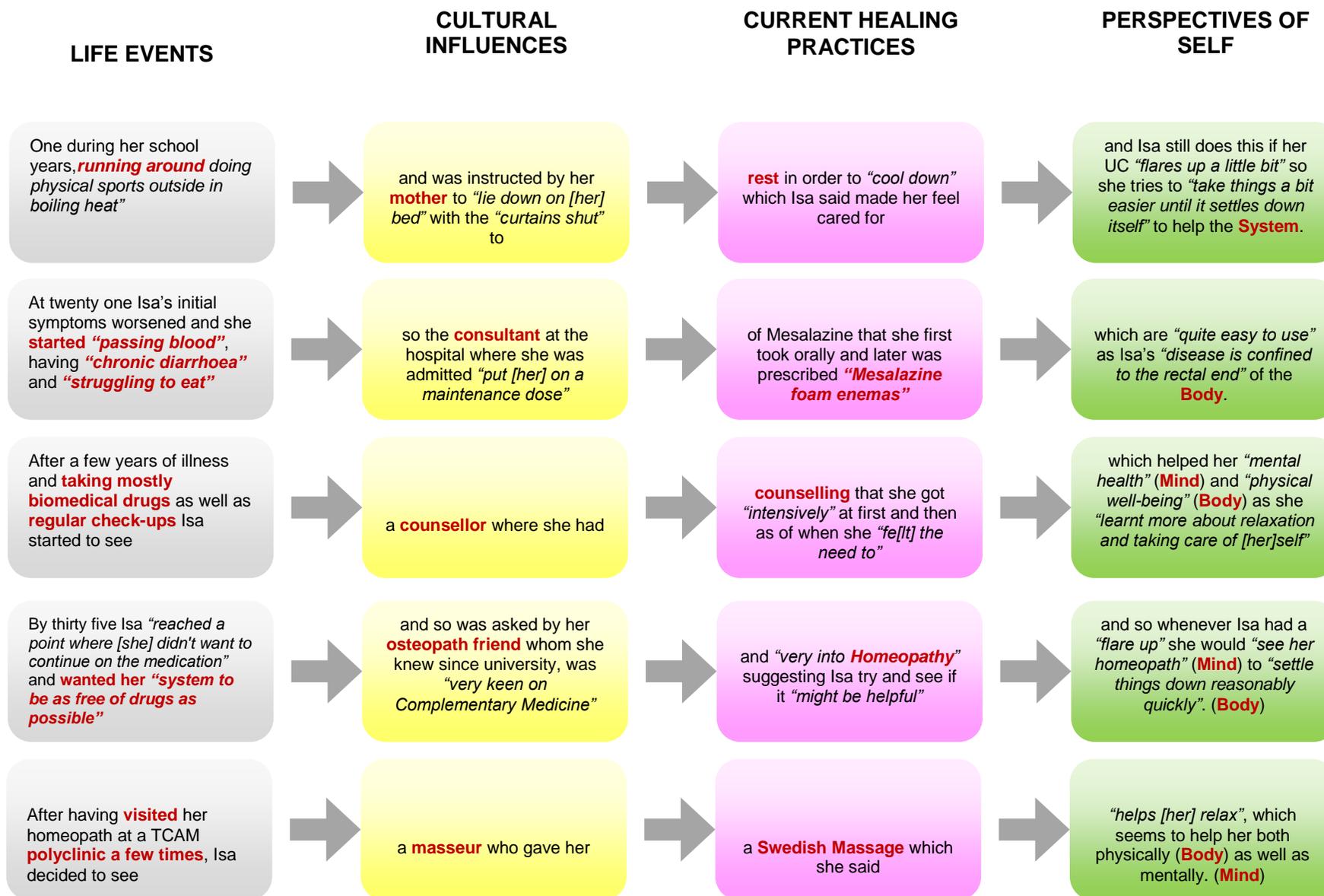
#### 5.2.4 Summary: Isa's Explanatory Model and Current Healing Practices

The following explanatory model (Table 5.2) shows a flow of ideas based on Isa's life events that have been constructed within the context of the thesis' underlying conceptual framework as a lens through which to interpret and make sense of how and why people with IBD use particular healing practices including TCAM. The first column shows the relevant life event, the second shows the cultural influence at the time of a particular life event described, the third column displays the recommended healing practice that the participant is currently using and the fourth column is the interpretation of how the choice of that treatment relates to perspectives of Self.

Table 5.3 presents the main types of healing practices and their current use by Isa. These are the active steps Isa takes to preventing and/or "*managing*" a "*flare up*" or "*relapse*" of UC. These have been made possible by the trial and error in the lived experience of what aggravates and soothes her bowel, the adopted suggestions made by cultural influences in Isa's life, and the access and availability of these healing practices when needed. Although there are two labelled categories of healing practices, preventive and curative, Isa may use each practice in a more fluid way; overall, it would appear that particular ones in each set tend to be used *more* preventively or *more* curatively.

Isa remarked, that, due to her healing practice pluralism use, "*people laugh at [her] and they make fun of [her] for it, think[ing] [she's] some sort of therapy junkie.*" In her interviews, Isa described using several healing practices and home remedies together, but these have not been included in the table as they are used only occasionally and only indirectly for her UC. Isa expressed her interest in using several healing practices by saying "*anything that keeps me kind of calm, relaxes me and means that I get a good night's sleep are all very helpful things for me.*" These include: Acupuncture, Reiki, Osteopathy and Aromatherapy baths and scented candles.

Table 5-2: Explanatory Model for Isa



**Table 5-3: Preventive and Curative Strategies for Isa**

Preventive	Having Swedish massages	<i>“well actually I feel that <b>having massage</b> helps me cause it <b>helps me relax</b>”.</i>
	Having counselling	<i>“through the counselling I <b>learnt more about relaxation</b> and <b>taking care of myself</b>” and “there’ve been times where I’ve been having [counselling] every week and then it’s gone to months and I’ve probably <b>seen a counsellor</b> a couple of times in the last three to four months. So I kind of <b>dip into it if I feel I need to</b> but certainly not as intensively as it has been in the past.”</i>
Curative	Resting at home	<i>“I’ve been really fortunate in that if [my UC] <b>flares up a little bit</b>, I’ve been able to just <b>rest up</b> and <b>try and take things a bit easier</b> until it <b>settles down itself</b>.”</i>
	Seeing a homeopath	<i>“I did go and <b>see the homoeopath</b> and I’ve managed to <b>settle things down reasonably quickly</b> through that. So yeah, if [a flare up] happens again I would go back and see a homeopath again and I’d <b>feel confident</b> that <b>that would help</b> me.”</i>
	Using Mesalazine foam enemas	<i>“my <b>disease</b> is <b>confined to the rectal end</b> so it’s quite <b>easy to use a foam enema</b> to reach it so I guess that would be an option if I had a flare up [and] I really <b>couldn’t control it</b>”.</i>

### 5.3 Case Study Two: VENEZIA

*“I think the crux of alternative health remedies is a facilitation of the awareness that you do it yourself from the essence of your being. You heal yourself.”*

#### 5.3.1 Section One: Overview of Venezia

##### **Who is Venezia?**

Venezia is a pensive, perceptive thirty-six-year-old white woman, with a supportive husband and two sons, who was enthusiastic about taking part in this research and telling her story. Although she seems to have a good relationship with her father and brothers, she said her mother is *“quite difficult”* and has *“become quite poorly with her mental health stuff”*. After sixteen years growing up in her city of birth, Venezia left for a residential, sixth form college in another neighbouring city until she was eighteen years old. She took a year out and then moved to another city to start her first degree in Sociology and Psychology. She described her life as an undergraduate as not a *“happy time”* and said she *“used to drink a lot of coffee and smoke a lot of cigarettes”* and *“wasn’t really looking after [her]self”*. Venezia also described the first three years of a relationship with her boyfriend as *“quite restrained and repressed”* as he lived in another city and she *“missed [him] quite a lot”*. She added that her parents had moved to a different town so she was *“quite upset that [she] couldn’t go home and see [her] old school friends”*.

##### **First Symptoms**

At the end of her first year as an undergraduate, Venezia started having *“really bad cramps”* but *“used to just try and ignore them”*. She also had *“irregular bowel movements”* and decided to visit the university GP after *“several months”* and was diagnosed with Irritable Bowel Syndrome (IBS). She *“was given some anti-spasmodics”* but *“they didn’t work”*. Venezia described feeling *“quite embarrassed”* about having these symptoms and so she *“wouldn’t tell people”* and continued this way for another two years. She would *“lie in bed”* when her symptoms were *“really bad”* but otherwise she did not take any medication.

##### **Getting Worse**

After graduating, Venezia decided to move to the city where her boyfriend lived so she could be with him and started a two-year part-time Masters course to *“facilitate that”* but *“it was just not what [she] really wanted to do”*. By the end of her first year, she had been burgled, which she described as *“stressful”*, and was under *“financial pressure to*

*get a job*” to pay back her *“rubbish student loan”*. She decided to stop smoking, adding that this caused a *“cellular change”* that *“kicked off”* her symptoms to become *“more aggressive”*.

Venezia was expected to do a presentation in front of her peers and tutors towards the end of her Masters. The thought of this would *“keep [her] awake at night”* because she had *“extreme anxiety about public speaking”* and so ended up not finishing her degree as a result. It was around this time that she *“started to lose blood with the diarrhoea”* and thought this symptom was not *“anything [she’d] ever read about IBS”* and so she was *“concerned”* and went to see her GP around three weeks later. Venezia was then referred to a clinic for Colitis at the city hospital.

### ***Getting a Diagnosis***

As an outpatient, Venezia was examined with a *“rigid sigmoidoscope”*, had blood tests and biopsies taken, waited a week for the results and was *“prescribed some steroids to take topically”*. She said she *“couldn’t do”* this as she *“had no experience”* of *“administering an enema”* so her GP prescribed *“oral steroids”* and then she *“started to get a little bit better”*.

Venezia was diagnosed with Ulcerative Colitis (UC) *“just before [she] was twenty three”* and spoke with disbelief that *“nobody at the hospital explained what it was”* and described the attitude at the time as *“this is what you’ve got; come back in three weeks”* adding that she was told she had to *“gradually come off these steroids”*. Venezia was prescribed Mesalazine by *“a specialist”* at the hospital and said it was her mother who *“picked up a leaflet”* about an IBD support group. She said she *“found out a little bit more about [UC]”* after contacting the support group as until then she thought it was *“just something that [she’ll] have just once”* and *“didn’t really realise the full implications of the diagnosis”*.

### ***Getting Worse Again***

At around the age of twenty seven, Venezia took a new job that ended up being *“a bad decision”* as it was *“a very stressful environment”* in which she *“became really unhappy and quite anxious”*. Her partner encouraged her to leave her job and *“take a break”* as her *“colitis was quite bad”*. Her health worsened so she went for a *“check-up”* at the hospital and *“was admitted straight away”*. She was in hospital for two weeks, which was *“pretty grim”* - she needed intravenous steroids and then high doses of oral steroids. She described this experience as *“really quite traumatic”* and that she was *“really unhappy”* adding that it is her *“belief now that actually [she] got worse when*

*[she] was at hospital because of the stress of actually being admitted*". When she got home she could not sleep as she had "muscle spasms" from "lying down" in bed for two weeks and so was prescribed sleeping tablets, which she said she did not take. She described that her "body was so overloaded with all these different drugs" that she was "in a bit of a bad way really for a few months".

After getting married, she indicated that she "wanted just to become really drug free", and tried "to come off all of the steroids" as she did not want to take them when pregnant with her first son. She was diagnosed with "steroid refractory disease" since "every time [she] came off them [her UC] would flare up again". Venezia also "came off the Mesalazine", which left her "really vulnerable to a really bad flare up" making her UC "escalat[e] really quickly". She was then "put on" Azathioprine for six months "leading up to having a baby" and so said she was coming off it as well because it is "a really toxic drug".

After five months after her first son was born when she was thirty, Venezia had another "bad flare up" and so they were admitted into hospital for a couple of weeks. She came out of hospital feeling "quite run down" for "quite a long time". During the next two years Venezia only used steroid enemas "when the symptoms were bad" but generally started to "feel better again" and got pregnant with her second son.

### **Crisis Phase**

Venezia was admitted into hospital again when her second son was five months old as she had "a very severe flare up" that she "didn't catch in time" and she "was on intravenous hydrocortisone". She said this was "traumatic" as, though her second son was with her, her first son was "upset [while she] was in hospital". Moreover, she "didn't want [her second son] anywhere near a hospital" and described being "upset" as they were on "the gastro ward" with "liver patients" and "a lot of alcoholics".

Venezia explained that the people at the hospital reasoned that since she had "pretty much been battling with this for over ten years" and that, as her "quality of life is being affected", she would "have to think very seriously" about having a "two-stage operation". The surgeon came to see her and suggested he operate around three days later. Venezia was "absolutely adamant" that she "just didn't want to" and said she "was just willing [her]self to turn the corner". The next day "they took [her] bloods again" and "it just seemed to pick up and [she] was better".

### ***Accepting the 'new' Self***

Venezia described this experience of being told to have surgery as a *“wake up call”, “a real shock to the system of actually making some really personal decisions”* as she did not to *“live [her] life constantly having flare ups”, “being poorly”* and being *“really tired”*, in general and with her sons. She indicated that, after ten years of UC, *“[she] didn’t really have any faith in [medical professionals] to treat [her anymore]”* and she *“didn’t really respect what they had to offer really”*.

Around this time, Venezia started *“to come around to the idea that there was an emotional component to when [she] had flare ups”*. She referred to UC as being *“somatic”*, while commenting that she had *“always resisted that as an explanation”* but perhaps she explained if she *“acknowledged that there was a psychosomatic component then that would almost undermine or negate the severity of the symptoms”*. She added that she *“really didn’t like to think that [her severe suffering] was just a bad case of IBS”*.

### ***Cultural Influences***

Venezia mentioned several cultural influences contributing to her way of life in living with UC. Most of the influences are people in her immediate family such as her husband (*“really, really, really supportive”*), one of her brothers (he sent her a chapter of a book *‘When the body says no’* by Dr. Gabor Maté that seemed to have had a profound effect in encouraging her to stop using medical drugs), her psychotherapist (he helped her to start looking *“at a lot of ways around how [she] deal[s] with emotional stuff”*) and her homeopath (who prescribed *“various remedies that shifted things”*). Other influences that Venezia mentioned mostly included books, some *“alternative health books”*, and her reading about: IBS, *“autoimmune disorders”, “emotional triggers”* and *“deeper, more psychological issue[s]”* in illness and healing.

### ***Healing Practice Pluralism***

Venezia used many ways of coping and healing practices. These included: *“lying down in bed”*, taking steroids, being *“on Mesalazine”*, being on Azathioprine, *“acknowledge[ing] that there was a psychosomatic component”* to UC, not *“repress[ing]” anger*, *“express[ing] emotions”* and having the *“process of having a relationship with a homeopath”* and *“believing that your body has the capacity to heal itself”*. Resigning from *“stressful”* jobs seems also to alleviate or avoid UC symptoms for her, and according to what Venezia expressed this can also be described as a way of healing.

## **Current Healing Strategies**

Venezia currently uses psychotherapy as her main treatment both curatively and preventively. She still occasionally uses homeopathic remedies but said she “[doesn’t] really know whether it fundamentally caused any cellular change” but thinks “the process of having a therapeutic relationship was what was healing” and because things “started to change for [her] personally at a very deep level”, that is how her “health has improved beyond belief”. Venezia added, “it was almost like [she] didn’t need to have to be ill anymore.” She mentioned she “occasionally used steroid enemas” curatively but also “rest[s]” regularly and “really look[s] at her diet” to prevent her UC from being aggravated.

### **5.3.2 Section Two: Exploration of Two Decision Points**

#### **Decision Point 1: Becoming “drug free**

“The first decision point of “becom[ing] drug free” can be seen more of a phase than an actual decision point. But, it is described as such as it relates to her purposeful attempts “trying to come off” medication, particularly steroids, which happened several times but mostly unsuccessfully. Although she was mostly ‘drug free’ at the time of data collection, on a few occasions when she had “quite bad flare-ups”, she would “go on steroids”. Her perspectives of lived experiences using medication prescribed by medical doctors seemed to reflect her perspectives of Self that formed over time in knowing what she does not want.

Her decision to stop using medical drugs seems to have been a mindful decision based on three main life events.

- Feeling “polluted” with drugs

Venezia spent the first four years since her diagnosis, being “on and off” steroids whenever she had a “flare up” with “horrible side effects”. She had “water retention”, described herself as “puffy” with “mood swings” and was “a bit loopy on them”. Although the flare up would “kind of die down”, she explained that when she “gradually came off” the steroids again, “it came back quite quickly”. Overall, her impression of “all the medication that [she’s] ever taken” is that “it’s not done any good”. She explained that although medication “saved [her] life”, she “had the feeling it was making [her sickness] worse” because it was “increasing a dependency on suppressing the immune system rather than getting it to a point where it could function by itself”. By the age of twenty nine she had reached a point where she “felt really polluted” and described being “full of drugs” and losing faith in Medicine.

- Losing “*faith*” in Medicine

In part this is encompassed in her use and views of medical drugs, as outlined above. But she also talked more generally, while still concluding, *“I’m not saying: ‘Oh, I’m completely ‘anti’ the medical profession and how they deal with Ulcerative Colitis’...”*

One example relates to the medical model: *“the whole ethos is: ‘you treat the organ’ and I just think it’s really fundamentally missing the point because if somebody’s not happy in themselves or they’re not looking after other areas of their life then they’re going to suffer more with Ulcerative Colitis”*. Here Venezia includes not just the Mind emotionally but the context of life events to be considered in assessing illness and proposing treatments to sufferers. Venezia emphasised that the medical model is more mechanistic.

Another example relates to medical professionals: *“if the doctors don’t have an acknowledgment of [a more social or psychological model of illness and healing] and they’re not putting any focus at all on the body and the whole person, then they’re under-treating people.”* This opinion seems to point towards a link between attitudes in professional treatment of patients by doctors being influenced by the medical model and suggests a lack of service on their part.

A third example relates to the “NHS” services: *“I felt like there was a push towards me having the bowel removed [because even if] there[d] still be follow up care from that, it would be less of a financial drain on the NHS in terms of, ‘my colitis is gone’.”* This perspective would suggest that Venezia believes that the treatment she receives from medical institutions and services is related to how much it costs for her to keep her bowel rather than treating her in order for her to suffer less. Linked to this were the hierarchical structures in medical hospitals – *“you see people as they progress through the medical ranks; as they advance in their training, and they’re all working under the main guys [who are] internationally renowned bowel specialists, completely well respected and know they’re stuff”* but *“I didn’t like the fact that they never seemed to think it’s of any relevance that there’s other stuff going on in a life that might’ve affected [UC]”*. Venezia seems to imply that it is not just the medical model or the attitudes of professionals that does not seem to include a more holistic view of illness and healing, but the hierarchical structures in the ‘culture’ or way of life in the hospitals.

A fourth example relates to *“relationships”* between doctors and *“drug companies”*. Venezia said she *“used to go on the Internet quite a lot and [she] used to look at the disparities in drug treatment around different [geographical] regions”*. She continued that she started *“to realise that [she would be] getting prescribed certain things”*

because of the *“relationship that [doctors] have with certain drug companies”* and that *“it’s big business”*. This would suggest that Venezia thought ‘the industry’ was treating her through other motives than for the purpose of making her better.

In linking her experiences of medical practice and cultural influences like medical professionals, and books that Venezia read about her illness and other ways of looking at ill health and healing, it is not surprising that she had concluded the following: *“I’d had a history of one doctor saying one thing and another one saying something else, different prescriptions and different ideas and after over ten years of it I just got to a point where I didn’t really have any faith in them to treat me. I didn’t really respect what they had to offer really”*.

- Having a baby

As Venezia had been trying to come off steroids and stopped using Mesalazine as well as Azathioprine, by the time she reached thirty years old she said she *“was really vulnerable to a really bad flare up and then it escalated really quickly”*. Things got critical after her first son was born and he was five months old. She had to be admitted into hospital with him and *“refused”* to have *“anything orally or intravenously”* since she *“didn’t want to take loads of drugs while breast feeding”*.

This life event seemed to be the final push towards stopping the use of medical drugs. Venezia appeared to have come to know what she did not want. By perceiving the Self as not just the Body but including the Mind and the role of being a Mother, Venezia made decisions and took action towards suiting herself with what she wanted to use as treatment. The period following this time left her open to finding other ways of perceiving her illness and healing and so she was open to recommendations from other cultural influences outside the medical profession.

### ***Decision Point 2: Using Homeopathy***

Venezia’s narrative demonstrates a major shift in thinking and embodying illness and healing of UC. This shift is a gradual change of times in her life where she has a realisation of something that she seems to accept as part of the Self and how she would like to be healed. Below are outlined three main life events that facilitated her use of Homeopathy.

- A book recommended by her brother

Venezia explained that in the midst of her last experience in hospital with her second son, one of her brother’s *“sent [her] a photocopy of a chapter from a book called ‘When The Body Says No’*. This book seemed to have a profound influence on her

perspectives of Self, Illness and Healing as it seems to offer a different perspective of *“autoimmune disorders like ME, asthma, eczema, Ulcerative Colitis.”* This book seemed to also become the facilitator towards Venezia starting *“to get interest in ideas and [so she] started to read all these other alternative health books”* from authors like Louise Hay<sup>5</sup> and Brandon Bays<sup>6</sup>. It seems that these cultural influences have been a source of different ideas to how Venezia perceives the Self, illness and healing.

- *“I don’t want to be this kind of mother.”*

Venezia described this “mind over matter” experience in hospital as “a real shock to the system”. She had to make some “really personal decisions around: ‘Okay, right, I don’t want to have the [ileostomy]’” and added that she did not “want to live [her] life constantly having flare ups [and] being poorly”. These changes in perspectives of Self were not just directed at changing her perspective as a ‘sick’ person but also involved her role as a mother to her two sons.

After having two sons and living with UC for over ten years, Venezia said she was *“finding with the kids that [she] was really tired”* and by the end of the day she would be *“so exhausted”*. She said she would *“have to rest all the time”* and thought to herself *“I don’t want to be this kind of mother.”* She added that she didn’t *“want to be somebody that’s not able to be with them all day”* and started thinking about *“what kind of parent [she] wanted to be and thinking about [her sons]”*. She also said that she wondered *“if they have something poorly, [that she didn’t] want them pumped full of drugs”*. It seems that homeopathic remedies could be seen as the opposite of drugs and this may well be one of the factors that influenced Venezia to use them as a healing practice. Venezia described that *“it was just round about this time where [she] was starting to make some real changes of attitude really”* and *“there was just like a lot of shifts going on in terms of how [she] was thinking about illness and how [she] wanted to live [her] life”*.

- Training to become a psychotherapist

When Venezia came out of hospital with her second son her GP *“referred [her] to a counsellor”* who *“referred [her] onto a psychotherapist”*. By then Venezia said she had already started *“to come around to the idea that there was an emotional component to when [she] had flare ups.”* Having psychotherapy seems to have made an impression

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<sup>5</sup> *“Today I can do anything I put my mind to”* from <http://www.louisehay.com/>

<sup>6</sup> *“Deep inside a huge potential beckons, waiting to open us to the infinite wisdom, freedom and love within. This presence is calling you home right now, longing to set you free.”* Brandon Bays from <http://www.thejourney.com/welcome.htm> (Europe)

on Venezia's outlook on life as well as the Self, illness and healing so much that she said that she is *"now a counsellor and [she is] training to be a psychotherapist"*. She retrospectively described that she made this decision whilst considering her *"journey"* from *"during [her] twenties"* being *"blighted"* by *"periods of being really poorly and not being able to really do stuff [or] go out because [she] didn't have any energy or was on steroids"*.

### **5.3.3 Section Three: Exploration of Venezia's Perspectives of the Self**

Venezia conveys her Self in a way that can be interpreted as pertaining to Mind, Body and being a mother. Although these are represented separately in this section, they are considered parts of a whole within the context of culture and life events. The following analytical explanation illustrates these perspectives by extracting information from the data presented in her narrative.

#### ***The Self as the Mind***

Venezia's narrative shows that the Self as the Mind is predominant in her perspectives of Self, illness and healing. This is because she expressed detailed views of a *"reparative" "gradual process"*, which involves having a *"change in consciousness"* of *"a journey through illness"* in the context of life events. This reparative process *"over the last few years"* of *"starting to unpick a lot of stuff"* involves three main parts: self-awareness, self-development and self-responsibility. Each is explored in turn and is reflected in her explanation of how to treat herself using mainly Psychotherapy and Homeopathy.

- ***"Self-awareness"***

Venezia talked about recognising two things related to the Self as the Mind that seemed to aggravate her illness: emotions and stress.

Firstly, there were *"emotional triggers"* – One example, below, regarding her experience when retrospectively making sense of her illness, she recounted related to repressing emotions. Venezia said she had *"a relationship for nearly four years with a man"* and *"had to hold back on how [she] felt and what [she] thought about things"* adding that because she had to *"pretend everything was fine"* when *"it wasn't really fine"*, this *"quite restrained and repressed"* emotion *"could have been a precursor"* to UC. In particular, Venezia mentioned that *"repressed anger"* was linked to *"why [she] would get flare ups"* because *"[she] wouldn't deal with it"* and *"pretend[ed] [she] was OK, wasn't bothered, upset or annoyed and then [she'd] have a flare up about a week later."*

Secondly, there was the issue of stress. Venezia mentioned stress as a trigger for “flare ups” when talking about the context of Christmas, particularly linked to her relationship with her mother (her being “quite difficult around Christmas” and making her unable to “cope with it”). She concluded saying she thought “that’s why the colitis escalated and [she] got quite bad” resulting in being admitted into hospital on New Year’s Eve. She also mentioned stress at work as another aggravating factor towards having a flare up. This happened just before she was admitted for the first time into hospital. Her job was “very pressurised and [she] was quite young to be in a position” as “campaigns manager” having to “manage quite a lot of people” describing that it was “very, very stressful and [her] symptoms really flared up” as a consequence.

Identifying the above aggravating factors would make it possible for Venezia to find ways in which to avoid these or ameliorate her Self, environment and/or lifestyle in some way in order to suffer less.

- “Self-development”

Venezia explained that taking steps towards implementing change is a very important part of the reparative process. She gave examples of this after having read books that introduced her to different perspectives of illness and healing. Venezia seems to have adopted their use of terms to explain her understanding of illness. For example, she spoke of “cellular change”. After being faced with surgery, initiating a “mind over matter” experience, she seems to have established that even though the “genetic susceptibility” is “still there”, getting a flare up depends on how she would “respond” to “external triggers” and “internal resources”. Venezia explained that, “whatever [illness] it is; whatever that cellular change in the body”, she said she thought “you can get some kind of interaction with it”. She added that “part of the problem for [her] was always thinking [she] was ‘this victim’ to this external disease that would flare up” and “it wasn’t until [she] started getting control over [her] own emotional health” that her illness “picked up” and she was “better”.

- “Self-responsibility”

Here Venezia talks in terms of making changes by “looking into alternative lifestyles” aimed mainly at ways in which to help the Mind part of coping with illness. This was around the time Venezia had been recommended to see a psychotherapist. She pointed to “learning to look after [her]self”. She commented, “if you are to invest any time, energy and money into any alternative health treatments, there has to be some consciousness that it’s a journey and what you put into it will be your reward” and that “actually it’s got to come from within”. She emphasised that if people come at it “from

*the same paradigm of the medical model where you're going to the expert to fix you, you're going to be disappointed". Venezia confirmed her understanding of illness saying "I think the crux of alternative health remedies is a facilitation of the awareness that you do it yourself from the essence of your being. You heal yourself."*

It is these explanations of Venezia's making sense of her illness and implementing changes that seem to lead her towards using Psychotherapy and Homeopathy. A very significant point observed in identifying and describing the Self as Mind that Venezia expressed throughout the interviews and in her written diary is her repeated use of the past tense when referring to her illness: *"I'll just talk about my experience of when I had colitis",* even though it is generally regarded as a long-standing condition. When asked why she referred to UC in the past tense she answered: *"I know cause I'm really positive that I've been so healthy the last year and a half, two years that I feel like even if I had another really bad flare up, I don't think it would be that bad or I would manage it differently."*

### ***The Self as the Body***

There are several ways in which Venezia has referred to her Body with regard to illness and healing. She expresses the body as a living object that *"responds"* to *"triggers"* by saying, *"I was conscious that this was my body's way of saying that I needed something that I wasn't getting in terms of emotional support, rest or space to express myself"*. Two examples illustrate the way Venezia expressed ways of perceiving the Body as a living object, in the form of comparisons.

- The Body as *"repressed"* vs. *"self-healing"*

Venezia used several terms of similar meaning when talking about different aspects of her Body as a living, responding object in relation to illness and healing. This arises when justifying her belief that her *"first bad flare up coincid[ed] with stopping smoking"*, pointing to *"nicotine suppresses the immune system"* and that *"people's symptoms diminished when they started smoking again"*. Again, it comes up when she talks about *"there isn't a cure"* for UC; all medicine really can do, Venezia said, *"is manage the symptoms by repressing them; squashing them down with drugs"*, but the UC *"is still going on underneath"* and *"you haven't actually changed what's going on inside your body."* An example of this was given when describing how Azathioprine *"completely depresses your immune system"*.

All these terms - suppress, diminish, repress, squashing and depress - are words that describe ways of life or treatments that Venezia has now rejected. In contrast, she uses terms that express opposite meaning when describing her preferred perspectives of the Self, illness and healing. Examples include when describing her beliefs on how *“the process of having a relationship with a homeopath”* (she expressed that *“believing that your body has the capacity to heal itself”* has *“triggered [her] physical and psychological capacities of self-healing”*) and her perspective of taking drugs (just *“increasing a dependency”* of the immune system instead of *“getting it to a point where it could function by itself”*). These terms: self-healing, capacity (to heal itself) and function (by itself) all express a sense of independence and autonomy from mainstream treatments as well as other ‘active’ substances consumed by the Body (for example Herbal Medicine).

- The Body as *“polluted”* vs. *“natural”*

Venezia described her perspectives of Self as the Body as a living object by speaking in terms of *“chemical”* and *“natural”* when expressing what she wanted to avoid and how she wanted to live her life in terms of illness and healing. In particular, Venezia talked about how *“polluted”* she felt after having taken medical drugs *“for over ten years”*, adding that her *“body was so overloaded”* that it *“got the better of [her]”* and she ended up in *“quite a low period”* in her life. Not only did Venezia want to be free of medical drugs, but she was extending this to encompass her home explaining that she *“was getting really interested in toxic free homes and having less chemicals in the home”* and *“wanting the boys to have a very clean diet and not be giving them lots of medicines”*.

In comparison, she expressed her preference of using *“natural”* methods of healing and ways of living. Venezia said that she had *“gravitated towards Homeopathy”* because she *“knew there was essentially plant or mineral extracts”* in it, which *“fitted with a natural living ideal that [she] was embracing”*. This attitude towards Self, illness and healing can also be seen in her choice of school for her sons (*“very child centred”* with *“wooden blocks and natural materials to play with”* where the children *“go outside everyday so they can celebrate all the seasons”*, a *“focus on creativity”* and the children are left to *“unfold”* and *“explore themselves at their own pace”*). Even though this example relates to what Venezia wants for her children, she explained that *“because [her] boys went to [this type of school], quite a lot of the families are quite hippy dippy and not into conventional medicine”*, adding that a lot of these families use and recommended her homeopath.

### ***The Self as a Mother***

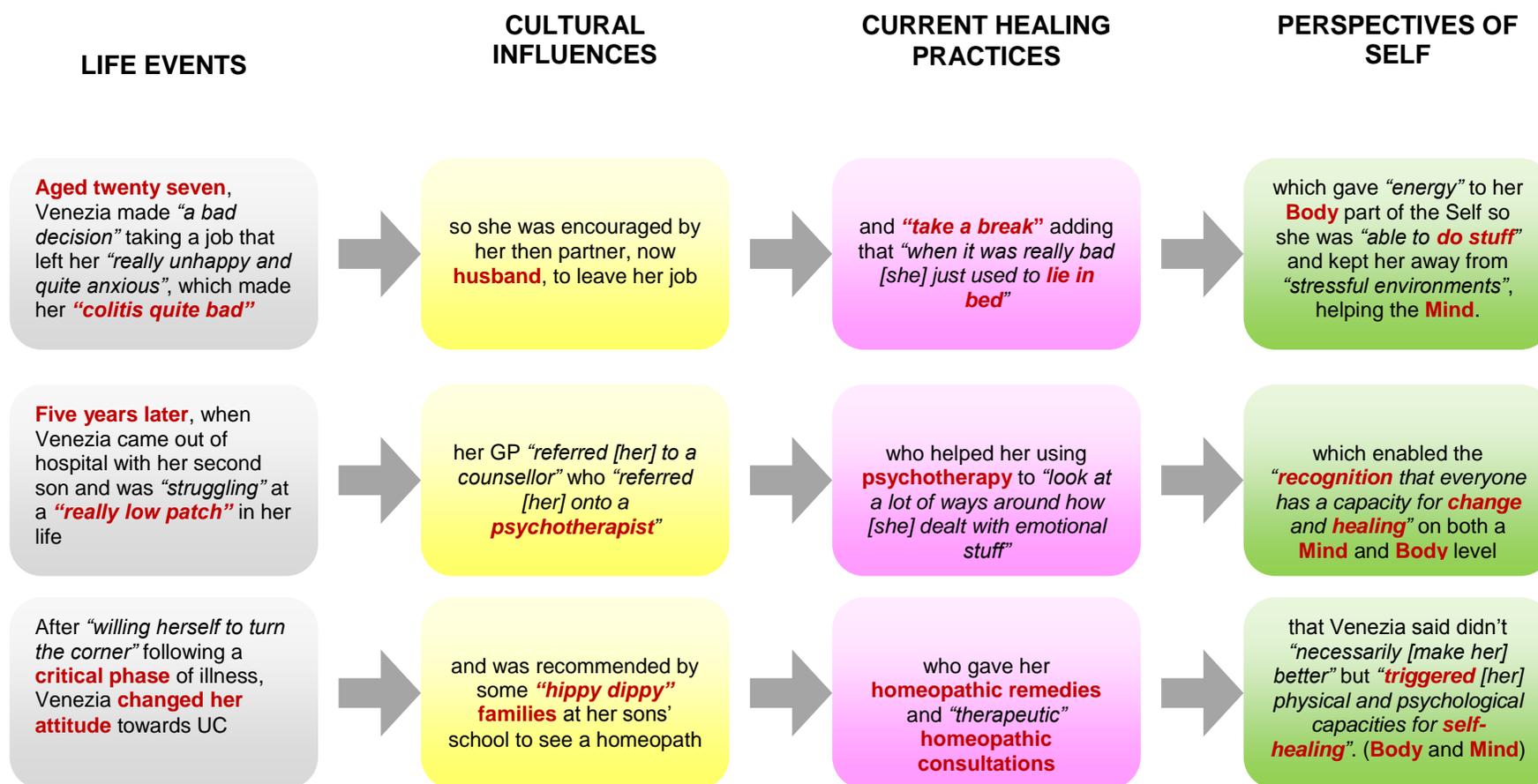
Venezia expressed her want to reform her life so that she could be less tired, “*explore more healthy ways of living and less medical things*” for herself as a mother to her two sons.

#### **5.3.4 Section Four: Venezia’s Explanatory Model and Current Healing Practices**

The following explanatory model presented in Table 5.4 shows a flow of ideas based on Venezia’s life events within the context of the thesis’s underlying conceptual framework as a lens through which to interpret and make sense of how and why people with UC use particular healing practices including TCAM. The first column shows the relevant life event, the second shows the cultural influence at the time of a particular life event described, the third column displays the recommended healing practice that the participant is *currently* using and the fourth column is the interpretation of how the choice of that treatment relates to perspectives of Self.

Although Venezia said that she has not “*actually had any symptoms for about twenty months*”, a number of healing practices are evident. These are, to some extent, still linked to the original cultural influence that/who recommended the healing practice. These are presented in Table 5.5, separated into preventive and curative, while recognising that these are, in reality, interrelated and used more fluidly.

Table 5-4: Explanatory Model for Venezia



**Table 5-5: Preventive and Curative Strategies for Venezia**

Preventive	Resting at home	Venezia said it is important for her to be “ <b>conscious</b> ” of what her “ <b>body is saying</b> [when she] need[s] something” like “emotional support, <b>rest</b> or space to express [her]self”.
	Psychotherapy	“I still see [a psychotherapist] now <b>every week</b> ” as a “preventive thing” and “that’s why I’m still very <b>in tune with what’s going on with me</b> at the moment because I have to carry on seeing a psychotherapist for the duration of my MA training.” “I <b>haven’t had a need to have a flare up</b> because it’s <b>already being processed</b> [“expressing emotions”] in the here and now.”
Curative	Seeing a homeopath and taking homeopathic remedies	“If I started to get proper symptoms like <b>proper diarrhoea or lose any blood</b> significantly that would be an indicator that <b>things were going downhill</b> and I would <b>see [my homeopath]</b> . I’d <b>take some kind of remedy</b> , which would be dependent not just on what the symptoms were but what was happening with me in terms of my emotional state.” “I’m not necessarily saying that [homeopathic remedies] cured me or made me better but I think the <b>process of having a relationship with a homeopath</b> and just <b>believing that your body has the capacity to heal itself</b> has <b>triggered my physical and psychological capacities for self-healing.</b> ”

## 5.4. Case Study Three: CALVIN

*"I don't really want to risk drinking anymore and aggravate [my UC] again ... [but] it is a bit annoying as well as I get funny looks for not drinking which is a bit weird."*

### 5.4.1 Section One: Overview of Calvin

#### **Who is Calvin?**

Calvin is a twenty-three-year-old white man who described himself as a *"quite shy and not very confident"* person. His parents *"split up"* when he was five years old and he lived with his *"mum"*, *"step-dad"* and brother until a couple of months before the first interview. After finishing school, he *"studied agriculture"* for a year at college before going *"into full-time work"* for three years at a *"local egg farm"*. He is now a butcher working in a supermarket and described his bosses as being *"really good"* about his illness. Calvin indicated that *"there's been support from everyone"* in his family including his grandparents since his UC diagnosis when he was 19 years old. Although Calvin seemed to be hesitant, expressing his narrative in a mumbling tone, he seemed very clear on what he liked and disliked especially with regard to using non-medical healing practices.

#### **First Symptoms**

When Calvin was fifteen years old and he had *"almost left school"* to go to college, he went to *"his friend's nan's funeral"* and got *"absolutely off [his] face"* on whiskey. He said it *"definitely was the trigger"* to his Ulcerative Colitis and after around two weeks he started to get his first symptoms. These included *"sloppy stools"* that were *"quite smelly"*, which *"didn't seem that bad at the time"* and so Calvin *"ignored it ..."*

#### **Getting Worse**

During the next four years, Calvin said he *"went to the doctor's a few times"*. On an occasion, he was told to *"give it a month or so"* and told *"it [would] clear up"*. As it did not, he tried getting something from the chemist but that did not work either. Calvin said that his *"stomach hadn't been right for a few years"* after his initial symptoms and felt *"dodgy"* until he got his *"first proper symptoms"* at the age of nineteen when *"it started getting quite bad"*. He described having *"bad diarrhoea"* with *"a rotten smell"*, *"going to the toilet five times a day"* with blood and being *"quite ill with that"*.

### ***Crisis Phase***

So Calvin went to visit the doctor again and was advised to *“give it another few weeks”* and wait to get a call from the hospital to see a specialist. This is when things *“started getting out of control”* and Calvin said he was *“quite ill”* having *“quite a rough time”* and *“lost about a stone”* because he *“wasn’t eating”* or *“doing anything”*. So his *“mum rang the hospital in the end because she was worrying”* and *“took him in”*. He was there for two weeks and that he was *“quite relieved to be in hospital at that time”*. He described *“going to the toilet almost ten times per day and pretty much just being blood every time”*. Calvin explained *“they did some simple tests, took some blood”* but *“they [were] not sure if it was some sort of virus, contagious thing, an ulcer or Crohn’s”*. He was given *“a steroid drip”* (*“hydrocortisone”*), *“blood thinner”*, *“anti-inflammatory tablets”*, *“an enema”*, *“some iron”* and *“some calcium”*.

### ***Post-hospital***

The hospital *“sent [him] back home”* advising him *“to rest and put weight back on and strength”*. He was *“off work”* for around four months until he felt *“better [enough] to go back to work”* but not *“fully better”*. Ever since leaving hospital, Calvin has been taking prescribed medication including: *“steroids”*, *“anti-inflammatory tablets”* and *“immunosuppressants”*. He said *“they had plenty of leaflets and information just to explain what [UC] was all about”*, at the hospital, and that it was his *“mum [who] found [them]”*.

### ***Accepting the ‘new’ Self***

Calvin explained that ever since his diagnosis, he found that *“going out”* and having a *“social life”* has been *“annoying”* because of *“not being on the same level”* since he *“[didn’t] really want to risk drinking anymore and aggravating [his UC] again”*. On the other hand, Calvin said that *“not having the dependence of having to get drunk or do drugs, just to feel like [he’s] having a good time”* is a *“positive thing about this illness”*. He added that *“it has only been the last two or three years that [he has] been going out and enjoying [himself]”*, such as going *“to see live bands”*.

Calvin also seemed to have identified a change in his personality since having UC saying *“[he] wasn’t confident”* but *“that changed in [him]”* and he is *“a bit more outspoken now”*. He said he *“used to care about what people thought about what [he] said, which is a bit daft”* but now he *“care[s] less about what people think”*. He also said that in the past he has *“always gone out of [his] way for people”* but *“with being ill, [he has] just had to say ‘no’”* and tell his friends to *“sort it out [themselves]”*.

### **Cultural Influences**

Throughout the years in living with UC, Calvin said *“there’s been support from everyone”* in his family. After reaching a critical state of ill health, Calvin was taken to hospital by his mum. His illness has *“upset and worried her more than it has done [him]”*. His *“dad wasn’t really sure what [UC] was until [Calvin] gave him the spec about what it was really”*. He described his *“dad”* being *“quite shocked about what it was and that and he was quite concerned”*. Since Calvin said his *“dad suffers from Irritable Bowel Syndrome”*, he has *“mentioned certain diets to try when things had settled”*. Calvin also mentioned that his grandparents *“have gone out of their way to do stuff for [him] or just find other treatments and alternative Medicines”*, adding that it was his *“granddad’s wife”* who *“recommended [her homeopath] to [him]”*. His bosses at work have also *“been really good”* and *“quite supportive”* about his illness and how it affects his work. Calvin described how he has *“three really close friends who understand”* his condition and said *“there are no problems at all when [they] go out”*.

### **Healing Practice Pluralism**

After one year of taking the prescribed medication, Calvin decided to try Homeopathy as recommended by his grandfather’s wife. He said he was *“quite keen on the idea for it being a possible solution for sorting this out”*. After around two years of occasional visits to his homeopath, Calvin said he *“thought it was working at the start but [didn’t] know if it was perhaps the power of belief that was working that it might solve it”* and so stopped using his *“homeopathic remedies”*. This behaviour and reasoning seems to reflect Calvin’s reassessment of his perspectives of Self in the way that he is ‘trying out’ healing practices one at a time and seeing which one fits his Self.

Apart from taking medication Calvin has used the following healing practices and habits in living with UC: eating *“clean”* and *“healthy”* foods and drinks; keeping a *“routine of exercise”*; *“listening to music”* to *“chill out”*; not doing *“anything that is exhausting”* and *“rest[ing] when [he] feel[s] he need[s] a rest”*. During his narrative Calvin mentioned *“reading about the Dalai Lama”* and being interested in trying *“meditation”* that *“Tibetan monks”* do.

### **Current Healing Strategies**

At this stage in his illness, after eight years of taking medication, Calvin *“just want[s] to stick to getting off medication really before anything else”* and said *“[he’s] pretty convinced that [he is] steroid dependent and just need[s] a longer period of time to wean [himself] off them”*. He also talked about his exercise routine including *“press*

ups”, “pull ups” and going “for a quick jog”. He emphasised “just eating well” including “plenty of fruit and veg”, not eating “sweets” or “artificial stuff”, not having “fizzy drinks” and drinking “plenty of water”. Calvin also said that “if [he feels] tired” he rests by “having a quick nap”, “making sure [he has] a good night’s kip and [gets] to bed in good time”.

#### **5.4.2 Section Two: Exploration of Two Decision Points**

##### ***Decision Point 1: Coming off Medical Medication***

This decision point has been selected as it stands out as one of the major turning points in Calvin’s narrative concerning the way he has lived with UC and the stage he has reached after four years of taking medical medication. Ever since his diagnosis at nineteen years old, with the support of his family, Calvin said he was advised “just to stick to [what] the doctors at the hospital [...] recommend[ed] and [told him] to do”. Calvin is the youngest participant in the study and has lived with UC symptoms and signs for the shortest time so he seems to be in the early stage of this long-standing illness journey.

Three main life events seem to lead up to Calvin deciding to come off all medical medication, starting with steroids (he identified himself as “obviously steroid dependent”).

- “Keen to come off steroids”

During his time in hospital, Calvin said he went through “leaflets” at the “[IBD] clinic” on “coping with [UC] and the side effects of the drugs”. Calvin listed the ones he remembered including: “mood swings”, “fatigue”, “weight gain”, “loss of appetite”, “puffy face”, “spots”, “thinning of the skin”, “thinning of bones”, “tiredness” and “sickness”. He added that he had “pretty much” experienced all of those but he does not “get any symptoms now” as he “suppose[d] [he has] got used to them”. It was later, when he started “coming off the steroids” as “recommend[ed]” by his doctors, that he noticed he was “getting a bit moody” and that “the symptoms would all come back again” in a “flare up” saying: “I’m pretty convinced that I am steroid dependent”. This is why Calvin said he “got a bit keen to come off the steroids” and eventually the other two “types of medication ... anti-inflammatories and immunosuppressants”, but at present was “not too fussed about them” as “apparently they are okay to take over a long period of time”.

- “Do[ing] it my way rather than their way”

The key issue here was his being unsure of their medical knowledge of UC. Calvin commented that he was “not really convinced they know what they are talking about...”

*They only have things to try and stop it from happening; loads of tablets". He said "they are just going by the text books" and even though "it's different for everyone apparently; so they've been saying", they "just didn't seem to be very open to [his] opinion on that".*

Calvin seemed very determined to do things his way. He missed his appointments, commenting it was *"a waste of time to go all the way down [there] and tell them how [he's] doing"*. He emphasised that this is *"just not a priority"* saying that *"it's not that important for [him] to go there because [he's] doing quite well on [his] own regime"*.

- Living *"clean"* and *"healthy"*

Another contributing factor to Calvin wanting to come off medical medication is seen in his use of the terms *"natural"*, not *"artificial"* and *"wholesome"*, as examples of what is *"clean"* and *"healthy"*. He used these terms when describing the two healing practices of homeopathy and *"diets"*, in comparison with taking medical drugs. Three elements were evident.

A first element related to being *"keen [on the] natural"*. Calvin's grandmother recommended her homeopath a year after Calvin was diagnosed with UC. He said the *"whole philosophy of it being more of a natural remedy rather than a man-made remedy that appealed to [him]"*. Calvin said he *"was quite keen on the idea for it being a possible solution for sorting [his UC] out, whether for putting it to rest or actually curing it"*. Regardless of the fact that Calvin stopped using Homeopathy because he thought it might have worked because of *"the power of belief"*, the perspective of something *"natural"* as opposed to *"man-made"* remains one of the main reasons for trying it. Calvin also used the term *"natural"* when talking about food. He said that *"[he's] had a few friends that have looked [up information] for [him], just general[ly], [food with] natural anti-inflammatory [properties] and having food that can promote anti-inflammatory [actions] and probiotics"*.

A second element was his having a *"wholesome"* diet. Calvin mentioned that his *"dad suffers from Irritable Bowel Syndrome"* and recommended Calvin to try the *"Candida diet"*. Although Calvin has *"not tried [it]"*, he expressed interest in having *"wholesome food"* saying he *"make[s] sure [he] eat[s] plenty of fruit and vegetables"* and *"just clean food, like no artificial stuff and no sweets"*. Calvin said that even though *"[he] was raised in the kind of family where mum's always cooked meals [like] veg and mash or a pie or chops"*, he *"wasn't taking that much care of [him]self that well until recently"*. Now Calvin *"just stick[s] to healthy foods and plenty of water"*.

A third element was having a too “*clean ... environment*”. Calvin talked about his “*mum [being] quite clean*” and that “*she always used to clean a lot so [he] obviously think[s] that the environment [he’s] grown up in is quite clean*”. In this case Calvin does not perceive “*clean*” as a positive thing, but connects this, seemingly ‘too’ clean environment as contributing to the onset of his illness, saying “*[he’s] not always really had a good immune system and [was] not used to fighting off things [which] has weakened [him] as [he] was growing up*”. He emphasised that he did not “*blame [his] mum but [thought] that perhaps if [he had] grow[n] up in more of not such a clean environment*” it would have given him “*a chance for [him] to [get] used to dust or anything*”.

It seems that Calvin is at a stage in living with his illness where he has acknowledged what he wants and how he wants to do it in observing the Self. In understanding how he perceives his illness in connection with the Self, he is reassessing the types of healing practices that ‘fit’ to suit the Self.

### ***Decision Point 2: Learning about Tibetan Meditation***

During recruitment to this study, Calvin sent an e-mail explaining that he was no longer using Homeopathy as he was using a different approach to healing and wondered whether it would still be useful to be a participant. After having understood the PhD’s interest in finding out how and why he came to use Homeopathy, as well as any other approach, for example, his use of exercise and “*clean*” and “*healthy*” food and drink, Calvin decided to join the study. Although Calvin talked about his use of Homeopathy, he seemed to have little to say about it. However, whilst talking about his perspectives of UC and how he lives with it in relation to healing practices, ways of coping or habits, he expressed a steadfast curiosity for Tibetan meditation. The relevance of this decision point is that it shows Calvin at an earlier stage in his life with UC just when he had been coming off steroids and having had enough lived experience to express his perspectives of Self, illness and healing using less mechanistic views.

Even though Calvin has not yet started meditating saying “*there were classes*” in his town, he said he was “*waiting to come off the steroids before [thinking] about anything else*”. The following two points illustrate the parts that contribute to leading up to this decision point embedded in different life events. These help to illustrate the importance for Calvin of the Mind as in “*control*” of the “*senses*”.

- Not “*letting [emotions] get you down*”

“Since [he] can remember”, he has “just had this ability to cope with problems without too much grief”, which he described as “weird”. He elaborated by saying that he has “just not [been] affected so emotionally by [his illness]” and has been “able to get on with it” emphasising that he has “always been that way”. Nevertheless, Calvin explained that when he “feel[s] quite sorry for [him]self”, this “doesn’t do [him] any good” and “think[s] it would make [his UC] more worse”, adding that “it gives [him] the enthusiasm and compassion to do a bit more about it”. He went on to say “it depends [on] how you look at it” and “not thinking about it and just getting on with it” has “helped”.

Here Calvin acknowledges a link between the Mind and Body parts of the Self emphasising self-pity as the emotion aggravating his bowel problems. His attitude towards developing his mindset seems to be something he is interested in cultivating. With this in mind, looking for healing practices incorporating development of a mindset with the aim or directly or indirectly helping him cope with living with UC would seem useful.

- *“Get[ting] to another level of consciousness”*

Calvin explained that although “most of [his] family are religious” and “are all Christians”, but he is “not really religious” and “[doesn’t] really like to commit to any religion”. Nevertheless, he said he is “quite interested in religious ways”, in particular, to do with “meditating”. He explained that in “the Tibetan culture and the way they meditate, they can get onto other levels of consciousness” and “they have control over their bodies”.

He went on to say that he “believe[s] that there is a possibility that [he] might be able to control [his] illness”. Calvin elaborated by saying he is “not really sure” “for what reason” “[his] immune system is attacking itself” but said “there might be some sort of trigger that [he] might be able to turn it off”. Meditating “would be a possibility that [he] would do, just the general [things]” adding that “it might be just good anyway to do it to stop worries” as “[he] find[s] it a lot easier just not worrying about things until they happen” and “tak[ing] each day as it comes”.

#### **5.4.3 Section Three: Exploration of Calvin’s Perspectives of the Self**

Calvin expressed perspectives of Self interpreted as relating to concepts of the Self as a System consisting of Body, Mind including consciousness and the senses, as well as the Self as a social being. The following analytical explanation illustrates this by extracting information from the data presented in his narrative.

### ***The Self as a System***

When Calvin talked about his “system” he described it in the context of using medical drugs. According to his understanding, these needed to have “*a steady flow through [his] system so that the tablets get to [his] intestine [and] get dissolved in [his] intestine*”. This implies that the system he is referring to is not just the intestine but the whole body including physical and physiological parts as well as the Mind (see Self as Mind below), with a particular interest in consciousness.

### ***The Self as the Body***

Calvin referred to parts of the body using different terms implying particular functions and motility:

*“Ruin[ing] [his] stomach”* Throughout his narrative, Calvin referred to his “intestine” mostly as his “stomach”, which he said was “*dodgy for quite a while*” and he “*ruined [his] stomach, or [his] intestine rather*” with his excessive alcohol consumption. This view of the digestive system is of something (alcohol) that has corroded his organ making it more sensitive and therefore needing better nourishment i.e. “*clean*” and “*healthy*” food and drink.

Whilst describing being careful when reducing the dosage of his steroid intake Calvin explained that “*apparently [there are] enzymes in your stomach; good and bad enzymes [and] it’s about having a balance of good and bad bacteria in your stomach [so] since [he] reduced [the dose of steroids] [his] stomach is a little bit disturbed*”. In this case Calvin uses terms used in Medicine talking about the microorganisms living in the physical body in explaining how he might have “*ruined [his] stomach*”.

- “*Flush[ing] [his] system out*”

Calvin also used the term “system” to describe the intestine when explaining how his UC got “aggravated again and caused [him to have] a relapse” after “they did [a colonoscopy]” where “[he had] to take a solution, [barium], just to flush [his] system out”. This is why Calvin said he “won’t have one of those again”.

- “*Feel[ing] his “intestines” and “colon”*”

Calvin emphasised not needing to have other colonoscopies saying “*[he] can definitely feel it’s all of [his] intestines when [UC] does set off; it’s quite painful really*.” He referred to his “colon” when he further justified not wanting colonoscopies by saying “*I can’t see what’s happening but I can feel when it’s worse and when my colon is worse*”. Calvin’s confidence in his feeling his intestines meant he did not want to have another physical examination in that area again.

This understanding of the body seems to have contributed to Calvin using more mechanistic healing practices. These include medication, which he wanted to regulate and reduce in his way and his time as well as having more “clean” and “healthy” food and drink and doing regular exercise.

### ***The Self as the Mind***

It is clear that Calvin perceives the Mind as part of the Self involving parts that affect UC.

- “Getting ill from [emotions]”

Calvin described how he “can get quite ill from” “worry in [his] mind” referring to it as a “mental strain” that can “pretty much control your body”. He described that “feeling sorry for [him]self” “doesn’t do [him] any good” either. Calvin also said that with having to take medical medication like steroids, they “can throw your mind out a little bit as well” with “mood swings”. Nevertheless, he said that “if your head is strong enough” and you “keep reminding yourself [of] a hopeful attitude”, it may affect you less.

- Having “mental stress”

Calvin talked about “the mental stress [of] being relied on to do stuff”, for instance “getting up to take [his] mate to work”. He described himself saying he has “always gone out of [his] way for people, to help them out and friends have got quite reliant on that, [him]”. Yet “with being ill [he has] just had to say ‘no’ and [tell his friends they] will just have to back off and sort it out for [themselves]”. He “struggle[s] to find a line between being selfish and not helping [his] friend out or [acknowledging] that [it] is [his] friend being a bit lazy or becoming too reliant on [him] helping them out”. Calvin concluded that “[he’s] got to chill out and look after [him]self” and “just put myself first a bit”.

- “Getting [to] that place in their mind”

Calvin described his interest in learning about meditation as he acknowledged the existence and importance of consciousness in the Mind part of the Self as well as the link between Mind and Body through senses. He talked about consciousness when referring to his understanding of what Tibetan monks do during meditation to “get onto other levels of consciousness” and “getting in that place in their mind where their senses can come passed them” and “perhaps, in that sort of way, [they] might be able to” “have control over their bodies”.

With these concepts of the Self as the Mind, Calvin explained that he “believe[s] that there is a possibility that [he] can control [his] illness” using the mind. Calvin described

that *“his immune system is attacking itself”*, which is why his UC *“flares up”* and that *“there might be some sort of trigger that [he] might be able to turn it off”* by *“control[ling]”* emotions by attaining a level of consciousness through the senses.

### ***The Self as a Social being***

For a young man of twenty three years, in what could be described as the ‘prime’ of his social life, Calvin expressed *“going out”* and have a *“social life”* as being the most difficult experiences of having UC. He described himself as *“not a great conversationalist”*, that *“[he’s] never been one much to speak”*. He added that *“that’s what [he] worry[ies] about; that [he doesn’t] have much to say”* and said he *“just need[ed] to not worry about it really”*.

Aside from this description of himself, Calvin talked about different scenarios and social behaviour of people around him, which he could not participate in because of his illness and the reaction and acceptance of others towards him. Three examples are given below.

- Not *“risk[ing] drinking [alcohol] anymore”*

Calvin said he *“definitely”* thought *“getting stupidly drunk”* on whiskey at fifteen years old *“was the trigger”* to his illness. He explained that he *“[hadn’t] drunk since then”* yet had *“tried half a pint”* but *“[doesn’t] really want to risk drinking anymore and aggravating [his UC] again because it would be just like another month of aggravation and getting over it again”*.

- *“Not having the dependence of do[ing] drugs”*

Calvin talked about *“hanging around”* people who were *“doing drugs”* feeling that he wanted to *“get in the moment with the rest of them and join in”*, which had *“bad effects on [his] stomach”* and *“didn’t do [him] any good”*. He described his view that *“you don’t need that”* saying *“it’s all about who you’re with really: good friends and you’ve got to make sure you go somewhere you enjoy”*. Calvin said for him *“it’s music”*, saying *“give me good music and I’m well away”*. He concluded saying that *“not having the dependence of having to get drunk or do drugs just to feel like [he’s] having a good time”* would be a *“positive thing about this illness”* but *“that would probably be the only thing though”*.

- Being *“paranoid of what people thought of [him]”*

Since Calvin left school at sixteen years old, he said he *“didn’t really want to go out at all”* because he *“was quite paranoid of just what people thought of [him]”*, which has improved generally but not with regards to having a girlfriend. Calvin said he has

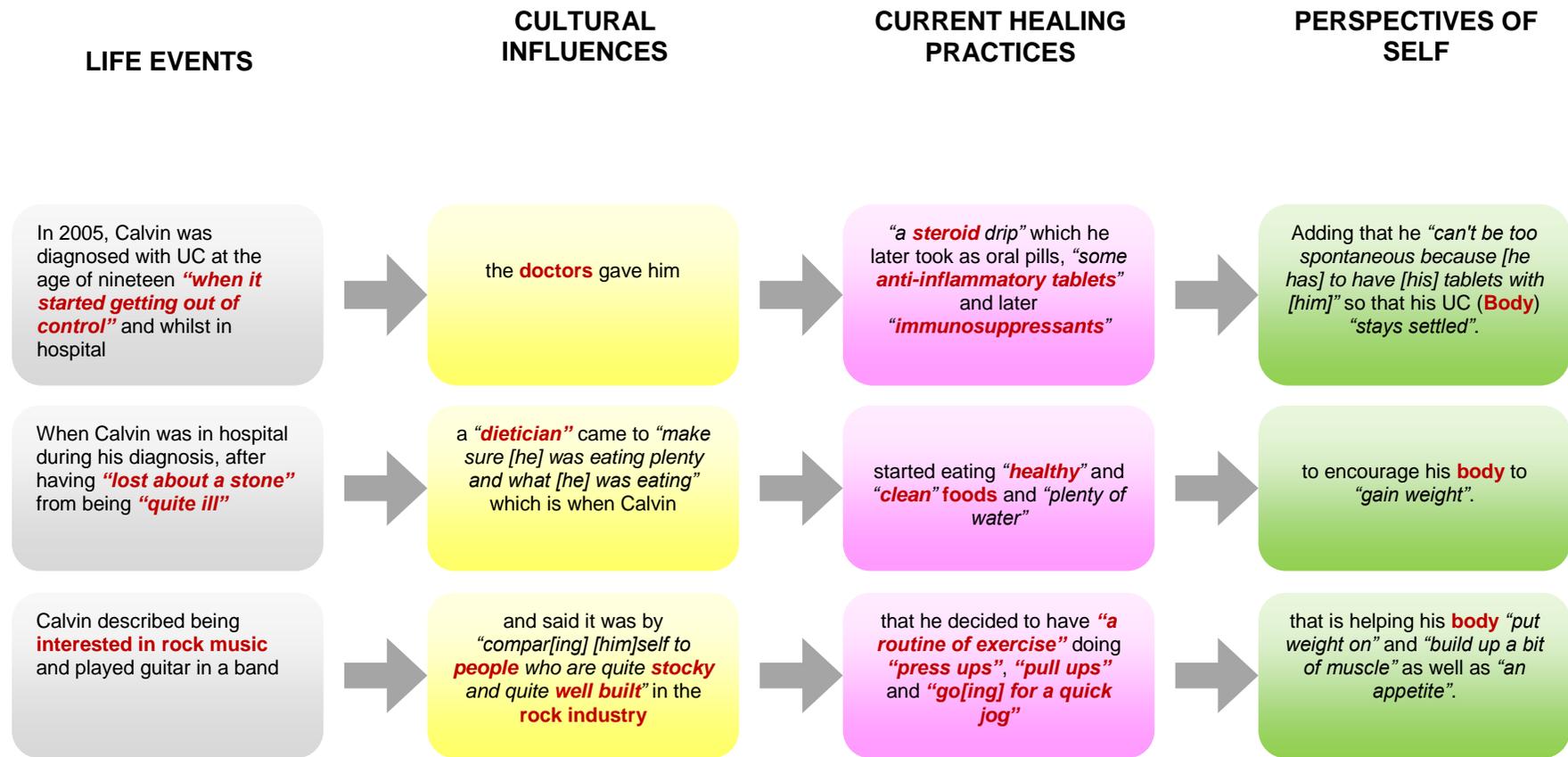
*“never been confident”* and that “what people think [of him] is still a bit of a problem” which he has been “putting up with until now” and he says has *“become who [he is]”*, so *“it’s been a bit of a battle”*. Calvin showed a genuine concern about what his potential partner might think about him not *“going out”* and being *“quite boring”* because of his UC, adding humorously that *“it wouldn’t be the best sort of thing to try and chat up a girl with though”*. He concluded saying he *“suppose[s] [he] just compare[s] [him]self to the wrong people”*, that *“not everyone thinks the same”* and he *“just need[s] to not worry about it really”*.

#### **5.4.4 Section Four: Calvin’s Explanatory Model and Current Healing Practices**

The explanatory model presented in Table 5.6 shows a flow of ideas based on Calvin’s life events within the context of the thesis’s underlying conceptual framework as a lens through which to interpret and making sense of how and why people with UC use particular healing practices including TCAM. The first column shows the relevant life event, the second shows the cultural influence at the time of a particular life event described, the third column displays the recommended healing practice that the participant is currently using and the fourth column is the interpretation of how the choice of that treatment relates to perspectives of Self.

Table 5.7 presents the main types of healing practices and their current use by Calvin either more preventively or more curatively oriented, as expressed in his narrative. Although Calvin expressed a strong interest in starting to use meditation as practised by Tibetan monks, he was still at the early stage of developing his curiosity and had not started taking lessons. The current healing strategies presented below are not exclusively preventive or curative but only represent a tendency of ways of coping expressed by Calvin during data collection.

Table 5-6: Explanatory Model for Calvin



**Table 5-7: Preventive and Curative Strategies for Calvin**

Preventive	Having healthy food and drink	This consists of “eating well [with] plenty of <b>fruit and veg</b> ”, “eat[ing] plenty of <b>meat</b> ”, “having <b>three meals a day</b> and having a little <b>fourth meal</b> before [he] go[es] to bed”. Calvin said that he “ <b>push[es] [him]self to eat</b> a bit more, like an extra meal just so that when [he is] exercising [he’s] <b>not losing weight.</b> ”
	Doing exercise	Calvin described having “a routine of exercise” where he “get[s] up in the morning and do[es] a few <b>press ups</b> and a few <b>pull ups</b> and go[es] for <b>a quick jog</b> ” to “get [his] day started”. He said he “saw it as <b>building</b> up a bit of <b>muscle</b> ” as well as “[his] <b>appetite</b> ” with the aim of “just try[ing] to get [him]self <b>looking good</b> as well so [he’s] <b>not as skinny</b> as [he is]”.
	Getting plenty of rest	Calvin said he “[has] to be really <b>careful what [he] do[es]</b> and get[s] plenty of <b>rest</b> ” <b>when he needs it</b> . So “if [he] feel[s] tired, [he has] a <b>quick nap</b> ” and “mak[es] sure [he has] a <b>good night’s kip</b> and <b>get[s] to bed in good time</b> ”, which he said gives him “ <b>strength</b> ”.
	Listening to music	This “could be anything from <b>heavy metal</b> to the <b>blues</b> , a bit of <b>jazz</b> , even a little bit of <b>classical</b> ” in order to “ <b>chill out</b> ”, which is why Calvin “quite like[s] listening to music” and “go[ing] to <b>see live entertainment</b> ”. He described that it “ <b>sets the mood</b> ”, “ <b>makes you want to have a dance</b> ”, “ <b>makes you smile</b> or <b>makes your hair stand on end</b> ”.
Curative	Taking medical drugs	Ever since leaving hospital at the age of nineteen, Calvin has been “ <i>taking <b>steroids</b></i> ”, “ <i>anti-inflammatory <b>tablets</b></i> ” and “ <i>immunosuppressants</i> ” to “ <b>settle</b> ” his symptoms of UC <b>when he has a “relapse”</b> . He said “[he’s] <i>obviously <b>steroid dependent</b></i> ” and “ <i>just need[s] a <b>longer period of time to wean [him]self off</b></i> ” the steroids so that his UC does not “ <i>flare up</i> ” again. He has been chiefly concerned with reducing the dosage of his steroids to such a low dose “ <i>so [his] <b>body hardly notices the change</b></i> ” when he stops.

## 5.5 Case Study Four: CELINE

*"[Having Crohn's] is like my brain is writing cheques that my body can't cash. The mind is willing but the body is saying naff off basically."*

### 5.5.1 Section One; Overview of Celine

Who is **Celine**?

Celine is an extroverted, outspoken forty-year-old woman with three sons and a daughter whose parents are West Indian who *"came over just after the wind rush"*. She described herself as *"first generation Black British"* and said that when she was growing up she *"knew [her] life wasn't normal"* because she *"just kept quiet about stuff"* that was *"going on at home"*. She was also *"a bit of a tom boy"* whilst *"everybody else [was] having a normal life at school"*. In 1988 Celine had her first son and described that period: *"[19]88 weren't a good time to be a single, black parent under Thatcher's era<sup>7</sup>"*. She went on to describe the context of her life at the time as being seen as *"bringing up the muggers and rapists of tomorrow"* and that the *"mental attitude"* towards her was of a *"single parent scrounging on benefits"* who should *"get out and work"*. By 1993 Celine had two sons and met *"a guy who was a nurse"* who suggested they both become nurses. She said the *"idea of nursing appealed to [her] especially with psychiatrics"* because her mother *"had psychiatric problems all through [her] life"* and as a child she said she remembered going to visit her mother in the hospitals and *"the one thing [she] noticed [was] that there was never any black nurses."*

#### **First Symptoms**

Celine had a lot of problems doing the nursing course due to *"early starts and shifts"* with having two children at home, which was *"always a stress and a worry"*. Around the age of twenty eight, Celine was three months from the end of finishing her nursing course and a single parent, who *"had a mother with illness"* and *"had a lot going on"*. She started to have *"a build up"* of symptoms: *"bloody stools, severe cramping across [her] stomach and abdomen, not being able to eat spicy foods [or] hard fruit"*. From reading *"bits and bats"* in publications during her nursing course, she *"put it down to stress"* and thought: *"Oh, it sounds like Irritable Bowel' to [her]"*. She went to see her family doctor, who'd known her from birth and did *"proper, all-round, holistic doctoring"*

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<sup>7</sup> She described "the conservatives" as "a very racist, very white elite, land owner, middle class organisation".

who said she was *“probably right”* and *“put [her on] a snap course of steroids, which seemed to ease it but not necessarily solve it”*.

After about eighteen months her doctor *“wasn’t happy with the fact that [she] still had problems”*, sent Celine for further tests and, after a colonoscopy, was diagnosed with Crohn’s Disease in 1996. At that time Celine said, *“there was the option of surgery”* but she refused it because she said she did not want to have a stoma. She also met her current husband in 1996 who has *“been virtually there from the start of [her] illness”* and became pregnant again.

### **Getting Worse**

During the next four years, Celine had to take a number of different medical drugs: *“there was a lot of issues around pain”*. Although her health gradually deteriorated, she described having her third son *“in the middle of an outbreak”* in late 1997. She also mentioned having *“spells in hospital”* during *“school holidays”*, *“a week at Christmas”* and *“summer holidays; just for the rest”*. She found that the weeks in hospital helped her *“[with] the pain and just calmed everything down”*. She thought it might be *“the extra stress because the kids were at home [that] affected her illness”*.

### **Crisis Phase**

By 2000, Celine said that things *“came to a head”* as she had *“got to a point where [she] was needing more medication”* and *“everything was at a max”*. She concentrated on trying to *“just survive”*; her attitude towards living was *“more on a day-to-day basis as opposed to long-term”*. She reached a critical point that *“either [she] had [her] surgery”* or *“if the Crohn’s didn’t kill [her], the medication would.”*

### **Post-surgery**

After having a daughter in 1999, Celine opted to have a loop ileostomy in 2000, which she described as a temporary step in the hope of reconnecting her small intestines to her rectum and anus. Unfortunately, after another four years of taking medical drugs with having to get used to living with a stoma bag, Celine had to have a permanent ileostomy in 2004.

Accepting the ‘new’ Self Celine’s ileostomy meant that she was *“getting to grips with the disease and also the physical aspects of a change in body image”*. It also meant *“getting used to a stoma and coping with accidents when you’re out”* with *“two young babies and two older children, coming into middle teen age.”* Celine explained that,

even though there was a nursing team for stoma care and a support group for “ostimists” (as she now identified herself), she *“just didn’t feel connected with them”*. She described the information booklets as having *“all these smiling old people, middle-aged”* and said that *“when you’re that age you can be wearing your flannelettes and pooping in a bag”* but it *“just set off a mindset of: ‘God, is this my life?’ Is this how I’m going to be?”* This *“just put [her] on a downer.”* Nevertheless, she said she *“was determined that it wasn’t going to control [her]”* and that she *“was going to control it.”*

### **Cultural Influences**

Other people are the main influences on Celine in making decisions about what healing practices to use for her ailments. These individuals include: her husband (very supportive almost the beginning of her illness, encouraging her to rest when needed); her children, especially her daughter (in influencing her decision to choose life instead of death by having surgery and carrying on particularly when she was going through a crisis period); her family doctor (treating her with *“proper, all-round, holistic doctoring”* since her birth); her consultant and surgeon (discussed and negotiated medical drugs and surgery with her); the specialist stoma care team (providing support and information on new stoma equipment and how to live as an *“ostomist”*); her school friend (telling her about different types of TCAM therapies and *“bohemian”* ways of life making her more open to other treatment possibilities like Homeopathy and herbalism); and her homeopath (she considered as a friend).

Other influences available that Celine drew attention to were: TV documentaries (on therapies like Acupuncture); academic publications and books about her disease, how to cope with illness and TCAM therapies; booklets and leaflets provided by an ileostomy support group and the specialist stoma care clinic about Crohn’s Disease and stoma care.

### **Healing Practice Pluralism**

Celine has used many different healing practices in coping with living with Crohn’s Disease. Apart from medical drugs, she has rested at home, adjusted her food, drink and diet, used self-prescribed homeopathic remedies as well as consulted a homeopath. Celine mentioned that she *“still wants to be out there dancing about and raving away”*, albeit finding it difficult to find *“mates”* who want to join her. This activity can also be seen as a healing practice since she explained that, *“[she’s] one of them [that] looks in the mirror and thinks [she’s] twenty-odd”* and *“[has] always been really active”* and so *“this [need] in you has to come out”*.

## **Current Healing Strategies**

Celine described three main current healing practices: resting at home (to prevent “a flare up”; by not “doing too much”) or in hospital (to help “calm everything down”); using homeopathic remedies or visiting her homeopath, both preventively to help give her “a better mind frame” or curatively in order “to work alongside and enhance the body’s own abilities to heal itself”; and Co-codamol “to keep [pain] at a level or it’s just a placebo effect for me.” More generally, Celine also takes vitamins.

### **5.5.2 Section Two: Exploration of Two Decision Points**

#### **Decision Point 1: Having ileostomy Surgery**

The decision point of opting to have ileostomy surgery seemed to be a life-altering experience for Celine and still has a significant impact on her perspectives of the Self, illness and healing (as explored below). Celine had to have a loop ileostomy at thirty three years old, but “[she] wasn’t prepared ... [having] fear of surgery itself” and, given her “highly medicated [state] for a lot of time”, was unsure “whether [her] body was strong enough to survive the surgery”. Indeed, she indicated that she “was fully prepared to die”. But her good relationship with the consultant and surgeon (“[we] had a good rapport”) helped, especially as “he [the surgeon] was quite happy to do it at [her] speed”. The following three life events lead up to her decision to have her first, loop ileostomy.

- “OD-ing [her]self on painkillers”

Aside from taking steroids since her initial diagnosis of IBS in 1994, Celine described taking a number of other prescribed medication: antispasmodics, anti-ulcerants, immune suppressants and painkillers. She expressed having “a fixation on painkillers”. Due to her knowledge of nursing, she was able to read the BNF (a list of medications, doses and side-effects) and “so could actually prescribe [her]self”. She mentioned having a “ritual around when to take painkillers” and that she “worked a system and a time-scale so that [she] kept [her] pain at a level, using different types of painkillers”. Celine added that this knowledge from her nursing education “might’ve been a bad thing cause at the end [she] was getting to really pushing boundaries and was really OD-ing [her]self”. It seems that “knowing [her] doctors and having an open relationship with [them]” made it possible to “get what [she] wanted”. She explained that if she needed something she would ask them and they would discuss it with her.

Although Celine's nursing education and knowledge of drug mechanism, function and negative effects made it possible to "control" her illness, this education as part of her Self seems to have made her more open to using medication as a healing practice.

- Opting for death

Aged thirty one, Celine was aware of the danger of continuing with *"the amount of medication [she] was taking or the Crohn's would kill [her]."* At this time, she was married to her husband with whom she had a third son and was pregnant with her fourth child. Celine mentioned *"always [wanting] four boys"* Celine mentioned that, if she had not had some nursing education and had not known what Crohn's Disease was, she might have considered having the surgery earlier

Celine described thinking that she *"wanted to have that last child and then [she] could die happy"*. She said she *"couldn't have open discussions about [her] death with [her husband]"* and confirmed that *"this was all [her], this is what [she] wanted to do."* She also said that she didn't tell her parents or other family members that she was preparing to die, as they were *"all very estranged"*.

- Having a girl

Celine described going to do *"an amnio"* and her midwife, who *"was never wrong"* said *"they say if the heartbeat sounds like a train, it's a girl [and if it] sounds like a horse, it's a boy."* She said her midwife just *"laughed and laughed cause it sounded like a train"* and all her friends thought it was the *"funniest thing ever, [her] with a girl."* At first, Celine seemed to have difficulty accepting this: *"it just wasn't going to happen, I was not going to have a girl! I kick footballs; I throw babies in the air... I don't do girly things! I don't wear dresses and heels and stuff."* She indicated that she *"never wanted to have girls"* and that *"life's too hard for girls"*, referring to family break-ups, *"the world's geared or just seems to be a lot easier [for boys]"* and *"[her] brothers seemed to be doing fine."*

Having a girl *"changed [her] perspective of leaving her [Celine's emphasis]"*. Celine added that she *"didn't want her not to have a mum"* and her daughter needing her as *"the kind of person to push [her] daughter forward to save the world, who knows? [laughs]."* She acknowledged the important role her daughter played in her survival by saying. *"if it wasn't for her, I wouldn't be here"*. It seems that Celine's perspective of the Self as her daughter's mother was reflected and had a major influence on her decision to have surgery. This not only had a healing effect on the physical body but her mind set as well.

## ***Decision Point 2: Using Homeopathy***

This is the decision point in Celine's life that enabled her to treat her Self and her illness. Celine described this healing practice as the main healing practice that she has been using since having her loop ileostomy. After having spent four years taking many types of medical drugs, Celine had "*seriously had enough of the amount of stuff [she'd] been taking.*" Celine was also in the process of getting used to her new Self as an "*ostomist*". The following three points emerged as the facilitators towards her using homeopathy.

- Knowing her "*Bohemian*" school friend

Until 2000, Celine said she had "*never seen a remedy*" and knew that Homeopathy "*was just an alternative kind of therapy*" through a TV programme and things she had heard from "*other people*". Her main influence in introducing her to various TCAM therapies was a school friend she knew since aged nine; her friend's parents Celine jokingly described as "*hippies with money in the bank [laughs]*" who "*were a bit alternative*". Celine described how her friend "*had a wide circle of adult friends doing alternative things*". Mentioned several times in her narrative, Celine appeared to be open to her suggestions and recommendations.

Celine's openness to "*alternative therapies*" was motivated by her reaching a point of stopping steroids after surgery and not wanting to take medical drugs as she now considered them a "*bad thing*". This is where Celine's perspectives of Self change as her "*diseased bowel*" has been removed but the Crohn's Disease is still there and she may not want to relive her suffering of having to take a lot of medication and showed that she was wanting to treat her illness in a more "*holistic*" way.

- Being part of a local community centre

Celine had "*always been interested in youth work*" and had "*links with youth workers in the community*". She had just had surgery and was "*trying to get out and about again*" and attended courses at the community centre. Celine "*was looking for other kinds of [alternative therapies]*" at this time and during a visit to the community centre in May 2000, a youth worker "*was trying to recruit for the courses that were being run*" and "*basically guided [Celine] [laughs] into the centre*" to do a course which turned out to be Homeopathy.

The community centre seems to be a place Celine went to with her older children "*because there was always toys*" and "*people to play with*" and the crèche enabled her to go and attend a course. This support and convenience as the centre was "*near*" her

residence, seems to have been an environment for Celine to interact with on many levels: as mother, student and part of her community.

- Meeting her homeopath

Celine met her homeopath at the Homeopathy course. She then *“first got into it [homeopathy]”*, doing the beginner’s course, an intermediate course and then *“book[ing] to see her”*. She described this experience as making it possible for her to *“get the knowledge [her]self”* and *“treat [her]self and [her] family through her [homeopath]”*. Celine got the remedies she needed through her homeopath either *“at the courses”*, through the post, or the homeopath would *“come to the house and see [Celine] as a client”*.

This type of treatment seems to reflect Celine’s interest in *“controlling”* her Crohn’s as she did with self-prescribing painkillers with her knowledge from nursing and rapport with doctors. The differences now seem to be that she is able to *“treat”* her husband and children with Homeopathy and that *“Homeopathy really, it’s a mindset thing”* and not just physical. This ability to treat her family using homeopathic remedies may also contribute to fulfilling her role as a mother.

### **5.5.3 Section Three: Exploration of Celine’s Perspectives of the Self**

Celine conveys her perspectives of the Self in ways that can be interpreted as pertaining to Body, Mind, being a mother to four children and perceiving herself as younger. Although these are represented separately in this section, they are in reality all part of a whole within the context of her own culture and life events. The following analytical explanation illustrates these perspectives by extracting information from the data presented in her narrative.

#### ***The Self as the Body***

Celine’s descriptions of the Body seems to have three main characteristics:

- The body as an active entity

Celine acknowledged a *“part of [her]”* and *“how [she] was before [Crohn’s]”* as *“always trying to be active and do stuff”*. She talked about ‘being active’ in different contexts. Examples were: taking part in activities with her children (*“go[ing] out, ‘mums and tots’ groups, climbing, weekends away, running about, going in the park”*); and, doing daily chores and running errands (*“I still have this battle with wanting to get up and run around and do everything”*). Since having Crohn’s, Celine seems to have struggled with a change in perspective of Self as an active person to a perspective of a

perspective with tiredness, this being one of her main symptoms. She seems to connect tiredness to physical movement in life events (*"I could be feeling a bit run down"*). She pointed to a change now: *"I've stopped running around. I've stopped trying to; it's like they say, 'it's one thing you're running around thinking that you're doing the best', when really you're not. I realised that I had to slow down"*. She is making the point that the body needs to restore itself in some way so that she can continue to be an 'active' person. In this way, it can be seen to be logical for her to look for a healing practice that enables the physical body to recuperate itself.

- The body as a communicating object

Here Celine personifies the Body as a separate yet connected, living entity that 'communicates' with the rest of the Self, pointing to: *"you always listen to your body and my body was trying to tell me to slow down"*. Through this description, Celine expresses her body as having a life of its own but working together with the rest of the Self. Celine seems to look beyond perceiving the body as a single entity and implies that it is part of a whole that needs to be healed together: physically, mentally and socially.

- The body as a pure object

In this case the Body seems to be something that relates to matter, something that is tangible and reacting at a physical level like a pure object that can be broken: *"I didn't listen [to my body] so it just broke, it made me stop and it did stop [me] in my tracks."* Since the onset of her illness, one of the main symptoms that Celine described experiencing was pain. This was her initial symptoms of CD (for example, painful areas including *"severe cramping across [her] stomach and abdomen"*) and *"steroids and stuff had left [her] with a lot of joint problems"*, adding that *"Crohn's can affect your joints."*

Again, it would seem appropriate for Celine to find healing practices that would permit her to *"control"* pain, recuperate her Body and, especially during her crisis period, find a healing practice that could heal her 'broken' body. Due to her description of her main symptoms of pain, tiredness and a *"diseased bowel"* as perspectives of the Self as the Body, it would also be reasonable that Celine was looking for more mechanistic healing practices for these ailments.

### ***The Self as the Mind***

Celine mentions stress as something that seems to aggravate her Crohn's. She first mentions stress when talking about the origins of her illness saying that her initial IBS

symptoms were *“more a build-up”* that she *“just put down to stress”*. At this time, stressors included: being a single mother with two children at home, her mother’s illness and her nursing course. In trying to explain what causes Crohn’s, she commented: *“if you can’t track [Crohn’s] definitely to a particular [cause], then in theory, anybody can get it cause you don’t know what causes it.”* For her, *“the only one link seems to be stress that seems to be everywhere”*.

During the course of her illness Celine described getting relief from *“the stresses of having a young family”*, especially during holiday seasons when her children were at home, by repeatedly going to stay in hospital for a few days. She described this by saying that *“however ill [she] was at home, as soon as [she] stepped into the hospital, everything seemed to calm down”*. She went on to question being uncertain *“whether that was a mental, a sub-conscious, mental thing”*.

Stress does not just seem for Celine to be connected to physical ability but to feelings of incapacity in social situations, and thus may affect the Mind part of the Self. After years of stress aggravating her Crohn’s, Celine seems to have recognised the need for a healing practice to treat this aspect affecting the Self as the Mind. In recognising what aggravates her Crohn’s, Celine expressed that *“[she] always ha[s] to keep an eye on stuff, [she’s] never going to be cured of Crohn’s. There is always a possibility that if [she gets] too stressed, or too tired, over a period of time, [she] could induce Crohn’s somewhere else along [her] tract”*.

### ***The Self as a Mother of Four Children***

Celine stated several times that she has *“always wanted four boys”*. In fulfilling this role, she said she would be able to *“die happy”*. Celine ended up having a girl as a fourth child. During Celine’s crisis period, when she originally opted for death instead of surgery, having a daughter as her fourth child was a direct motivation for her to accept a healing practice that would take away her *“diseased bowel”* so that she could survive.

### ***The Self as Younger***

During her interviews, Celine made many references to the way she saw herself in terms of aging, both functionally and aesthetically. She links age to feeling alone, in terms of finding other sufferers who are in a similar situation as she is. Yet, she noted, most are not the same age: *“I perceived myself as younger. I mean, I’m forty; I don’t feel forty. I’m one of them, look in the mirror and think I’m twenty odd cause [chuckles]”*

*I always feel disconnected because I'd always been really active even with the children."*

Celine went on to describe how Crohn's has changed her physical functionality yet not the mind part of her feeling younger. *"I've always been really active and Crohn's really stopped me in my tracks and I really lost out on about eight to ten years of natural progression with my mates."* Now that Celine is feeling better, she expressed wanting to live the youth she missed out on: *"I'm getting to this point now where I can go out again and I've got the energy"* and *"all my mates are [like], 'no we're older now, we've done that; we've settled down, we've got jobs' [laughs]."* Since she is unable to find people her age with the same mind-set she has only the younger generation to share this with but as she put it: *"obviously I'm too old for the younger ones [laughs] cause I'm just some old person."*

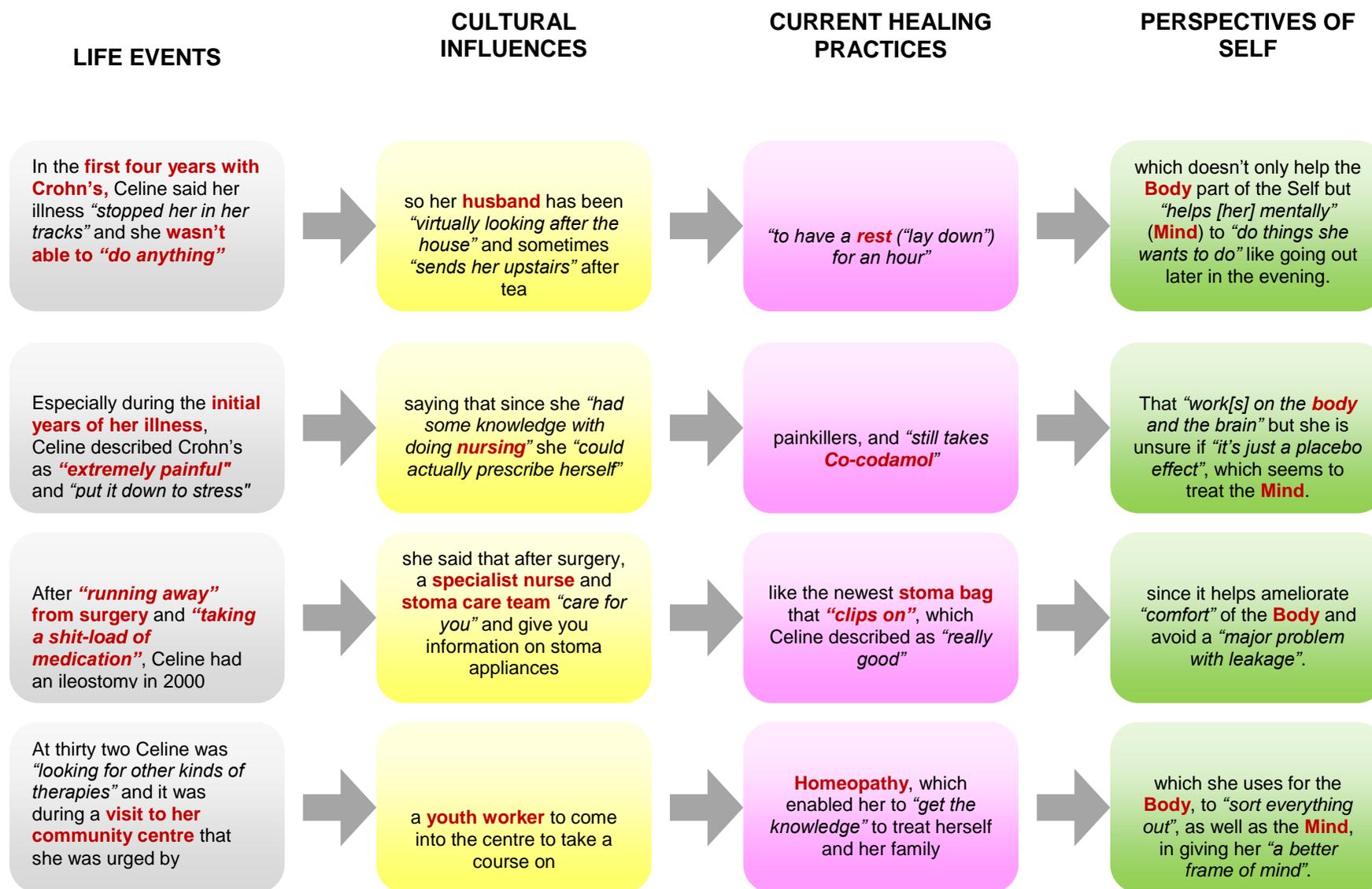
This perspective of Self as younger means that Celine has an awareness of Self that may influence the characteristics of healing practices that enable her to connect to aspects of life which seem predominantly connected to youth, such as body image in terms of fashion trends and physical movement. Again, it would seem that a healing practice enabling her to be more comfortable physically and aesthetically would be ideal for her living with Crohn's, being active and youthful.

#### **5.5.4 Section Four: Celine's Explanatory Model and Current Healing Practices**

The explanatory model presented in Table 5.8 shows a flow of ideas based on significant life events within the context of the thesis's underlying conceptual framework as a lens through which to interpret and make sense of how and why people with UC use particular healing practices including TCAM. The first column shows the relevant life event, the second shows the cultural influence at the time of a particular life event described, the third column displays the recommended healing practice that the participant is *currently* using and the fourth column is the interpretation of how the choice of that treatment relates to perspectives of Self.

Table 5.9 presents the main types of healing practices and their current use by Celine. These are the following healing practices which Celine still uses that are, to some extent, still linked to the original cultural influence who recommended the healing practice to her. The table below separates into two sections, preventive and curative, but these are, in reality, intertwined and used more fluidly.

Table 5-8: Explanatory Model for Celine



**Table 5-9: Preventive and Curative Strategies for Celine**

Preventive	Resting at home	<p><i>“If I <b>want to do stuff on a night</b>, then sometime <b>during that day</b> I’ve <b>got to sit down and have a rest</b>.” “If we’re <b>going out later in the night</b>, <b>after</b> I have <b>tea</b>, then my <b>husband sends me upstairs</b> and I <b>have a lay down for an hour</b> and then go out.” “I have to <b>incorporate a new life style</b>, which <b>fits me</b> cause then I still <b>manage to do things I want to do</b>.”</i></p>
Curative	Using homeopathic remedies	<p><i>“[Homeopathy is] the use of <b>natural elements</b> to create remedies to <b>work alongside and enhance the body’s own abilities to heal itself</b>. If you take an element of an illness, water that element down, you can then use it to treat that illness to <b>kick-start your body</b> into <b>aiding that illness</b> or ailment.”</i></p>
	Visiting her homeopath	<p><i>“I like to class her as <b>my homeopath and a good friend</b> as well”. “She’s been <b>treating me</b> or I’ve been <b>looking to her</b>” and “it’s just the fact that [Homeopathy] is so <b>holistic</b> you have to <b>get more into the person and the illness</b> of that person <b>to get the right thing that works for you</b>”.</i></p>
	Taking Co-codamol	<p><i>“I <b>take Co-codamol</b> and I don’t know if that’s more <b>to keep [pain] at a level</b> or it’s just <b>a placebo effect</b> for me. I don’t know why I still take Co-codamol.”</i></p>
	Using ‘clip-on’ stoma bags	<p><i>“You always have to <b>be prepared everywhere you go</b> cause you never know” cause “your major <b>problem</b> you have is <b>with leakage</b>”. “As new things come out, you try them and they either work or they don’t” and you’re “<b>fiddling about</b> with not just the pouches; there’s all the paraphernalia with it: the sprays, the adhesive removers and the skin protectors”. It’s “<b>a rolling process</b>” “<b>to get more comfortable</b> really”.</i></p> <p><i>“the new [stoma bag] that’s just come out is a <b>click mechanism</b> where you have a plate that you stick permanently around your stoma and then you just click this [plastic ring] round and I’m <b>finding them really, really good</b>. I was a bit dubious cause obviously once you have more than one piece there’s always more scope for leakages but these are really good.”</i></p>

## 5.6 Case Study Five: EDEN

*“[...] you don't want to aggravate the situation for your partner; makes an extra burden. So you often put on a better, braver face than you would normally. You feel a lot. You live a lot inside.”*

### 5.6.1 Section One: Overview of Eden

#### ***Who is Eden?***

Eden is a seventy two-year-old lady with a grown-up son and a “*wonderfully supportive*” husband. Her narrative was taken over the telephone and she came across as kind, sensitive, organised and patient during her interviews. As interviews with this participant occurred over the telephone, it was more difficult to observe their physical characteristics and carriage to make any observations about their person.

#### ***First Symptoms***

In 1962, when she was twenty five years old, Eden went to a GP with symptoms of having to “*go to the loo many times*”. After seeing her own GP, she was referred to hospital where she was prescribed “*drug therapy*” after being diagnosed with Ulcerative Colitis (UC). Eden's son was born in 1964.

#### ***Getting Worse***

Over a period of nine years, her health deteriorated and her consultant gastroenterologist urgently recommended she had an ileostomy. She said she was at this time diagnosed with Crohn's Disease (CD) and that she was “*quite desperate to clutch at anything that might work*”. In 1971, Eden developed an anal fistula and had a “*miserable year*” with great discomfort from “*weeping boils between [her] legs*”, which meant she had to wear sanitary towels and needed a “*rubber ring*” to sit down on because it was painful. She added that she had blood in her stools, needed to go to the toilet often and had pain that she would end up having a “*ghastly appearance*”. She described taking different types of painkillers, self-administered enemas, bulking agents, electrolyte salts and eventually, when things got really bad, Azathioprine (a highly toxic drug) before needing an ileostomy. She described her general health as so poor that it affected her “*involvement in [her] son's formative years*”. She described herself as “*being a mum whose energy levels were not good*” and explained how she sometimes struggled to get her son to school.

In retrospect, she described feeling frustrated at the missed opportunities during this period of her illness, being unable to share in things like attending her husband's degree ceremony and doing “*fun things*” as a family. She added that there was a lack

of understanding and feeling from people in and outside her family who might not have been familiar with the extent to which she suffers with IBD. Even nowadays, she expressed still having to *“live with disappointment on a daily basis”* due to her physical symptoms hindering her everyday life.

### ***Crisis Phase***

In 1972 aged thirty five years old, Eden had an ileostomy. Although *“the experience of surgery was traumatic”*, she *“was very lucky”* to have developed a friendship at that time with a lady whom the surgeon used to get to visit patients in hospital, to be *“the good presentation of the ileostomy”*. As Eden described, the visitor was *“to give [IBD sufferers] a view of what [their] life could be like afterwards and talk to [them] about it.”* Later on Eden described how strange it was to have a stoma bag as *“[she would] never be free of this new ‘friend’”*, which she said *“at first [she] couldn’t bear to look at.”*

### ***Post-surgery***

Post-ileostomy, Eden was worried the stoma bag would fall off. She was *“frightened to death”* and was *“having to concentrate on the ‘new thing’ under [her] clothes”*. In due course, she indicated that she got it *“well managed and became no longer aware of it being there”*. She mentioned having *“thirteen trouble-free years”* and started doing things with her family such as: *“taking [her] son swimming”, “going down lead mines” and “going out into the countryside”*. She was careful of what she ate and got some *“great advice”* from an IBD Support Group meetings, which *“help[ed her] do the best for [her]self”*.

Accepting the ‘new’ Self In 1985, aged forty-eight, Eden started having *“occasional debilitating upsets”* or *“attacks of flux”*, *“churning out watery output”* in [her] stoma bag and having *“terrible feelings of lassitude and lack of energy”*. She described having several tests done over the period of twelve years. These showed *“no recurrence”* of CD; all her test results came back *“satisfactory”*, which was *“puzzling”*. At this point, Eden described having to use large amounts of bulking agents, electrolytes and occasionally taking high doses of steroids and painkillers.

By 1994, she started to suffer from *“really bad migraines”* gradually getting up to *“six attacks a month”*, for which she now takes beta-blockers. Eden then recalled having *“eleven attacks of flux”* in 1996 alone and described these as *“a threat that completely disrupted your life”*, which left her wanting to *“creep into bed”*. Eden described being in an *“absolutely desperate”* and *“miserable”* situation and was advised by a friend, who was also *“a fellow Samaritan”*, that perhaps she would like to visit the same *“Chinese*

*Medicine doctor” her daughter had been seeing, with “remarkable results”. Eden ended up seeing two “Chinese doctors” for Acupuncture and Chinese herbs. She described her experiences as “absolutely brilliant”. While “the process of healing [takes] longer” especially with regard to “the herbs”, Eden added that “if you had the time they are a good, powerful way of ensuring a long-lasting benefit”. Unfortunately Eden and her husband’s “financial situation had changed so drastically” that even though “the actual consultation fee was very modest, it just mounted up”. She had “to withdraw buying all these things”. This she did “with great regret” adding that she “was always very grateful to the Chinese doctors for the help they gave [her], especially at the time that they did it.”*

### **Cultural Influences**

The main cultural influences in Eden’s life directly involved her use of ileostomy surgery and Chinese Medicine (acupuncture and herbs). It was her surgeon, her consultant gastroenterologist and her ileostomist friend who encouraged her to have ileostomy surgery. In contrast, her use of Chinese Medicine arose from a recommendation of two of her Samaritan friends, one of the latter’s children who was familiar with this type of healing practice and, as it elaborated below, her remembrances of her mother using Herbal Medicine and going to a herbalist shop.

### **Healing Practice Pluralism**

During her journey in living with IBD, Eden has used a number of healing practices in a variety of different ways, at particular times, for specific purposes. From her telephone narrative, two particular healing practices (ileostomy surgery and Chinese Medicine) must be highlighted, given that their use represent two major turning points in her life in treating and living with her illness under desperate circumstances. In addition to these, a variety of both healing practices and ways of coping were identified from her narrative, which she took over the many years in living with IBD: *“the old white mixture, Codeine Morph”, “drug therapy” for IBD (including “Prednisolone”, “Azathioprine”, “pretzel enemas” (“self-administered”)), “little gas bottles of Optil Nitrite”, Sando-K, Dioralyte, Bonviva, Timolol, iron tablets and injections, sanitary protection, a pad to sit on, bulking agents (fibre sachets, Celevac tablets, Imodium, Fibre-gel), resting in bed and reading letters written by IBD support group members.*

### **Current Healing Strategies**

Eden uses a variety of healing practices both preventively and curatively for her ill health. Her preventive current healing strategies include: regularly taking bulking

agents, taking Bonviva *“to protect [her] bones”* and Timolol to prevent migraines, *“watch[ing]”* her intake of food and drink, and resting when necessary. She described using her curative current healing strategies when she has an *“attack of flux”*. These include: occasionally taking high doses of steroids for short periods of time for *“really bad attacks”*; using Metronidazole (an antibacterial drug) to *“control this bacteria, which is what [causes] the trouble”*; taking Omeprazole, which *“helps to dry out the output”* in her stoma; and taking supplementary electrolytes. She also said that she occasionally takes painkillers such as Paracetamol and receives physiotherapy for her osteoarthritis symptoms.

## 5.6.2 Section Two: Exploration of Two Decision Points

### ***Decision Point 1: Having Ileostomy Surgery***

Out of all the life events expressed by Eden during her interviews and from her written diary, the first decision point of having ileostomy surgery was described as *“momentous”* and *“life-changing”*. It had and still has a significant impact on Eden’s perspectives of Self, illness and healing. The decision to have ileostomy surgery came at a critical point in Eden’s life when she was in a *“desperate situation”* and her health had deteriorated so much that it was necessary to use this healing practice. The outcome of this healing practice enabled Eden to have *“thirteen trouble-free years”* even though she said she still had to *“watch what [she ate]”* and needed to *“manage”* her stoma and stoma bag.

There are three main life events leading up to Eden needing to have ileostomy surgery.

- Having *“missed opportunities”*

During the first ten years of illness, Eden described feeling frustrated at *“the missed opportunities to go places and to share things”* as well as experiencing disappointment *“on a daily basis, even if [she had] an appointment just to have [her] hair cut; just to do something quite ordinary, [she could] never be sure that it’s going to be accomplished”* making *“life very uncertain all the time”*. This constant *“frustration”*, *“ang[er]”* and *“disappoint[ment]”* was amplified by the fact that Eden could not join in family activities and assume the role of being a mother, after her son was born in 1964. She was not able to participate in her son’s formative years because her *“energy levels were never wonderful”*. For example, when they went out as a family she said she needed *“to sit in the car or in a chair at the side of the car while [her] son, went off with [her] husband and did the fun things and [she] couldn’t join in because life was very difficult.”*

These restricting circumstances seemed greatly to have affected the way Eden lived with her family, in particular, when this involved physical activity like “going down lead mines”, which was her husband’s “passion”.

- “Drug therapy” no longer “doing the job”

Since the onset of her symptoms in 1962, Eden implied that there did not seem to be many options for IBD treatment provided by the healthcare system at that time. Over the next nine years, Eden was “treated with the drug therapy of the time” including “self-administer[ed]... pretzel enemas” and a variety of painkillers. As her health deteriorated, she had to take rehydration salts and sugars and eventually had to have bowel surgery where “little snippets from all through [her] bowel” were taken out. Unfortunately, as her illness worsened to the point of developing an anal fistula, she was “put on Azathioprine” to “clear [it] up”. Her situation had reached a point when her gastroenterologist suggested she have ileostomy surgery.

- Having an “ileostomist” friend

Around the time the consultant gastroenterologist made clear that Eden urgently needed surgery, she described having met up with a friend whom she knew from “a club [she] belonged to”. After telling her friend that she had been advised to have an ileostomy, it turned out that her friend not only was an “ileostomist” herself but that she “was the person that [the surgeon] used to get to visit patients in hospital to sort of be the good presentation of the ileostomy.”

Eden considered herself “very lucky” to have had an “ileostomist” “of [her] very own” describing her as “so supportive” and “very easy to talk to”. This gave Eden a more positive outlook on ileostomy surgery, particularly with regard to the expected body image changes she said she had about this healing practice on the Self. As Eden described, she “just couldn’t believe that this person in front of [her], looking so well and such a jolly person was in fact an ileostomist.”

### **Decision Point 2: Chinese Medicine**

This decision point was selected since Chinese Medicine was the main TCAM method of treatment that Eden used apart from Medicine. Eden’s views on the use of this healing practice emerged when asked about home remedies, habits or ways of coping around healing she may have experienced in her childhood. Her narrative started from childhood memories of inherited methods of care and evolved into comparing these with her experience of using Chinese Medicine.

The impact of Chinese Medicine herbs and Acupuncture on Eden's struggles with CD, *"especially at the time that [the Chinese doctors] helped her"* is something she said she *"was always very grateful"* for. Eden visited two practitioners who originated from China but had to stop her treatment due to *"[her and her husband's] financial situation [which] had changed so drastically"*. This left her feeling *"so powerless to do anything to help [their situation that] the one thing [she] could [do] was to withdraw buying all these things"* alas *"with great regret"*.

There were three main life events that led up to Eden using Chinese Medicine.

- Remembering her mother's use of Herbal Medicine

During her narrative Eden recalled her mother visiting a *"herbalist"* when Eden was a child. She described the experience of going to the herbalists as *"a fascinating shop [that] had got the most gorgeous smells when you went in. It was a small shop and it seemed to be stacked from floor to ceiling with all these containers; beautiful little drawers with all these labels on."* She liked the environment saying *"it was [...] the ringing of the bell when you went in the door and this wonderful smell that greeted you"*. Eden also recollected her familiarity with herbs as a child when her *"mum always used to buy [her] liquorice sticks, not the black liquorice stuff; it was like twigs."* Eden connected these pleasant past experiences of going to a herbalist shop as a child and her subsequent use of Chinese Medicine, saying that the herbalist shop *"was our equivalent of the Chinese herbs when you went to the Chinese doctor."*

- Having *"attacks of flux"*

After having *"thirteen trouble-free years"* following her ileostomy, Eden started having *"occasional debilitating upsets"* at age forty-eight, resulting in watery output, extreme fatigue and lack of energy. Over eleven years post-ileostomy, her situation gradually worsened and she recalled having as many as *"eleven attacks of flux"* in 1996. To make matters worse, Eden also started having *"debilitating migraines"* since 1994, which gradually went up to *"six attacks a month"*.

Throughout these years, Eden continued to have periodical tests but the results came back as *"satisfactory"* with unfortunately no reason as to why she was still experiencing these symptoms. She expressed her frustration by saying: *"you've got this new situation, you don't know what the hell's going off [and] why everything should have changed"*. In consequence, she took *"enormous quantities"* of *"bulking agents"*, occasional steroids again in high doses. She reached a point where she described *"there [was] nothing [she could] do about it but lie back and get on with the medication"*.

The “*puzzling*” nature of this “*awful situation*” added to her frustration and she expressed feeling “*very angry*” and “*alone*” in her suffering.

- A personal recommendation by a “*fellow Samaritan*”

Eden had been a Samaritan for nine years and described having made a friend there whose daughter was born with “dreadful eczema”. The daughter’s “routine care was so difficult... [that] had to be covered in certain creams and special bandages every night” followed by a “period of cortisone creams, which thin the skin”. It was around this time that her friend’s daughter had heard about the first “Chinese doctor” from “a programme on the radio or on the television”, whose clinic was around hundred and fifty miles away. Eden’s friend’s daughter was advised “to cut certain things out of her diet straight away” and take herbs. Her friend described the results as “remarkable” and said that the “Chinese doctor” had “completely cleared this problem for her” and “for the first time in her life, she had this marvellous feeling of being free from [her eczema]”.

It is important to note that, when asked directly whether her childhood experience of her mother’s use of “*our equivalent of Chinese herbs*” played a part in influencing her own subsequent use of Chinese Medicine, she said: “*No, I don’t think so. I think what influenced [my decision to use Chinese Medicine] was my friend who was a fellow Samaritan*”. The fact that her friend’s daughter’s illness had similar aspects to Eden’s struggles with CD influenced her own use of Chinese Medicine, for example, the long-standing nature of the illness, the extent to which symptoms disrupted her life, the problems connected to self-esteem from body image changes and the little success in using medical drug treatment.

### **5.6.3 Section Three: Exploration of Eden’s Perspectives of the Self**

Eden expressed perspectives of Self interpreted as relating to concepts of Body, Mind, Vitality and being a mother. The following analytical explanation illustrates this by extracting information from the data presented in her narrative.

#### ***The Self as the Body***

According to Eden’s descriptions, the Body seems to have the one main characteristic:

#### ***The “big bowel” as a pure object***

Here the Body is something that relates to matter, something that is tangible and reacting at a physical level. Eden uses terms to express her view of her bowel with

mechanistic characteristics, on four occasions as “*plumbing*” and on one occasion as a “*spin drier*”, after her ileostomy surgery:

*“Let’s face it, the big bowel is really a great big spin drier when you think about it because when you’ve got an ileostomy the output into your bag is a much more sloppy mixture. So when it goes into the big bowel, in the normal way, it’s there that the majority of the liquid content is withdrawn.”*

Eden’s use of these more mechanistic terms could reflect views of the bowels as a pure object that can be taken out and ‘fixed’ with surgery, like a mechanic fixing a car and replacing parts of the car’s ‘anatomy’.

### ***The Self as the Mind***

During her narrative, Eden mentioned four emotions that she connected to living with CD.

- Grief aggravating UC

During Eden’s second interview, she mentioned that grief was an emotion that certainly aggravated her bowel but was unsure if it caused her illness as the onset of her symptoms occurred three years after her mother died. Eden said it was the IBD Support Group Journal that suggested grief caused UC and even though she expressed being “*overwhelmed*” by grief after both her parents died, with it being especially difficult for her after her mother’s death, she did not make a connection between the origins of her illness and grief. This perspective of Self as Mind seems to imply that, for Eden, grief has an impact on her CD.

- Other emotions involved in living with UC

Throughout her narrative, Eden also mentioned three particular emotions that seem to have been an expression of how she was coping with her illness: frustration, disappointment and anger. Whether before her ileostomy surgery or after her use and eventual cessation of Chinese Medicine, these emotions kept being mentioned connected to the “*countless things [she’s] missed*” due to being hindered by her physical symptoms. Eden emphasised that these emotions are interrelated with varying degrees of intensity: “*you could say my second name is frustration. Depending on the degree of frustration, sometimes I feel so angry.*” With this perspective of Self as Mind, perhaps Eden was searching for healing practices that would heal not just the Self as Body but the Self as Mind particularly in the case of these emotions.

### ***The Self as Vitality***

Eden mentioned “*vitality*” in her first interview when she described how her “*attacks of flux*” affected her, saying: “*it’s just as if all your vitality goes with [the outpouring from the stoma very, very quickly]. It really does sap your energy and your well-being in no time at all.*” It is not clear what exactly Eden meant by vitality but perhaps her use of the terms “*energy*” and “*well-being*” are what make up vitality for her. Perhaps Eden used this perspective of Self in connection with “*being laid up in bed*” and “*look[ing] ghastly*” on those occasions when searching for healing practices to help her “*vitality*”, “*energy*” and/or “*well-being*”.

### ***The Self as a “Mum”***

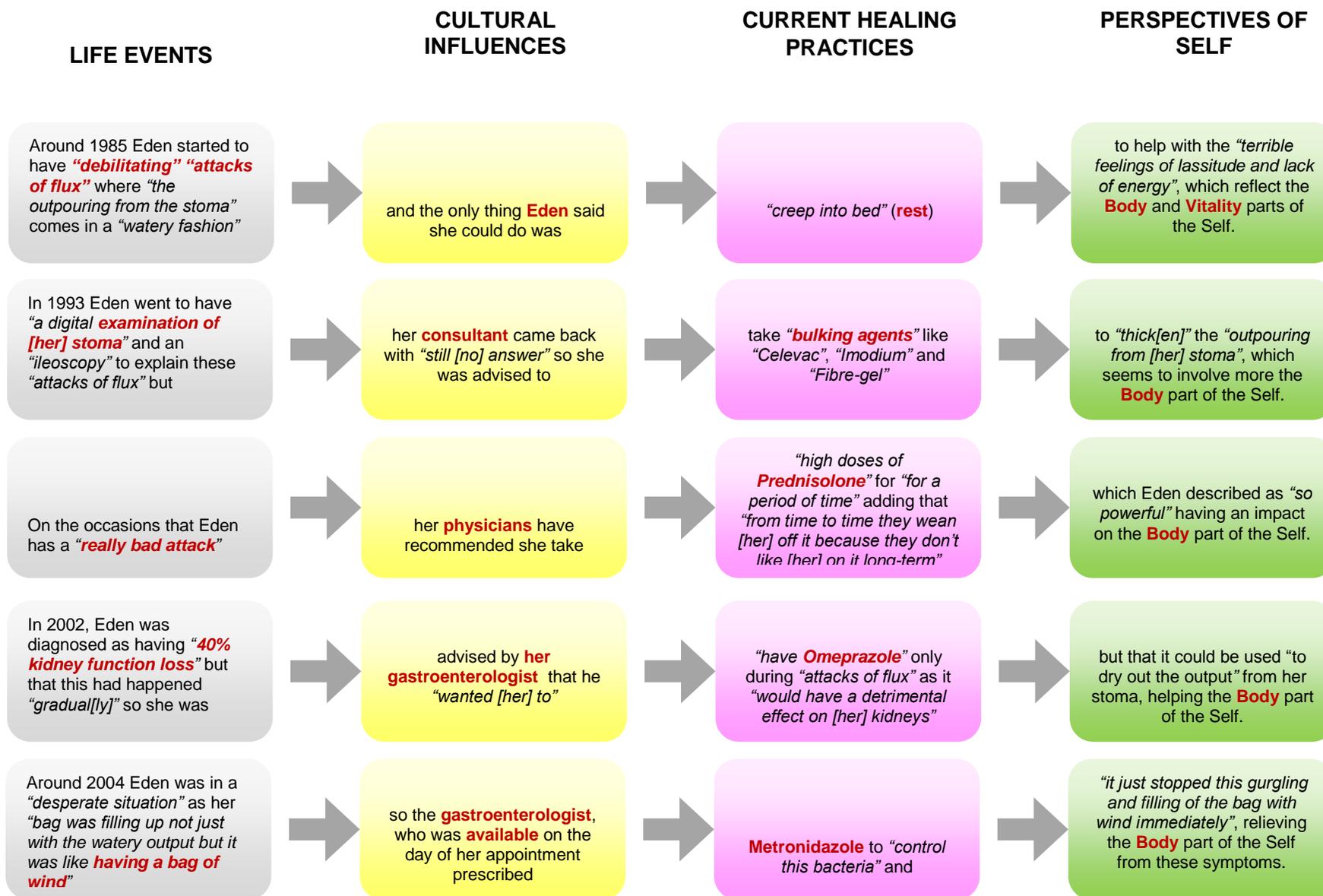
Due to the physical symptoms of illness, Eden described not being able to be the mum she had hoped to be during her son’s “*formative years*”. This was due to low “*energy levels*” that hindered Eden’s participation in her son’s life and family culture, her being incapacitated and unable to join in activities. Eden talked about a “*ritual*” that happened “*everyday*” after the family meal and “*nine times out of ten*”; her son would ask her “*[not to] go to sleep*”. But as she was unable to “*fight it*”, she would “*[have] a nap*” whilst her son “*play[ed] quietly*”. For Eden and her perspective of Self as a “*mum*”, ileostomy surgery might be considered not just as a lifesaving healing practice but also as a social and cultural necessity to enable her to participate in family life.

### **5.6.4 Section Four: Eden’s Explanatory Model and Current Healing Practices**

The explanatory model presented in Table 5.10 shows a flow of ideas based on significant life events within the context of the thesis’s underlying conceptual framework as a lens through which to interpret and make sense of how and why people with UC use particular healing practices including TCAM. The first column shows the relevant life event, the second shows the cultural influence at the time of a particular life event described, the third column displays the recommended healing practice that the participant is currently using and the fourth column is the interpretation of how the choice of that treatment relates to perspectives of Self.

Table 5.11 presents the main types of healing practices and their current use by Eden. These are divided into those which are either more preventively or more curatively orientated, as expressed in her narrative. The current healing strategies presented below are not exclusively preventive or curative but only represent a tendency of ways of coping expressed by Eden during data collection.

Table 5-10: Explanatory Model for Eden



**Table 5-11: Preventive and Curative Strategies for Eden**

Preventive	Resting in bed	"I had occasional <b>debilitating upsets</b> when I would start <b>churning out</b> the <b>output</b> in a <b>very watery</b> fashion and having <b>terrible feelings of lassitude</b> and <b>lack of energy</b> ". "[T]he only thing you can do is <b>creep into bed</b> . It really is that bad."
	Taking bulking agents	During the course of her illness Eden said " <b>food went through [her]</b> at a hell of a rate" and since she <b>had "to slow that down"</b> since after "eating a meal" [her bowel] does "not hav[e] the time to produce the goodness that [she's] going to need", she would need to be " <b>taking a great many bulking agents</b> " to " <b>thick[en]</b> " the " <b>outpouring from [her] stoma</b> ". Eden added: "I'm still taking the <b>Celevac</b> and the <b>Imodium</b> but it's now <b>Fibre-gel</b> that I have to take. I take enormous quantities per day, you'd think I'd be set like concrete but that's far from the case."
	Having to watch what she eats and drinks	"I think it's important that people do eat as well as they can; <b>proper food</b> ; proper things that we're supposed to eat. I'm not talking about people with less plumbing like myself cause we <b>have to watch what we eat</b> because of it causing <b>undue problems</b> . I know my <b>husband's passion</b> [is eating] <b>fruit, vegetables, salad</b> and anything like that so I'm so used to producing those sort of things for meals." Eden added that "if you have <b>diarrhoea and sickness</b> you're <b>not supposed to take milk for at least two days</b> ." "[...] <b>lactose isn't a good thing</b> to have apparently."
Curative	Taking steroids	"[...] if it was a <b>really bad attack</b> , I was allowed to take <b>higher doses [of Prednisolone]</b> for <b>five days</b> . Eden said she also took Prednisolone "on a <b>daily basis occasionally</b> ". Eden added that it was "the <b>only thing</b> that seemed to <b>keep things under control</b> ."
	Taking Omeprazole	Eden said her gastroenterologist "started [her on <b>Omeprazole</b> ] on a regular basis" but "now [she] only [has] to take that <b>when [she has] an attack of flux</b> " "because it <b>helps to dry out the output</b> ".
	Taking Metronidazole	Another gastroenterologist advised Eden "to start taking <b>Metronidazole</b> 400 mg, three times a day" and said this "should <b>control these bacteria</b> that are <b>producing all this gas</b> ." Eden said "it was <b>absolutely dramatic</b> " the way this drug "just <b>stopped</b> this gurgling and <b>filling of the bag with wind immediately</b> ".
	Taking Dioralyte	After an <b>attack of flux</b> Eden said she " <i>always takes <b>Dioralyte</b> for the <b>first 2 days</b>, especially <b>high doses of [it]</b>". Otherwise she said she "<i>takes <b>2 sachets of those a week</b>" to "<b>top up the electrolytes</b>" and "<b>help replace lost water and body salts</b>".</i></i>

## 5.7 Case Study Six: CRISTALLE

*“Someone said that you only get ‘normal’ on a washing machine”*

### 5.7.1 Section One: Overview of Cristalle

#### **Who is Cristalle?**

Cristalle is a white, fifty-three-year-old mother of two daughters, who said she *“couldn’t have got better support from [her] family to [her] doctors”* during her life with UC. She mentioned having a *“really bad history”* of bowel cancer and other bowel problems on both sides of her family. She seemed particularly happy and grateful when talking about the outcome of her illness and treatments, and was looking forward to being discharged with *“a clean bill of health”* a month after her second interview.

#### **First Symptoms**

In 1992 Cristalle’s father passed away and around six months later she *“started to have loose stools and bleeding”*. She said she recalled trying to *“remain strong because [her] mum’s health wasn’t good and [she’d] got two small children that had lost their granddad which they dotted on”*. In retrospect, Cristalle said that *“maybe if [she’d] have broken down, been more emotional and cried more, [and had] let it out that way”*, it would not have been *“coming out in [her] colon”*. She said she thought that the grief from her father’s passing was *“a trigger for [her] condition of Ulcerative Colitis”*. Matters were made worse when she got *“an own-diagnosis medical book, read through the symptoms, compared them and convinced [her]self that [she] had got bowel cancer”*.

After visiting her GP she was *“reassured”* that it was not bowel cancer and was *“sent to hospital”* to see a general surgeon. She had a sigmoidoscopy and was diagnosed with Ulcerative Colitis (UC) in 1993. She was prescribed Sulfasalazine, which she had to stop after a week as she had an allergic reaction to it. She was then *“put on”* Asacol that *“kept [her] condition under control”* for *“quite a while”* even though she had *“little flare ups but nothing too severe”*. She had to change medication after around a year and be *“put on”* Colazine because her general surgeon *“decided that [her] body had got some resistance to the Asacol”*. Aside from this medication she also took steroids orally and intravenously when it was necessary to *“reduce inflammation”* but tried to wean herself off them when possible. She took medical medication for her UC for around thirteen years.

### **Getting Worse**

In late 1997, Cristalle saw the general surgeon because of her *“dramatic weight loss”* and her medication dosage was *“upped”*. In June 1998 the factory where she worked shut and Cristalle started working as a healthcare assistant at the hospital. About a year later, she had a *“flare up”* and was *“quite ill”* with *“bloody, mucus-y stools”*, *“not having control of [her] bowel”* going *“ten to fifteen times a day”* accompanied by the *“embarrassment”* of a *“horrendous”*, *“pungent smell”* thinking *“Oh, can anybody else smell it?”* As she had to wait three months to see the general surgeon, a neighbour and friend of her best friend who had tried Acupuncture for IBS at a Chinese Medicine clinic in a neighbouring city suggested to she try it and see if it helped. She did and it *“improve[d] for a little while”*. Later, as she had *“a [hospital] appointment”*, she stopped both going for the Acupuncture and taking the Chinese Medicine because she *“didn’t feel as though she was getting anywhere”* and felt *“safer”* *“taking medication under the hospital”*.

### **Crisis Phase**

Cristalle was referred to her *“occupational health”* worker at the hospital. This was her *“life saver”* who introduced her to the *“specialist nurse”* who was working alongside a gastroenterologist (a *“great guy”* who was *“very keen and interested in patients with these problems”*). Her medication was changed and she *“felt as though [her] quality of life was improving”* and her UC *“started to get under control”* with steroids.

In May 2002, Cristalle and her best friend started to do their *“nurse training”*. Two years before, Cristalle’s mother was diagnosed with Alzheimer’s, with Cristalle looking after her, but just before the nurse training began, as she *“couldn’t cope”*, Cristalle *“had to put [her] mum into a care home”*. Just after two weeks *“into her training”*, her mother passed away, which Cristalle described as *“another trigger”* to her UC as it caused *“a horrendous flare up”*.

After being in hospital for sixteen days, during which time *“they just could not get the swelling [in her colon] down”*, a doctor explained she would need surgery and a stoma bag. This news *“really frightened”*; the thought of having a stoma bag had been *“a big fear”* throughout her illness, the idea *“mortified”* her. Whether or not *“it was psychological”*, she *“turned a corner”* and *“things started to improve a little bit”*. She came out of hospital in mid-August 2002 and was prescribed Azathioprine. This does not suit her (*“{!} came off it because [her] hair was falling out”*, being told this was a negative effect of the drug), was tried on *“a spin-off from Azathioprine”* (but *“the same*

*thing happened again*) and so she stopped taking any medication ( *“there wasn’t a [great] deal of medication that [she] could take that was suiting [her]”*).

Finally, in September 2005, Cristalle had “*ileoanal pouch*” surgery (*“they removed [her] colon, brought the small intestine out and [gave her] a stoma bag till [her] pouch had healed”*), living with her stoma bag for around twelve weeks. This experience *“just filled [me] with disgust”* because she *“couldn’t get them to adhere”* and there was *“leakage”* with everything *“getting stained”*. She said she thought that having a bag was *“more of a problem” “than the colitis”* because she thought *“at least [she’d] have a bit of control”* but she did not because of the *“leaking”* and *“was very conscious of it”*. She described the *“changing of the stoma bag”* as a *“family meeting”* or *“MDT”* (multi-disciplinary team) with her *“two daughters sat on the bath, [her] on the toilet [and] [her] partner with a hairdryer making the glue sticky so it would adhere”*.

### **Post-surgery**

At the end of February 2006, Cristalle said she had the second stage of her surgery when she *“had it reversed”*, but *“could not tolerate just a bit of water on [her] lips”*, went from sixty-five to fifty-eight kilograms from *“vomiting all the time”* and had *“a lot of pain around [her] stoma site”*. It turned out that Cristalle had *“a small abscess”* because *“a swab”* had been *“left inside [her]”*. In December of 2006, after it was *“cut out”*, she went to see the consultant again and said *“they just seemed to be tippy toeing around [her]”*. She described having a conversation with him and wondered *“whether he thought [she] was going to sue them”* but afterwards said *“you’ve put it right now and I’m grateful”*.

### **Accepting the ‘new’ Self**

Cristalle explained that afterwards it was about *“just building [her] appetite up”*. She had to be *“careful about what food [she] ate”* (bland food and plenty of starch) and drink lots of water. While it had taken awhile to recover from the surgery, she indicated that she *“would recommend [ileoanal pouch surgery] to anybody who has this problem”*. Cristalle said she *“feel[s] very lucky with what [she’s] done and [her] quality of life that [she’s] got now”* as well as having the *“opportunity to have this and not have a permanent stoma or permanent medication”*. Cristalle considers herself to be *“normal”* since having her surgery.

### **Cultural Influences**

Cristalle had quite a few influences around her in the way she lived her life that pointed her towards different healing habits, ways of coping and practices. Firstly, there was her family and the inherited methods of care she observed that they chose to use for

their bowel problems as well as describing that it was her mother who took care of her when she was a child doing *“just what the doctors said”* or taking things *“over the chemist counter”*. Secondly, it was the nursing course, motivated by her daughters’ childhood illnesses, which seemed to have enriched her understanding of medical perspectives of Self, illness and healing. Thirdly, after her father passed away, through *“word of mouth ... from friend to friend”*, Cristalle said she *“went for readings”* finding mediums and clairvoyants that *“they’d had a reading”*. Finally, there was her IBD specialist nurse who worked with her gastroenterologist, with whom she *“discussed the hopeful opportunity”* of ileoanal surgery *“for a good while”*.

### ***Current Healing Strategies***

Cristalle currently uses one preventive healing strategy (diet related, watching what she eats) and two curative healing strategies (drinking more water, and seeing a medium) for her ill health. Cristalle described having *“to be careful about what [she] ate”* prior to her surgery, but currently she *“can eat anything”* she wants. Since her father passed away, she has been *“very into spiritualism”* and has seen six clairvoyants since then, which gave her *“comfort”* and *“reassurance”*.

### ***Healing Practice Pluralism***

Cristalle mentioned using around ten different healing practices, habits and ways of coping in living with UC. These include: resting, around three types of medical drugs (steroids, anti-inflammatory and immunosuppressant drugs), ileoanal pouch surgery and another surgical procedure, Chinese herbal *“concoctions”* and *“tablets”*, Acupuncture, Moxibustion, seaweed pills, modifications to her diet and consulting *“medium[s]”* and *“clairvoyant[s]”*.

Cristalle used surgery as her main healing practice to *“get rid of [her colon]”*. Prior to this, she used medical medication to *“control”* her UC (it felt *“safer”*) but expressed understanding that taking drugs on a long-term basis *“did have an effect on your liver”*. During the time that she had to wait for a referral to see a gastroenterologist at her *“worst point”* in UC, she was *“trying to find something to help [herself]”* and so went with her best friend’s neighbour’s suggestion of trying Acupuncture, ending up having Moxibustion and Chinese Herbal Medicine (which *“probably did improve [her UC] a little bit”*). By the time of the interview, she no longer was using a TCAM healing practice.

## **5.7.2 Section Two: Exploration of Two Decision Points**

### ***Decision Point 1: Having “Ileoanal Pouch” Surgery***

This decision point has been selected as it stands out as one of the major turning points in Cristalle's narrative concerning the way she lived with, managed and as a result of this surgery, eradicated her Ulcerative Colitis. As a child, her mother cared for her using mainly Medicine, reinforced by the way other family members had been using Medicine to treat their *"bowel problems"*. It seems plausible to infer that these inherited methods of care as well as her own interest in becoming a nurse influenced her perspectives of Self, illness and healing with quite a resolute view that Medicine was the *"safer"* healing practice to treat her UC compared to using Chinese Medicine.

The following life events, happening over a 13 year period from her UC diagnosis, are the main contributing factors leading up to her opting to have ileoanal pouch surgery. The analytical descriptions below link to cultural influences in Cristalle's life as well as her Perspectives of the Self, illness and healing that changed in the course of these events.

- Medication was not *"suiting"* her

Over the years when Cristalle had UC, she took a variety of medical drugs, but at some personal ill-health cost. She experienced allergic reactions to Sulfasalazine ( *"after about probably a week of taking it"*) and *"put on Asacol"*(*"[this] was okay for quite a while [as] it kept the condition under control"*). Over time, she developed resistance to Asacol and put on Colazine. In general, Cristalle could over tolerate steroids, but she was told she *"[couldn't] go on as [she was] with steroids"* as *"[they're] going to start damaging other things"*. She began to wean herself off these, reaching 40 mg. But then her UC *"would flare up so [she'd] be back on 40 mg"*, which is *"how [she] was for like three years"*. She also had side-effects from Azathioprine (her hair starting to come out) and then was put on a *"spin-off from Azathioprine"*.

Cristalle described to what extent her situation worsened by saying that the neighbouring town's hospital *"did a lot of searches, testing medications on Ulcerative Colitis to see if there was another tablet [she] could try that would suit [her]"*. In summary, this combination of drug-related factors contributed to her thought to *"get rid of [her colon]"*; she was *"not [need to be] bothered anymore about medication"*; having surgery would *"hopefully be an end to it"*.

- Becoming a nurse

Throughout their childhood, Cristalle's daughters *"were always poorly"* (one with eczema, the other asthma) and Cristalle used to sit in hospital with them thinking *"[she'd] love to come and work [there]"* in the children's ward. There were two main reasons influencing Cristalle's use of surgery, which related directly to her experience

in becoming a nurse. Firstly, it enriched her encultured knowledge of Medicine. Secondly, studying nursing and doing the exams added stress. She described having “flare ups” due to “emotional” “triggers” from the “stress and being in university and doing exams” after thirty two years since leaving school “with minimum knowledge”. Cristalle emphasised that it was when she “had the opportunity to unwind” from “doing [her] school work” that she “became ill” as well as “worrying that [she] wasn’t retaining [her] knowledge” and not feeling “cheeky enough to ask for further” “extensions”.

Cristalle’s confidence in medical healing practices and services was reinforced by her studying nursing. Nevertheless there seemed to be a lack of confidence in her abilities to deliver her knowledge in the time she had whilst living with UC particularly just after losing her mother.

- Not “getting anywhere” with Chinese Medicine

After graduating and having worked for “roughly about a year on the children’s ward”, Cristalle “had a flare up and was waiting to see [the general surgeon] again” but “it was a three-month wait” and even though she “tried to pay privately”, “he didn’t do private”. So she resorted to taking her friend’s neighbour’s advice and tried Acupuncture at a polyclinic in the neighbouring town. She also described having Moxibustion as “this little square thing that [the Chinese practitioner] used to place on [her] tummy” that “reminded [her] of the end of a cigar” that “used to burn”. She also took “Chinese concoctions” that she described as “the most disgusting potion [she’d] ever put into [her] system”. She said that “initially [she] did improve for a little while” but thought she “wasn’t getting anywhere” and “felt safer that [she] was taking medication under the hospital”.

### **Decision point 2: Getting “Readings”**

This decision point has been selected as it was one of the only non-mainstream healing practices that could be considered as having a healing influence on Cristalle. Cristalle decided to use “medium[s]” and “clairvoyants” ever since her father passed away in 1992. The relevance to this study is her continued use of this practice and how it reflects her perspectives of Self as Mind and Spirit in getting “readings” for “comfort” and “reassurance”, especially when she was “griev[ing]” for her parents.

It is important to note that, although Cristalle was recruited to the PhD study to explore how and why she came to use Chinese Medicine, she seemed reluctant to talk about it at any depth, making it clear that the experience of using, especially, Chinese Herbal Medicine “disgust[ed]” her. Whilst being gently probed to elaborate on her use of this

healing practice she said *"you are opening too many wounds"* adding that *"I don't think I would recommend it because it didn't do anything for me so it wouldn't be any point me saying 'go for this'."*

There were three main life events that led up to Cristalle getting *"readings"*: Firstly, there was grieving *"properly"* for her father. She indicated that it was *"definitely emotions"* that *"trigger[ed] [her] condition of Ulcerative Colitis"*. When her father died, it was *"just a shock"* at *"how quickly [her] dad went"*. She *"didn't grieve properly for [her] dad"* because she was *"too busy worrying about her mother and 'being strong for [her] girls cause they were very close to their granddad"*. She described the *"grief"* *"build[ing] up inside [her], like stress, instead of crying", "shouting", "screaming" or "getting upset"*. She acknowledged that *"maybe if [she] had broken down and been more emotional, cried more"* and not *"bottling it up"* she *"would've let it out that way instead of it coming out in the colon"*. This presents a perspective of Self as the Mind in that her emotions, primarily grief, that were embodied and manifested into UC symptoms and signs.

Secondly, there was knowing *"group[s] of people"* getting readings. A year after her father passed away, Cristalle came into contact with different *"groups of people [she] mingled with"* *"at work"* and later *"at university"* when studying nursing, who *"had a reading"* and sharing their experiences of going to *"medium[s]" or "clairvoyant[s]"*. She said *"telephone numbers"* and descriptions of information from readings are spread *"from friend to friend"* through *"word of mouth"*.

Thirdly, there was *"put[ting] mum into a care home"*. Cristalle had been looking after her mother until six months before she was to start the nursing training. She said she *"couldn't cope"* and *"had to put mum into a care home"*. Just two weeks *"into her training"*, her mother passed away, which caused *"a horrendous flare up"*. In retrospect, when comparing her *"being very fortunate"* in the outcome of her UC with others who have *"probably had a bad deal"* and *"don't get the satisfaction that [she's] come across through [her] illness"*, she pointed upwards and said *"someone's looking after me"*.

Cristalle said that ever since her father passed away, she has been *"very into spiritualism"* and since the loss of both her parents said *"they're both up there"*. She repeated that going for readings was *"just a bit of fun"* and that she has had *"doubts whether [her parents] have been there [during readings] but more often than not there is some part of the reading that gives [her] proof that they are around with things that*

*have been mentioned*". In this case the perspectives of Self involve both Mind relating to emotions being embodied and Spirit pertaining to non-corporeal substance.

### **5.7.3 Section Three: Exploration of Cristalle's Perspectives of the Self**

Cristalle expressed perspectives of Self interpreted as relating to concepts of Body, Mind and Spirit. The following analytical explanation illustrates this by extracting information from the data presented in her narrative.

#### ***The Self as a System***

It is difficult to know exactly what Cristalle meant when she referred to her System but there is enough data to infer the inclusion of a physical Body that is personified as reacting to emotions, thoughts and feelings in the Mind and Spirit as a non-corporeal substance. She used words such as: flare up(s), the condition of UC, my/the condition, my UC or 'you've got colitis/the colitis', and this/the disease or 'it's a disease.'

#### ***The Self as the Body***

Cristalle referred to the physical body several times during her narrative using different terms. This perspective of Self as Body using different terms could possibly link to more mechanistic healing practices in treating UC. Three examples are provided:

- *"My body"*

Cristalle talked about her body when explaining why she had to stop taking Asacol and start taking Colazine: *"my body had got some resistance to the Asacol and I was put on Colazine."* Here the context is medical drug treatment and the advice she was receiving about how to adapt that healing practice to her needs, which from a medical perspective, involves the Self as the Body.

Cristalle also mentioned the term 'body' when describing her family's reaction to discussing potential ileoanal pouch surgery: *"[...] they just said 'whatever you want to do, we are here for you. It's your decision. It's your body'".* In this context, Cristalle is discussing the possibility of ileoanal pouch surgery, which she said changed her life and contributed to her perspective of the Self as *"normal"* by saying *"it's just 'normal'".* *[Laughs] Somebody said 'you only get normal on a washing machine'."* It seems her and her family's inherited methods of care as well as the language used to express these are taken from medical perspectives of illness and healing with more mechanistic terminology.

- *“My colon”*

This is another way in which Cristalle referred to the Self as Body using the anatomical term for that part of her body that was *“disease[d]”*. She used this term when talking about her experience in being hospitalised for 16 days during the critical phase of her illness when she was being faced with a *“big fear”*; having a stoma bag. *“They just could not get my colon; the swelling down. [The doctor] thought my colon would go...”*

- *“My system”*

Cristalle used this term in two contexts, both concerned with the physical digestive system. In the first case, Cristalle talked about the healing practice of Chinese Herbal Medicine *“the most disgusting potion I’ve ever put into my system”*). In this case, her system may include something more than the physical digestive system. In a sense as if she did not want to be scarred again (involving Self as Mind) by the experience of *“gripping over the sink”* and having to *“shove [a] mint in”* after swallowing the *“concoction”*. The second context in which Cristalle used this term was when she described losing a lot of weight from having UC: *“if you are eating and it’s going straight through your system and you aren’t benefitting from the food, you do get weaker”*.

### ***The Self as the Mind***

There were two main areas mentioned that were interpreted as Cristalle’s perspective of Self as Mind. The first related to *“bottling up”* emotions. Cristalle talked about emotions being *“built up inside you”* from *“being strong”* and not expressing emotions, in particular *“grief”*. The context of this ‘pent up’ grief happened after Cristalle’s father passed away, which she said *“was a trigger for [her] condition of Ulcerative Colitis.”* The second was her comment that UC *“[is] stress-related”* – Cristalle said she *“[does] believe [UC], in [her] case”* *“[was] stress-related”*. She described *“being in university and doing exams”* as *“stressful”* especially as this happened *“thirty two years later, trying to sit exams with minimum knowledge”* compared to *“young ones today like [her] daughters”*.

In perceiving the Self as Mind, in relation to emotions and stress being embodied into the colon manifesting as the “condition” of UC, it seems likely that Cristalle would want to search for an environment in which to *“let [these emotions] out”* especially related to her parents passing away.

### ***The Self as Spirit***

Cristalle mentioned believing *“there is a God but [that she doesn’t] go to church unless it’s an occasion”*. She said *“the only time that [she’s] prayed”* is when she *“went down”*

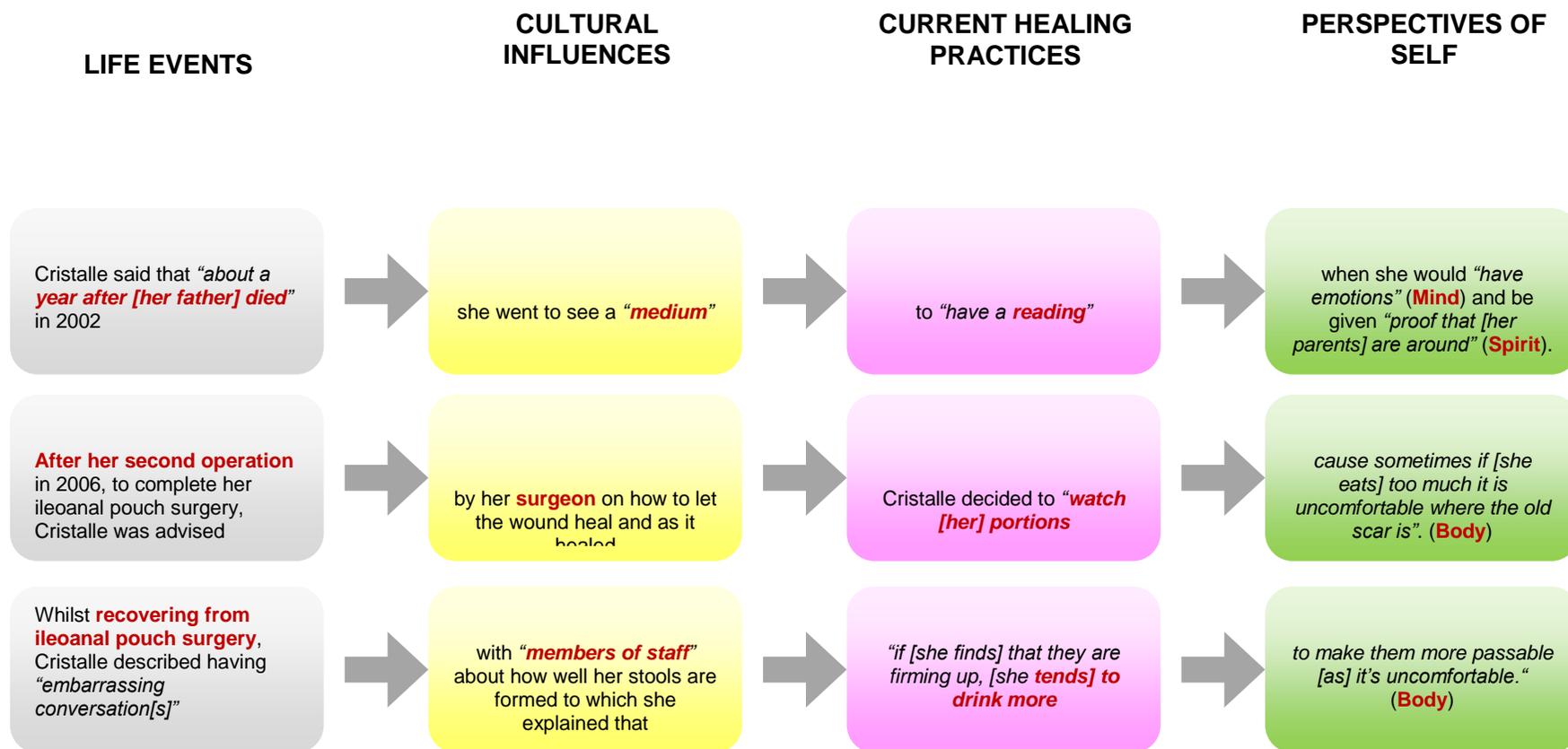
and “used to say ‘please God make this pain go away’.” This perspective of Self could be interpreted as pertaining to Spirit although there was no mention of a ‘soul’ in the religious sense. However, when describing being “*very fortunate*” and feeling “*very lucky with what [she’s] done and [her present] quality of life*”, she pointed upwards and said “*someone’s looking after me*”. When asked what she was implying, she said “*I’m very into spiritualism and when my dad passed away*” “*I always think ‘oh, he’s looking after me’, or well my mum now, or they’re both up there*”. This can be interpreted as the Self as Spirit relating to a non-corporeal substance that can be communicated with.

#### **5.7.4 Summary: Cristalle’s Explanatory Model and Current Healing Practices**

The following explanatory model (Table 5.12) shows a flow of ideas based on Cristalle’s life events that have been constructed within the context of the thesis’s underlying conceptual framework as a lens through which to interpret and make sense of how and why people with UC use particular healing practices including TCAM. The first column shows the relevant life event, the second shows the cultural influence at the time of a particular life event described, the third column displays the recommended healing practice that the participant is currently using and the fourth column is the interpretation of how the choice of that treatment relates to perspectives of Self. These represent the active steps Cristalle has taken to keep connected to her parents as well as using coping mechanisms in living with her ‘new’ digestive system excluding a colon, post-surgery. These have been made possible by the trial and error in the lived experience of what makes her uncomfortable and what ways of coping have been put into place to give Cristalle the best “*quality of life*” after ileoanal pouch surgery.

Table 5.13 presents the main types of healing practices and their current use by Cristalle. Although Cristalle said she no longer has UC, the following healing practices, ways of coping and habits have been incorporated into her way of life for particular reasons but tend to be used *more* preventively or *more* curatively. In the case of ‘seeing a medium’, this way of healing has been put into the ‘curative’ category as initially Cristalle used readings after her parents passed away and now visits mediums roughly once or twice a year.

Table 5-12: Explanatory Model for Cristalle



**Table 5-13: Preventive and Curative Strategies for Cristalle**

Preventive	Watching her portions	Although Cristalle said she “can <b>eat anything</b> ” she added “I <b>watch my portions</b> cause sometimes if I <b>eat too much</b> it is <b>uncomfortable</b> where the <b>old scar</b> is”.
Curative	Drinking more (water)	“I won’t say [my stools are] ‘normal’ because you’re <b>still quite watery</b> . [...] ‘how I’m passing and going to the toilet now, I’m <b>happy with its consistency</b> .’ I think I’d feel <b>uncomfortable if</b> it were any <b>firmer</b> . If I find that they are firming up, I <b>tend to drink more</b> anyway to <b>make them more passable</b> ”.
	Seeing a medium	“I think it’s for <b>comfort</b> and <b>reassurance</b> [...]. The statements they gave you [...] used to be <b>emotional</b> and <b>funny</b> . [...] it’s just <b>a bit of fun</b> the reading [...] it’s not life or death.”

## 5.8 Case Study Seven: CHARLIE

*“After I had Crohn’s Disease, I couldn’t take any stress at all ...If I had a little bit of stress, just say a household bill really, I’d have to run to the toilet.”*

### 5.8.1 Section One: Overview of Charlie

#### **Who is Charlie?**

Charlie is a sixty four-year-old white man who said he was *“a really nervous kid”*. He *“remember[ed] having diarrhoea then”* and compared it to *“kids [who] tend to wet the bed”* when *“their parents are arguing”*. He said he *“was close”* to his sister who was *“nine years older than [him] and was like [a] mother [to him]”* because his *“mother wasn’t there half the time”*. Charlie described feeling *“very angry”* and *“guilty”* that his *“mother [was] married [and] she’d been going with this fellow, five years before [his] dad died”*. Unfortunately Charlie’s *“dad had emphysema”* and he remembered that he *“had to do everything for him”*, *“was really streetwise at thirteen”* and *“was never really at school half the time”*, adding *“that’s why [he’s] not really academically bright”*. At eighteen years old, he started *“doing concrete floors”* and then *“worked for a firm”* delivering *“coach windscreens”*, as well as working *“for a courier firm for a while”*. After being made redundant in 1989, he *“thought [he] would try it out on [his] own”* and became *“self-employed”* for a few years but said it was *“really stressful”*. Charlie said he *“got married in ‘69”*, had a daughter born in 1970 but *“was divorced in ‘89”*. At the end of the first interview Charlie said he *“appreciate[d] [me] listening to [him] actually”*. He seemed sensitive and *“laid back”* whilst presenting his narrative albeit wanting to stop recording once and needing the toilet a couple of times.

#### **First Symptoms**

Charlie said *“it all started in 1994”* one morning when he was *“on a delivery”*. He had been told to not *“get [to the depot] too early [to] let the other drivers get away first”* and, since he had to wait, he *“thought [he’d] have [his] breakfast before [he] went into the depot to load up”*. There was a *“chucky wagon”* there so he *“had this breakfast in a bun”* with a *“sausage”* that *“felt really cold”* and *“didn’t taste right”* but he *“didn’t take too much notice of it”*. Later, after the morning’s work, *“the chap in the depot ...a mashing from home: like tea and sugar mixed together and he’d got some milk in a bottle”*. But *“it had gone off because there was little bits floating on top”*. He drank some of it, and then *“two days after that [he] was getting terrible pains in [his] stomach and [he] was being sick [with] complete diarrhoea”*.

Charlie “*went to the doctor’s*” who told him he had “*gastric enteritis*”, gave him some pills to take over the weekend and to “*just take fluids*”, adding “*[he’d] be right as rain by Monday*”. But he “*was still the same by Monday and in fact [he] was worse*”. This went on for another week. He described getting “*really desperate*” as “*everything [he] seemed to eat or drink just seemed to go straight through [him]*” and he said he “*[got] to the point where [he] was trying [to] starve [him]self*” to “*get it out of [his] system*”. Finally, “*eight days afterwards*”, as he “*couldn’t stand the pain anymore, [he] was bloating and feeling sickish*”, he went to see the emergency doctor at an all-night service, but she “*[didn’t] really know what to give [him]*” because “*[they] could be firing stuff at [him] and [they didn’t] know what it is*” so he was advised to “*go back to [his] doctor*”.

### **Getting Worse**

Things just got worse. “*It was getting up to fifteen days ...the pain was so awful ... and [I] had to ring an emergency doctor*”, who then rang for an ambulance. As it was a holiday period, at the hospital “*they couldn’t send the stools away*”. This experience of waiting for a diagnosis was “*really weird*”; “*he was drained*” and “*when you don’t know what’s happening to yourself and trying to, your mind can go [a]mok*” adding that he “*thought [he’d] got a growth actually at the time*”. He mentioned “*just drinking milk*” but “*when you have complete diarrhoea*” and are “*going to the toilet at least ten to twelve times a day*”, it makes the “*little hairs on your intestines*” get “*washed away*” so “*there’s nothing for the food to cling on to*”. He said “*they put [him] on a ward and finally diagnosed [him] as having [Campylobacter]*”. But “*[he] still had all these pains and ... diarrhoea*”.

### **Crisis Phase**

Charlie was “*shifted to another ward under a doctor [at the hospital] [who’s] a consultant for [the] bowel and digestive system*”, who “*started to give [Charlie] steroids [20 mgs every day]*” but “*they just wasn’t doing any good*”. By then Charlie had been “*in hospital for a full month*” and “*went from thirteen stone ten to eight stone in seven weeks*”. His “*friend thought [he’d] got cancer*”. Though “*cured*” of the campylobacter, “*what it left [him] with, was [his] bowel had blown up like a case ball and they were frightened of it bursting*”. He was very weak, unable to wash or go to the toilet himself, and needed to be fed intravenously “*because [he] was losing at least a pound and a half [to] two pounds a day*”.

He described a visit from *“the Mister, which is the Knife Man”* who told him *“[they were] gonna have to operate”* but Charlie said he *“[didn’t] want [him] to operate because [he] fe[lt] too weak to take this operation”*. He said the doctor described how they would operate and that he *“might have a colostomy [bag]”*. Charlie said he *“couldn’t accept that really [and] just cried”*. He was told *“[they were] gonna leave it for a few days” with the doctor saying they “need[ed] to get some protein into [him]”*. So Charlie said they *“sen[t] the dietician up to see [him]”* who said *“[he was] gonna have to try [and take] at least nine [112 mg supplements] a day”*. Gradually, he put on some weight (*“started to put on a pound”*) but he *“still had the pain”* and needed *“to have an epidural every night for the pain on [his] back side”*. One night when Charlie was in pain he described thinking: *“I’m going to beat this. I am. I’m not going to have that operation.”*

### **Recovery**

Charlie said he *“always remember[ed] [his] first solid meal”*, which was *“some chicken”* that unfortunately *“made it worse”* again *“so [he] had to go back on the forty sips”*. This recovery period was *“awful”* because he was in pain and had to have examinations where the doctor *“put his stethoscope against [his] stomach to see if the bowel were working”* and *“hear when it was gurgling”* as well as having *“cameras up [his] backside”* and *“down [his] throat”*. He described these life events as *“a personal thing”* given that he also had *“diarrhoea”* and explained that he *“just felt [he] just wanted to die”* and *“did feel at one point that [he] was gonna die with being so weak”* but put these thoughts down to *“how [he] was feeling in [him]self at the time”*. Then one day, *“they used to give [him] pure peppermint to try and make [him] burp”* adding that he *“[didn’t] know what happened but the pain just [came] away from [him] like in a wind and [he] thought it was a miracle actually because [he’d] been getting all this pain”* and since *“then [he] started to recover”*.

### **Accepting the ‘new’ Self**

Being in hospital for four months led to Charlie feeling *“institutionalised”*; he indicated that he *“didn’t want to come out because it was a safe house”*. As he *“started to put on weight and feel a lot better [and] stronger”*, and the hospital indicated he could go out *“[on] the weekend ... [he] wanted to look at [his] flat”*. A friend picked him up who *“was used to driving JCB’s diggers and drove really slow”*, which made him *“so scared”* that he *“just couldn’t explain to anybody, what it was like to see this traffic”*. One way Charlie described himself was by saying *“what happened to [him was] when [he] did come out [of hospital], [he] came out very, very, very psychic; it was really, really funny”*.

### **Cultural Influences**

Charlie has had several cultural influences contributing to decisions to use a variety of healing practices. When he was initially ill with food poisoning, Charlie was advised by his G.P. To “[not] eat anything” and “just take fluids”, which is a way of coping he still uses when he has “flare ups”. After his diagnosis with CD in hospital, he said he was told “[he’d] be on these tablets [Mesalazine] for the rest of [his] life”. Charlie also said that “[he] used to have some steroids at home but [he doesn’t] anymore” and that “if [he is] that bad [he] go[es] to the doctor’s [G.P.]”. He explained that “after [being discharged] [he] had to watch what [he] ate” and was advised by a dietician “to avoid all pulses like beans [and] peas” as well as “spicy foods and alcohol” but he humorously said “[he] didn’t take much notice [concerning alcohol] actually”. After his sister passed away from bowel cancer, he described going to a course “about living with pain”, which introduced him to his community centre course where he took “relaxation classes” and learned “skills for life”.

### **Current Healing Strategies**

From his narrative, it was evident that Charlie uses over ten healing practices for various ailments. Those used in helping him cope in living with CD are: resting, taking Mesalazine and “watching what [he eats]”, all being used more preventively to avoid getting “flare ups”; and taking steroids, stopping eating and relaxation, being used more curatively when he feels he is getting a flare up. Charlie explained that he normally tries “[not to] do anything strenuous ... like watch telly” and said he takes “Mesalazine tablets” to avoid his CD “blow[ing] [his] bowel up”. He is careful with his diet “cause [he] used to get wind” and said “[his] Crohn’s doctor has told [him] that if [he] get[s] it really bad, to ask for steroids”. When Charlie said he “used to get these pains in [his] stomach again”, he explained he “used to go to the toilet and then used to lie on [his] bed” and “relax [his] bowel”, which would make the “trapped wind” “just come away from [him]” and “then [he’d] be alright”. Although it does not seem to be something Charlie does very often, “after [his] sister died in 2003”, he went with “another friend of [his]” to “the spiritual church” adding that he “used to get some nice messages”.

### **Healing Practice Pluralism**

Charlie has used several healing practices, some more curatively or others more preventively, depending on the particular context. For example, since his first symptoms, resting is used as a way of coping to recuperate energy physically by not “do[ing] anything strenuous”, “just relax[ing]”, “watch[ing] telly” or “go[ing] to bed”. If his

condition were to worsen, he would use different healing practices (steroids and relaxation) to subdue inflammation and cope with symptoms like “*diarrhoea*” and/or “*terrible pains in [his] stomach*”. In this way, Charlie considers his environment and the cultural influences in it in order to strategise which healing practices to use, when and for what purpose.

### **5.8.2 Section Two: Exploration of Two Decision Points**

#### ***Decision Point 1: “Not Going to Have the [Bowel] Operation”***

This decision point has been selected as it represents a life-changing event for Charlie. It arose early on in his experiences with CD, leading to his determination not to go with the mainstream medical recommendation of having bowel surgery during a critical phase of ill health.

It was after several “*awful*” experiences in hospital care that Charlie said “*[he] just lay there one night*” wondering if “*[he was] going to ask for another injection*” as “*[he] couldn’t stand [the pain] anymore*”. At that point he explained that “*[he] thought: I’m going to beat this... I’m not going to have that operation*”. During this period, he said he “*felt [he] just wanted to die*”. But suddenly, “*the pain just left [me]*”. He said “*it was like trapped wind*” that had “*just come away from [him]*”.

The following points illustrate the life events that contributed to leading up to Charlie’s decision not to have a bowel operation.

- “*Feel[ing] too weak to take this operation*”

After being “*cured*” of campylobacter, the doctors in hospital told him “*they were frightened of [his bowel] bursting*”. He described reaching the point when he was unable “*to wash [him]self in the sink [because he] was that weak*” and was “*losing at least a pound and a half [to] two pounds a day*” and “*[they were] gonna have to operate*”. They told him “*[he] might have a colostomy [bag]*”. He said “*[he] couldn’t accept that*” and “*just cried*” telling the doctor “*[he didn’t] feel that [he] could go through [with] this operation [because he] fe[lt] too weak*”.

- “*Get[ting] some protein into [him]*”

Agreeing to “*leave it for a few days ... [and] try and experiment with [him]... to get some protein into [him]*”. The dietician came and asked him “*[to] take some of these forty sips*”, explaining that “*they’re supplements that they give to old people*” and “*come in vanilla, strawberry or chocolate*” with “*no lactose in them*”. He was recommended “*to try at least, working it out by figures, [to] take nine of these a day*”.

This seemed to give Charlie a challenge which he could accomplish for himself in order to gain weight and strength. He described his strategy to taking these supplements: *“they got a supply [of supplements] in different flavours”* but *“after a while [he] got the taste for this vanilla”* and kept *“[his] own supply and put it in a cupboard”*. His weight levelled off (*“ [I] started to put on a pound”*). He joked that *“[he] was gonna die of vanilla poisoning!”* After he had gained more strength and weight, he gradually tried to eat solid foods, interspersed with *“the forty sips”*, waiting till his condition stabilised. He was determined to get better by strengthening his body.

In this case, Charlie seems to have observed the Self and determined that his body was so weak that he might not survive an operation. Ever since his food poisoning diagnosis and treatment, Charlie has been mostly following what medical professionals have advised but after reaching this critical point he seemed to want to become more autonomous in his choice of healing practices.

### ***Decision Point 2: Taking “Skills for Life [...] Classes”***

Although this decision point does not represent any particular healing practice, it expresses the choice made by Charlie in finding a context where healing takes place not just on a physical level but more on a social and psychological level. This decision point represents a turning point when Charlie was introduced to a number of TCAM practices within a socialising context.

In November 2008, Charlie attended the ‘Skills for Life’ set of classes which was offered free at his community centre. He indicated that he *“liked everything about it ...all the practical and physical things ...Meeting people [...] was a good thing”*. Charlie explained how he experienced various TCAM healing practices, in taster (*“half an hour sessions”*): Acupuncture, Reiki, Reflexology, Massage, Yoga, Homeopathy and relaxation sessions. He described *“feel[ing] really good about [him]self”* as he had *“done something positive in [his] whole well-being for a day so [he] felt good”* as well as having done *“something positive to make [his] life a bit better”*. Charlie said he *“used to look forward to coming and making an effort to come [on]”*. After the classes were over, he had the option to get in contact with practitioners to arrange for private treatment. He concluded by saying that *“[he] just feel[s] sometimes that [he] keep[s] going to somewhere and it’s the same old thing all over again”*. He *“wanted to feel like [he] had moved on from that”*, which is why he took part in this six-month programme that *“help[ed] [him] to keep on looking for things [so he could] get [on with his] life”*.

The following points represent the life events Charlie considered, including cultural influences, which guided the way he perceived the Self, leading up to his decision of attending the free *“skills for life classes”*.

- *“Bec[oming] depressed”*

Charlie indicated that the *“worst”* for him *“between ’94 and ’96”* was *“depression”*. One leaving hospital in 1994, he described *“bec[oming] very depressed”* about several life events. These include his *“divorce in ’89”* and his feelings when losing his sister (while *“relieved that she wasn’t in any pain again”*, *“it all [brought him] a lot of trauma”* including *“having to sort things afterwards”*), the flare-ups he experienced (it would *“just catch [him] out”* and he would *“have to wear pads sometimes in case [he] couldn’t hold it to go to the toilet”*), his lengthy four-month hospital stay (describing it as making him *“institutionalised”* but also as *“a safe house”*) and his subsequent *“living in a church”* (*“[this] was very depressing in itself really”* as it was *“renovated and was really small”* with *“little windows”* from which *“[he] couldn’t see out”*).

During this time, he *“couldn’t work, was reliant on benefits”* and remembered a time when he *“used to sit in [his] flat in the dark because [he] had no money”*. He added that *“go[ing] for the rigmarole of claiming”* like going to *“tribunals”* and *“all-work test[s]”* was *“stressful”*. Charlie explained that this *“pressure”* was something *“[he] couldn’t take any[more] at all”* after the onset of his illness and that even *“a little bit of stress”* like *“a household bill”* would make him *“run to the toilet”*.

Charlie described his illness as *“a disease”* or *“a nervous reaction”* and said he has been *“struggling”* in *“finding himself”*. He indicated that *“if [he] hadn’t got anything to worry about [he] would find something to worry about”*. He described how his illness had developed *“as the Crohn’s went away, then became Colitis and [...] now it’s sort of IBS”* albeit *“still hav[ing] flare ups but not as frequent[ly]”*.

All these life events *“accumulat[ed]”*. Charlie went *“to see a psychiatrist”* and got *“antidepressants”* and *“at times [he] felt [he] was walking around like a zombie”*. He was told by a physician that *“when you get a chronic illness”* sometimes *“you get something else chronic as well”*. He described *“fe[eling] suicidal and decided in ’96 to try and get out of where [he] was [living]”*. He said he moved to *“another area where [he] had a few friends”* and it *“made [him] feel a lot better but [he] still was depressed”*.

In summary, it seems that Charlie was searching for a way to come out of his depression and find new ways of coping with life in a more positive manner, which could have made him more receptive to these *“skills for life classes”*.

- *“Living with pain”*

Throughout his illness, one of the main symptoms Charlie has had to live with is pain, pains in his stomach and his backside, and relating to his back and neck. When he gets “*flare ups*” he still experiences these pains which he relates to “*trapped wind*”.

Around 1996-97, Charlie had a “free assessment” with his gastroenterologist and was “suspected of having” spondylitis after getting “pains in [his] shoulders and mostly [in his] fingers [which were] getting numb”. But “it got worse and [he] couldn’t keep [his] balance ... more or less isolating [him]self ...[and] having problems walking”. He saw a neurologist, had X-rays and two lumbar punctures and then was told he had to have an operation “or else be in a wheelchair in two years’ time”. Charlie had surgery on his neck in 2000; even though “the operation was a success”, “the outcome wasn’t” as it “didn’t do [him] any good”. Subsequently, he was referred to the specialist pain clinic at the hospital, had some physiotherapy and offered another operation, which he refused (“[I am not] going through that again”).

In 2007 Charlie was referred by the pain clinic to do a “[“Living with Pain”] programme” “once a week for six weeks” “about living with pain, pain management and taking steps to understanding [how to live with it]”. It was after “[he] had been on that programme” that Charlie said “[he] got recommended to this [Skills for Life] programme” that he did once a week for “six months”.

Looking overall, it seems that Charlie has moved towards finding a more positive environment within a socialising context to adopt new coping mechanisms to living with CD. This could be interpreted as a reflection of the Self pertaining to Mind, in relation to his “*accumulated*” emotions expressed as “*depression*”. Another aspect of the Self, as a social being reflected in his search for healing, is when he mentioned having an interest in “*learning [from] someone else*” who might “*ha[ve] an answer*” to finding new ways of coping with illness.

### **5.8.3 Section Three: Exploration of Charlie’s Perspectives of the Self**

Charlie expressed perspectives of Self interpreted as relating to concepts of Body, Mind, being spiritual as well as the Self as a social being. The following analytical explanation illustrates this by extracting information from the data presented in his narrative.

#### ***The Self as the Body***

Charlie referred to parts of his body using different terms implying specific functions and structures. From the terms used, there seems to be two main categories as described below:

- The body as a pure object:

The *“bowel [blown up like] a case ball”* summarises one part of Charlie’s perspective. This arose in the critical phase of *“[his] Crohn’s”*, when he was in hospital and diagnosed with *campylobacter*. This was connected to the mechanistic description of the recommended *“operation”* (*“take out the bad part of the bowel”*) and the perspective of the surgeon as *“the Knife Man”*.

A second part of this perspective relates to the *“stomach”* as a *“working”* object or organ. Examples include: the emergency doctor feeling his stomach; the surgeon explaining the surgery procedure; or his doctor *“put his stethoscope against [his] stomach to see if the bowel was working”*. The use of these terms is analogous to a mechanic ‘feeling’ the surface of parts of a car engine or ‘listening’ to the sound the engine makes to know whether it is ‘working’ properly.

A third part of this perspective relates to his description of *“[his] backside”* as *“a personal thing”*. By using the term *“backside”* instead of *“bowel”* or *“stomach”*, Charlie seems to be in the context of observing a pure object; but in this case the object belongs to a human being with feelings. The use of the term *“backside”* when describing the tests he had to have on his bowels expressed a more invasive procedure connected to the ‘private’ Self even though it concerned medical diagnostic procedures. In this way the context of a more mechanistic procedure was linked to his feelings in a disparaging sense.

- The body as a functional object

Another way Charlie perceives the Self relates to the functionality of digestion with regard to IBD. Here he used the term *“system”*, describing the lack of functionality of digestion. For example, after he had had food poisoning, he was told not to eat anything, to *“just take fluids”* as well as *“tablets”* to *“settle his stomach”*. Charlie explained that these strategies helped to *“get it out [of his] system”*. Later in his first interview, Charlie added that he takes *“an antacid tablet for [his] digestive system”*, demonstrating that the perspective of the Self as Body as a functional object is linked to the breakdown and absorption of food.

### ***The Self as the Mind***

Charlie used several terms to express the Self as Mind in connection with CD. Three main mind-sets that affected his CD were identified.

- *“[Not] tak[ing] any stress”*

Charlie drew attention to several life events as “*stressful*” situations, each arising after his four-month hospital stay. These included: paying “*a household bill*” (even “*a little bit of stress*” would make him “*run to the toilet*”); the “*pressure*” of claiming “*benefits*” (“*how [he was] going to manage*” and “*the stress*” of “*go[ing] [through] the rigmarole of claiming*”, “*go[ing] to tribunals*” and having “*to go for all-work test[s]*”).

Charlie talked about the link between the Self as Mind in terms of what “[he] call[s] pressure and stress” that affect his Crohn’s. He explained that “*multi task[ing]*”, “*being bombarded by different things*” and “*then not being able to cope*”, “*probably built up in [his] mind*”, which led to a “*nervous breakdown and then everything shuts down*”. He said “*in the early years, if [he] got a bit of stress [his bowels] sort of bloated on and it’d go as quick as it came*” but now that “[he’s] retired”, he said “[he] still [has] flare ups but not as frequent”.

- “*Bec[oming] very depressed*”

Charlie defined depression as the “*accumulation*” of several things stemming from a number of life events since his diagnosis with Crohn’s in 1994. These included: the difficulty of accepting “*Crohn’s*” (during his time in hospital, he mentioned “*want[ing] to die*”); “*not [being] able to work*” after leaving hospital and being unemployed (he had spent the previous five years “*working for [him]self ... something [he] really missed*”); and, from 1994 to 1996, living in a “*depressing*” “*flat*”, being alone, and “*living in a church*” that had been “*renovated*”. The doctors gave him some anti-depressants, he saw a psychiatrist and had a CPN come to see him ( but “*it never really got better*”).

Only once Charlie “*got [his] benefits sorted out*” did “[he feel] a lot better”, while describing “*blam[ing] [him]self for things*” with regard to family issues and that “*internalising*” “*the pain into [him]*” “*destroys*”. This seems to express a connection between the Self as Mind and the physical body where Charlie felt he needed to “*reverse that process*”.

- “*Thinking differently*”

Charlie said “*everyone’s temperament is different*” adding that in the past, before the onset of his illness, “[he] was *impulsive*” and “*would get worked up*” with stress. He described himself as “*always wandering all [his] life*” and that he was “*really selfish*” before “*[he] went into hospital with Crohn’s*”. While the doctors felt the onset of his illness came about from food poisoning, Charlie linked it to “*pressures of life*”, such as “*being on [his] own and worrying about not getting enough work to live*”. Charlie talked about “*finding himself*” and “*struggling*” as he “*sometimes put obstacles in [his] way like*

*the person that worries a lot*”, which he said he used to do adding that *“sometimes life can be one big worry”*.

It was after he got CD that Charlie said that *“things happen to make you think differently”* and whilst in hospital, he said there was a nurse who told him *“[he] had to think positive”*. He then thought *“how do[es] [he] think positive when [he’s] got all these negative thoughts ...[that] destroy [one’s] self?”*. During his critical illness phase, *“[he] just turned it round”* because he had *“decided [he’d] had enough”* and *“wasn’t prepared to give up”*. He emphasised that it was *“just will power really”* adding that *“it’s something in [the] mind”*. Charlie expressed his perspective of *“the mind as a powerful thing”* with *“power over everything”* that made it possible to heal so he would not have to have an operation. Nowadays, he described himself as *“a bit more laid back”* and *“the stress doesn’t happen anymore”* as he has found *“piece of mind”*.

### ***The Self as Spiritual***

Charlie had mentioned that *“when [he came] out [of hospital] in 1994, [he] came out very, very, very psychic”*. After having started seeing a psychiatrist for depression in 1996, Charlie said he *“used to go to a psychic church”* and *“got just into it with a friend”* who *“used to go to the spiritualist church”*. He described that it was *“healing”* as *“it was all nice stuff”* with *“nothing horrible about it”* and *“they were all nice people”* who were *“very supportive”* so *“it made him feel good”*. He went again after his sister died in 2003 during a time when *“[he] was trying to get [his] life together”*. A later example arose when a new minister from the church next to where he was living came to visit. After some time chatting, Charlie said she had *“asked how [he] was”* when *“[he] couldn’t stop crying”* and *“all emotions started coming out of [him]”*. He said *“it was just after the time when [he] had lost [his] sister and [he’d] broken up with somebody, and it was an accumulation of a lot of things”*, adding that *“the feeling was unbelievable”* and *“[he’d] felt like [his] sister had sent her”*.

### ***The Self as a Social Being***

Charlie talked about *“being on [his] own”* after *“[he] was divorced in ‘89”* and that *“talking about [his] issues”* with *“anybody [who] wants [him] to talk about [his] issues”* instead of *“bottling [them] up”*, like at the *“Skills for Life classes”*, *“help[ed] [him] to keep on looking for things that [he could] get [his] life on with”*. In particular, he said it was *“hav[ing] a discussion... [about] what [they had] been doing and how did [they] find this and how did [they] find that”*, with *“nice people in the same boat like [him]self”* that he *“enjoy[ed]”*. Charlie emphasised that *“hear[ing] other peoples’ problems”* made him

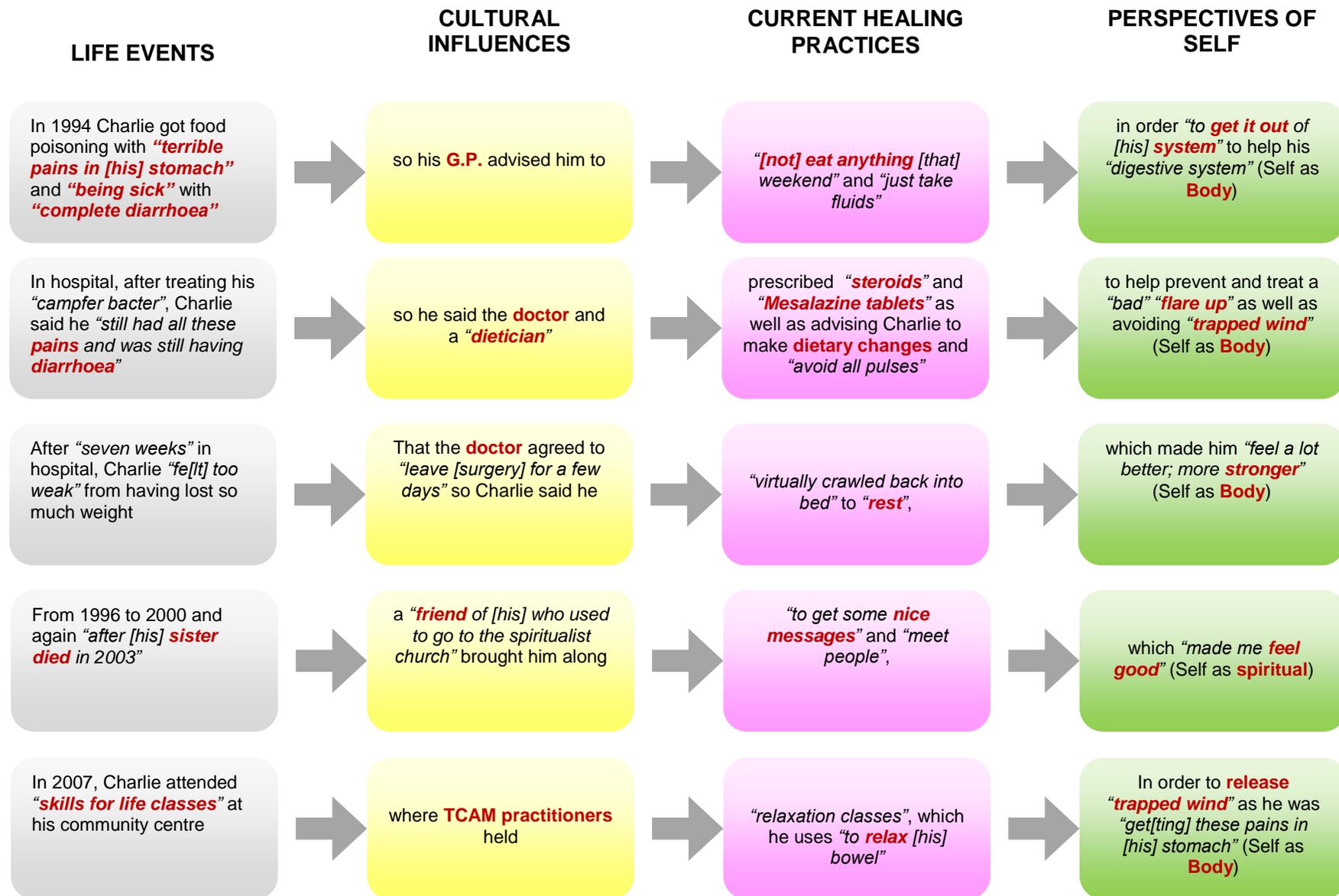
think “[he hadn’t] got any problems [him]self” as “sometimes [he thought he was] the only one in that position”.

#### **5.8.4 Section Four: Charlie’s Explanatory Model and Current Healing Practices**

The following explanatory model presented in Table 5.14 shows a flow of ideas based on significant life events within the context of the thesis’s underlying conceptual framework as a lens through which to interpret making sense of how and why people with IBD use particular healing practices including TCAM. The first column shows the relevant life event, the second shows the cultural influence at the time of a particular life event described, the third column displays the recommended healing practice that the participant is currently using and the fourth column is the interpretation of how the choice of that treatment relates to perspectives of Self.

Table 5.15 presents the main types of healing practices and their current use by Charlie. These are divided into those which are either more preventively or more curatively orientated, as expressed in his narrative. The current healing strategies presented below are not exclusively preventive or curative but only represent a tendency of ways of coping expressed by Charlie during data collection.

Table 5-14: Explanatory Model for Charlie



**Table 5-15: Preventive and Curative Strategies for Charlie**

Preventive	Taking Mesalazine	Charlie said that “after [he] came out of hospital” his <b>doctor</b> told him “[he’d] be on [ <b>“Mesalazine”</b> ] <b>tablets</b> for the <b>rest of [his] life</b> ” although “[he] used to take them like four in the morning and four at night [of] 400 mgs”, he said “[he’s] cut them down”.
	Watching what he ate	After being hospitalised with food poisoning, Charlie said “[he] couldn’t drink [or] eat anything” but milk, which is what he “preferred” but in retrospect said that “what [he knows] now” is that “ <b>milk was the worst thing for [his bowels] really</b> ” because “ <b>milk has lactose in it</b> ”. When Charlie left hospital he said “[he] had to watch what [he] ate” and was advised by the <b>dietician</b> at the hospital “to <b>avoid all pulses, like beans, peas and that sort of thing</b> ” as “[he] used to <b>get wind</b> ”. He said she also said “that certain foods might affect [him like], <b>spicy foods and alcohol</b> ” but “[he] didn’t take much notice actually”.
	Getting nice messages and meeting nice people	Charlie explained that “when [he] was trying to my life together”, “[he] used to go to church and <b>psychic church</b> ” with a “ <b>friend</b> of mine who used to go to the <b>spiritualist church</b> ”. He said he “went once between ‘96 and 2000” and then “again <b>after [his] sister died</b> in 2003” adding that “[he] used to <b>get some nice messages</b> ”. Charlie said that “[he] go[es] round the church sometimes”, like “every Saturday [for] the men’s breakfast”, to <b>meet others</b> he described as “all <b>nice people</b> ” and “ <b>very supportive</b> ”.
	Resting	Charlie talked about “ <b>feeling weak</b> ” during his acute phase of illness in hospital. He said that now when he thinks he is just about to have a “ <b>flare up</b> ”, he “ <b>would go to bed</b> ” and “ <b>rest</b> ”. He also said that he “ <b>just tr[ies] to relax</b> ” and “ <b>[not] do anything strenuous</b> ”, like “ <b>watch telly</b> ”.
	Thinking positive	Charlie said he took “ <b>skills for life</b> ” classes and “learn[ed]” about “relaxation”, which “helps [him] to keep on <b>looking for things that [help him] get [on with his] life</b> ”. He linked being “ <b>more relaxed</b> ” with being “a bit more <b>laid back</b> ” and “ <b>think[ing] about nice things</b> ” like “taking [him] self-off to a little house by the sea” or thinking about “rain on the roof” and “the sound of water” in order to “ <b>think positive</b> ”.
Curative	Not eating	After getting food poisoning, Charlie experienced “ <b>terrible pains in [his] stomach</b> ”, “ <b>being sick</b> ” and having “ <b>complete diarrhoea</b> ”. He was told by his doctor “ <b>[not to] eat anything</b> ” and “ <b>just take fluids</b> ” adding that if he tried to eat something, “[he] used to <b>feel really bad</b> ” and “[was] getting to the point where [he] was trying to <b>starve [him]self</b> ” because he thought “it’s <b>better not to eat</b> for a few days” and “ <b>just take fluids to get it out [his] system</b> ”. Charlie said that if he got a “ <b>flare up</b> ” he “ <b>won’t eat</b> ” for around two days and “ <b>might drink fluids</b> ” like “ <b>water or tea</b> ” and perhaps “ <b>some light toast</b> ”.
	Relax[ing] [his] bowel	Charlie talked about having “awful” “flare ups” that would “catch [him] out” when he would “get these <b>pains in [his] stomach</b> ”. He said he “used to go to the toilet and then lie on [his] bed”, “ <b>relax [his] bowel</b> ”, which would make the “ <b>trapped wind</b> ” “ <b>come away from [him]</b> ” and then “[he’d] be alright”.
	<b>Taking steroids</b>	After <b>two days</b> if his “ <b>flare up</b> ” does <b>not get better</b> , Charlie said “[his] Crohn’s <b>doctor</b> has told [him] that if [he] get[s] it <b>really bad</b> , to ask for steroids” if he does not have any “at home”. He mentioned taking “ <b>slow release</b> ” steroids at “200 mgs only for about three weeks” and that it would take him “a week to come off” them.

## 5.9 Case Study Eight: HALSTON

*“When I’m not well I do tend to close down [and] I’m not very communicative”*

### 5.9.1 Section One: Overview of Halston

#### **Who is Halston?**

Halston is a sixty-year-old white man who is married and has two children. He mentioned that in his family history *“[their] digestive systems [have] never been brilliant”* adding that he had *“pyloric stenosis as a child”* although he was unsure *“whether that’s been instrumental in any of this [illness] or not”*. After finishing school, Halston went to university to study economics and *“taught for a couple of years”* before getting married and moving city. He described working *“in the early eighties”* with some *“early computers”* and said he *“progressed through from there”* and has been working in a *“computer branch”* in his current city of residence since 1982. Halston said he used to smoke more when he *“was younger and before [they] had the kids”* but that *“now [it’s] mainly when [he’s] on holiday”*. He mentioned having read *“the stuff”* that says smoking affects IBD but said he *“[didn’t] think it does otherwise [he] would notice a big difference whenever [he] started smoking on holiday and [he didn’t]”*. During the interviews Halston presented his narrative in a prudent, reserved and succinct way.

#### **First Symptoms**

Halston said that in his late forties he started to *have “some pains just under [his] ribs that caused [him] to be sick”* which *“happened about three or four times a year”*. He described this *“weird”* experience saying *“it started like late morning, lasted for the afternoon, built up to this period where it was quite sharp pains and then [he] would be sick, then [he’d] go to sleep and then [he’d] be alright”*. After going to see his GP, Halston was referred to see a consultant at the city hospital as a *“day patient”* and had a *“series of tests”* done but these proved to be *“inconclusive”*. He said that this *“lasted for maybe two or three years”* adding that he *“[didn’t] know if they were associated with the Crohn’s Disease or not”* and that *“that’s never been confirmed”*.

Around the age of fifty, Halston said he *“woke up in the morning”* and *“started getting other pains”* that he *“thought [were] appendicitis”*. He was *“referred straight up to the outpatient”* of the city hospital by his doctor and had to stay there *“a few days”* for *“various tests”*, which *“determined that it wasn’t appendicitis”*. Further tests were carried out and he was diagnosed with Crohn’s Disease (CD).

He confirmed that *“[he’s] never found anything that triggers it one way or another, either emotionally or diet or anything”* and described his illness and *“get[ing] ups and downs and [that] it levels out and then nothing happens for some time”*. When Halston has “attacks” symptoms include: *“diarrhoea”, not “want[ing] to eat” as “it does tend to suppress your appetite”, “go[ing] to the toilet all the time” and “get[ing] abdominal pains”*. Ever since his diagnosis Halston was prescribed Pentasol (Mesalazine) and steroids that he would *“have to take for the foreseeable future”, which is something “[he] found was one of the hard bits”* of coming to terms with this life-changing event.

### **Getting Worse**

Halston described how around *“December time 2003”* he *“was in a lot of pain; abdominal pain and strange pains in [his] shoulder”* because a *“liver abscess”, which “they fitted a drain for” “maybe a year prior to that” “had returned”*. *“They put a pipe in through [his] side to the abscess and then that drains off into a bag”,* which he had for *“a couple of weeks”* and found *“quite amusing”* having come out from hospital on Christmas Eve with the family *“[going] to the cinema”* with *“this [bag]...on the inside of [his] trousers”*. He said *“a leaking intestine was causing [him] to subsequently [have] the abscess on [his] liver”*. By *“January time it wasn’t getting a deal better”* and he was *“slowly deteriorat[ing], was badly dehydrated and had lost a lot of weight”*.

### **Crisis Phase**

In February 2004, Halston *“was taken into hospital and they carried out various tests”* and after *“about a week or so”* he said *“they decided that they knew enough by then”* and needed to operate. He described his bowel as *“very leaky at that point”* and that he *“didn’t have an option really because of the state of it”* adding that the doctors said the surgery would *“give [him] another five or ten years”*. After *“build[ing] [him] up”* for another two weeks, Halston had an operation where surgeons *“ended up removing about a 30 cm chunk and an 8 cm chunk”* of his small intestine as *“they [had gotten] ulcerated”* and *“perforated”* which caused him to *“get leakage into [his] abdominal cavity and that’s what had caused the infection with the liver”*.

### **Post-surgery**

Halston stayed in hospital for *“about a month”* and described it as *“a strange place”* as *“you walk in through the door and you almost become a bit numb. Things happen to you. People do things to you ...[so] “your ‘normal’ [i.e.] what you might feel - upset, disappointed or whatever - just don’t seem to arise”* and *“you become detached from yourself”*. He added that this *“detachment” “worked quite well”* while he was in hospital

as he described *“feeling a bit helpless”* as *“after the operation, you just can’t do anything”* and *“as you start to recover, then you start to get concerned in terms of how much you will recover”*. Nevertheless, Halston said he has *“not had any pains or anything like that”* since the operation and has *“been reasonably good”* to which he added *“from that perspective [that’s been] quite successful”* even though *“sometimes with these things you tend to be quite loose occasionally”*.

### **Accepting the ‘new’ Self**

After being diagnosed with CD, Halston said *“it was the, ‘you’ll take this medicine for this foreseeable future’ bit that hit [him] quite hard at the time”* and that he *“wanted to take some control back”*. He explained that this was the reason he sought TCAM healing practices. In talking about taking medical medication, he found it *“a bit worrying when there’s something that you can’t just stop taking”* and *“have to tail off”* as well as the fact that *“they just don’t seem like a good thing to be doing”* and *“seem to be too potent”*.

Halston pointed out that *“the nature of Crohn’s Disease is that nothing happens and then things happen and then things stop happening and then things don’t happen for a long time”* adding that this *“unpredictability”* is often *“at the back of your mind”*. He also talked about *“when you go anywhere, the first thing you’re looking for is making sure you know where the toilets are”*, which he described as *“a real drag”* as *“things get interrupted”* and *“that obviously has a big impact on whoever you’re with”*. This *“inconvenien[ce]”* with *“the responsibility for causing disruption”* is what Halston said makes him *“feel guilty that [he’s] causing that kind of distress”*. However, Halston said that *“now [he] got used to it; what it’s about”* so he is *“more accepting of it”* in his opinion *“because it’s in remittance”* but that *“maybe when it flares up again [he’ll] feel similarly distraught”*.

### **Cultural Influences**

Halston mentioned his wife as his main support in living with CD although *“a few friends came and saw [me] as well”* when he was in hospital. After his diagnosis he said he *“didn’t want just to be stuck taking conventional medicine for the rest of [his] days”* adding that he *“wanted to take some control back”*, thus his seeking *“alternative”* healing practices at the time.

Halston was unsure where exactly he found out about Acupuncture, saying it happened *“by osmosis”*, but Acupuncture *“[is] around ... in the papers... on the news”* and *“you see it on the Internet”*. When asked about how he found his Chinese Medicine

practitioner, he said *“let’s say I looked in the yellow pages”*, not *“by some recommendation”*. While having a friend who is a Homeopath, Halston indicated that he *“would have been disappointed”* if the friend had made any suggestions or talked about Homeopathy. It was *“when [he] thought it would be a good idea”* and *“asked her if she could recommend somebody”* that she did. Halston also tried consulting a nutritionist to try the Stone Age Diet saying they *“might have been [recommended] in an article in the paper or something like that”*.

Although Halston no longer uses what he now refers to as *“complementary”* healing practices, he runs as his main way of coping and potential healing practice, . He started running when he *“got to [his] mid-thirties”* and *“start[ed] to think about [his] condition”*, *“how healthy [he was]”*, *“how fit [he was] and what impact that’s going to have and all that”*. The context in which he was living at the time made a big difference; *“[I’ve] always been in sedentary employment”*, *“plus the fact [that] it was around the time of the marathon boom”*.

### ***Current Healing Strategies***

Halston seems to use three healing practices preventively and one curatively. With regard to preventive healing practices, he described *“run[ning] in and out of work”*, which is *“about two miles each way”* and said it *“can be very relaxing and very therapeutic”*. He added that he *“think[s] it helps [his] mental health because it keep[s] [him] calm and it helps [him] cope with all the stuff that’s going on”*. Halston also talked about *“cutting down on dairy and wheat”* as well as *“non-gluten based bread and things”*, which he explained *“might not be ‘the cause’”* of flare ups but avoiding those foods *“might help”*. Another preventive healing practice Halston uses Mesalazine, which he said he takes to avoid getting *“flare ups”*. As a curative healing practice, Halston also takes steroids in acute phases of illness to *“alleviate”* his *“abdominal pains”*.

### ***Healing Practice Pluralism***

Halston tried Acupuncture, Homeopathy and later consulted a nutritionist. He *“wanted to take some control back”* rather than *“just passively take drugs effectively for the rest of [his] days”*. He also continued to run. Halston eventually stopped following the *“Stone Age Diet”* and using Homeopathy as he thought the remedies *“didn’t seem to have any noticeable effect”* on his illness. He continued having Acupuncture as it was *“successful in terms of controlling the pain”* but stopped using this healing practice about a year before his research interviews, adding that *“[he’d] probably start*

*Acupuncture*” if he “*deteriorate[d] again*”. He regulates his diet and “*think[s] it probably helps [his] not having a lot of cheese, milk and bread*” although he intended to just “*ease it off*” whilst on holiday. Halston continues to take Mesalazine and sometimes steroids.

Halston expressed the belief “that you are a whole person, not a combination of bits” and disagreed with others who think “*there’s always that silver bullet*” or “*do this one thing and everything will be hunky dory*”. He insisted that “*there never is one thing that will cure everything*” likening it to religion saying “*they serve up this one thing that will solve all your problems*” but then he concluded that “*it doesn’t work that way*” acknowledging that “*things might make life a bit easier and might alleviate*” ill health.

## **5.9.2 Section Two: Exploration of Two Decision Points**

### ***Decision Point 1: Having Bowel Surgery***

This decision point has been selected as it represents a life-changing event following a number of experiences that led up to a critical point in Halston’s life after living with CD for around six years. His health started to “*deteriorate*” around four years after his diagnosis. During this time, he took medical drugs to prevent him from having “*attacks*” and tried different healing practices whilst observing the Self to understand how to “*alleviate*” symptoms. These comprised Chinese Medicine including Acupuncture, Chinese herbs and moxabustion (but, “*it wasn’t really achieving very much in terms of stabilising [his] condition*”, although he would “*...look at going back for pain relief*”); Homeopathy ( “*(while) the chatting helped ... [he didn’t] think the medication did anything*”); and telephone consultations with a nutritionist (“*things like this [CD] often have an allergy basis*”), trying the Stone Age Diet (but “*didn’t work*” and “*didn’t reveal anything either*”).

The following life events are the main contributing factors to Halston’s decision to have bowel surgery comprising “*remov[ing] a couple of bits of bowel*”. Halston described the surgery as “*quite successful*” as “*[he’s] not had any pains or anything like that*” and “*been reasonably good*”.

- Having an “*abscess on my liver*”

Halston started to get gradually worse such that by 2003 “*Christmas time*” he “*was in a lot of pain*”. He described that as a “*result of a leaking intestine*” he had developed “*an abscess on [his] liver*”. Halston said “*they fitted a drain*” for it. Unfortunately by January 2004, the “*abscess had returned*” and “*it wasn’t getting a deal better*”. Halston

described this life event as *“one of those things when you slowly deteriorate”* and that he *“was badly dehydrated and had lost a lot of weight”* so he *“was taken to hospital”*.

- *“I didn’t have an option[...] because of the state of the bowel”*

Halston went into hospital for a set of tests, After *“be(ing) in about a week or so”* and because *“[he] wasn’t eating very much”* and had *“lost about a couple of stone”*, Halston explained that *“they had to build [him] up”*. It was *“at that point they decided that they didn’t need any more tests”* and *“knew enough by then”* so *“that’s when they decided to operate”*.

Halston emphasised that he *“didn’t have an option really”* and said he *“couldn’t not do [the operation]”* as he *“couldn’t keep going because of the state of [his] bowel”*. This is because *“this disease is in [his] small intestine”*, it got *“ulcerated and then [got] perforations and leak[ed]”* and *“that’s what had caused the infection with the liver”*. After *“they said if [they] do this [operation] then that’ll give [me] another five to ten years of reasonable stability”*, he agreed and commented *“I knew that it was just going to get worse and it just wasn’t any good”*.

### **Decision Point 2: Going Running**

This decision point has been selected as it is the most ‘practised’ healing approach that Halston uses to prevent stress from affecting his *“condition”*. It is one of the only non-medical healing practices he always has used in living with CD. Almost every day, Halston has been running since the age of thirty five, before being diagnosed with CD. Even though it is not a TCAM healing practice per se or a home remedy, Halston expressed that *“running helps dramatically”* and that he has *“always found it useful in times of going from home to work [as] a slow transition”* so that *“by the time you get there, home’s back home and work’s where you are”*. He described that *“once [he] got [to] a reasonable [level of] fitness”*, he *“started running further and did a few marathons”*. Nowadays, aside from his daily running *“on roads”*, which he said is *“a bit boring”*; *“most of any other running [he does] is in the hills”*.

The following issues represent the life events Halston considered, including cultural influences, which influenced the way he perceived the Self, leading up to his decision of going running, and in particular to continue running to help living with CD.

- Relating age to being *“fit”* and *“healthy”*

When Halston *“got to [his] mid-thirties”* he said he *“start[ed] to think about [his] condition”*, *“how [he was doing] to how healthy [he was]”*, *“how fit [he was]”*, *“what impact that’s going to have an all that”*. After his surgery, Halston talked about running

saying he has *“done some big races but nothing much of consequence since [he’s] been poorly”*. This is because he said *“it obviously [took him] a little while to get [his] fitness back”* adding that he was *“get[ing] older [which] does have an effect as well”*. He described having to *“build up [his] muscles”* by *“start[ing] walking in to work and back to work rather than running”* for *“a couple of miles”* before *“gradually build[ing] up again”*. He commented that this was *“(an) age thing as well”* and not just the consequence of being very ill with CD. He confirmed that *“[he’s] feeling happy about [his] running again now”* and is *“content”*.

- Being in *“sedentary employment”*

Halston described his work as *“always [having] been in sedentary employment”*. He talked about *“getting tense”* by going *“in and out of work”* by car for *“only a short distance”*. He expressed a link between the activity of running as *“a slow transition”* between work and home and as *“very relaxing and therapeutic”*. Running for him is not just a physical activity but something that heals the Mind part of the Self in the context of space between his work and his home.

- Needing to *“switch off”*

During his times in hospital, Halston has described finding *“hospital a strange place.”* As *“you walk in through the door and you almost become a bit numb to the whole thing”*, a place where *“things happen to you”* and *“people do things to you”* and *“(you) relinquish control”*. He explained that the *“normal”* things *“you might feel [like being] upset, disappointed or whatever, just don’t seem to arise”* and *“you just go [into] this strange, almost detachment”*. Halston himself drew the analogy to running: *“(although) that numbness thing tends to be when in the ‘hospital-y’ thing but it’s not dissimilar in some ways... (I) tend to switch off when running”*.

These perspectives of Self pertaining to emotions in the Mind are directly connected to the Self as Body. This is because Halston described physically moving away from his stress at work or at home and the transition between the two locations, or the times when he is running *“in the hills”* seem to enable him to *“switch off”* these emotions in combination with his concern with keeping fit. Halston has described this *“therapeutic”* activity as a *“coping strategy”* in living with CD.

### **5.9.3 Section Three: Exploration of Halston’s Perspectives of the Self**

Halston expressed perspectives of Self interpreted as relating to concepts of Body, Mind and the Self as natural and whole. The following analytical explanation illustrates this by extracting information from the data presented in his narrative.

### ***The Self as the Body***

Halston referred to parts of the body using different terms implying specific functions and structures. Two examples illustrate this.

- The bowel as a “leaky” pipe:

Halston used the terms “*bowel*” and “*intestine*”, his “*bowel (being) very leaky at that point (of needing surgery)*” and his liver abscess arising as a “*result of a leaking intestine*”. He identified the physical location of his illness as “*in [his] small intestine*”. These terms express his understanding of the severity of his situation as explained, mostly likely, by doctors at the hospital and perhaps language he has borrowed from them. These more mechanistic terms and perspectives of the bowel as a pure object seem to mirror the use of surgery as a healing practice with medical perspectives of illness and healing.

- Describing the “*digestive system*” function

Halston also used medical terms when describing his family’s medical history, for example, “*our digestive system has never been brilliant*” or when he talked about tests at the hospital. He mentioned the functionality of his intestines, for example, when commenting “*it probably helps my digestive system if I don’t eat as much cheese*”. Here there is more implication of a functional object that is moving and has a purpose and not just an anatomical structure in a living being. By watching what he eats and drinks, Halston’s awareness of his food and drink intake is reflected in his use of the word “*system*” to include more than just anatomy but also “*digestive*” as physiological function of his intestine.

### ***The Self as the Mind***

Throughout the interviews, Halston seemed reserved and protective of the information he was giving in his narrative saying, for example: “*[I’ve] never found anything that triggers [his condition] one way or another, either emotionally or diet or anything*”. The following points illustrate how he felt towards certain life events as well as illness and healing, linked to emotions involved in living with CD.

- Being worried

Although on the one hand Halston said that he did not think emotions trigger his “*condition*”, he did mention these when explaining life events and his impressions of how he affects others. At work, Halston talked about the “*inconvenien[ce]*” of having to “*interrupt a meeting*” because of needing the toilet, which he said is “*worrisome*”. On holiday, he expressed the worst thing about CD, apart from pain and needing the toilet,

as *“it’s that unpredictability”*. He added that *“since the operation, things have been a bit stable-r but prior to that, when anything was planned, there was always that at the back of your mind as to whether you’d be alright”* and *“what impact it’s going to have on the holiday”*. When talking about his children, Halston expressed a worry about his children getting CD. He said: *“you do think about it”* and *“you would feel guilty”* even though he *“know[s] you can’t help it and it’s not something you’ve done but it worries [him] somewhat”*.

Halston also expressed worries about medication and fitness. After being prescribed medication to take for the *“rest of [his] days”*, Halston described his concern about the *“side effects”* of the drugs, for instance that *“[it’s] not much fun”* having to *“go on to steroids”*, *“when you look at the list of side effects; they tend to be rather longer than the beneficial bit”*. He added that *“it’s also a bit worrying when there’s something that you can’t just stop taking. You take them for so long and then have to tail off and they just don’t seem like a good thing to be doing”* emphasising that *“they seem to be too potent!”* In relation to fitness, when in hospital after surgery, Halston indicated that *“there was that worry whether [I’d] be able to do that again”*. He also said *“as you start to recover, then you start to get concerned in terms of how much you will recover”*.

- Getting *“very detached”*

Halston drew similarities between the *“becom[ing] detached from [him]self”* in hospital and his *“tend[ency] to switch off when [he goes] running”*. He described this as a *“coping strategy”* and said he would *“attentively become not very communicative and tend[s] to be quick and insular”* when normally *“[he’s] a bit more open”*. Halston pointed out that *“in some ways it’s better if [he’s] not around”* because *“if [he’s] not very well then [his] wife gets worried about what’s happening and how [he] is feeling and [he] just tend[s] to close in somewhat”*. He added that he *“[didn’t] think that helps her at all”* although for him *“it’s best”*.

Other terms Halston used synonymously with *“switch off”*, were: *“shook things off”*, *“turn things off”*, *“tend[ing] to shut off”* and *“when [he’s] not well [he] tend[ing] to close down”*. Halston concluded that *“[he] didn’t like it [being detached] and [he] didn’t dislike it”*.

### ***The Self as Natural***

In commenting on his use of Chinese Medicine and Homeopathy as *“alternative therapies”*, Halston indicated *“it was about choice”* rather than using a *“more natural”* healing practice. Nevertheless he agreed that even if his choice could have been *“any*

*alternative therapy*”, it would have been non-conventional Medicine. This is “*because the conventional medicines are that; they are medicines; they’re tablets and pills and potions*”; he “*wanted something that wasn’t so pills and potions-oriented*”. He elaborated on this by saying that “*whenever you get your tablets, there’s leaflets inside that tell you what all the side effects are and so on and it was that, that I wanted to move away from*”. For him, Homeopathy “*tablets*” and Chinese Medicine “*pills*” were “*more natural because they’re based on roots and herbs*”.

Other occasions when Halston described life events linked to “*natural*” things was when he mentioned finding running on roads “*a bit boring*” as opposed to “*run[ning] on the hill*”, describing different popular mountainous regions in England. He also talked about going for “*a walking week*” in “*the Alps*” but said that he and his wife also liked going to “*see a few plays*”.

### ***The Self as Whole***

Halston talked about his perspectives of the Self as a “*whole person*” saying that “*there’s two aspects*” to living with CD: “*one is how you cope with these things [having the illness] and the other one is your physical and mental well-being [that] will help in terms of symptoms*”. He went on to say that “*if you’re physically and mentally fit then it probably helps you stave off*” or “*alleviate some of the symptoms*” but that “*you can’t stop it altogether*”. Furthermore, “[*I believe*] that you are a whole person [*and*] not a combination of bits” adding “[*your “mental” and “physical health” are*] obviously connected”. Halston then pointed out that “*if [he] can keep physically fit and mental[ly], reasonably calm, [he] reckon[s] that helps [him] physically*”. In this way, it “*helps keep that [Crohn’s thing] at bay*”.

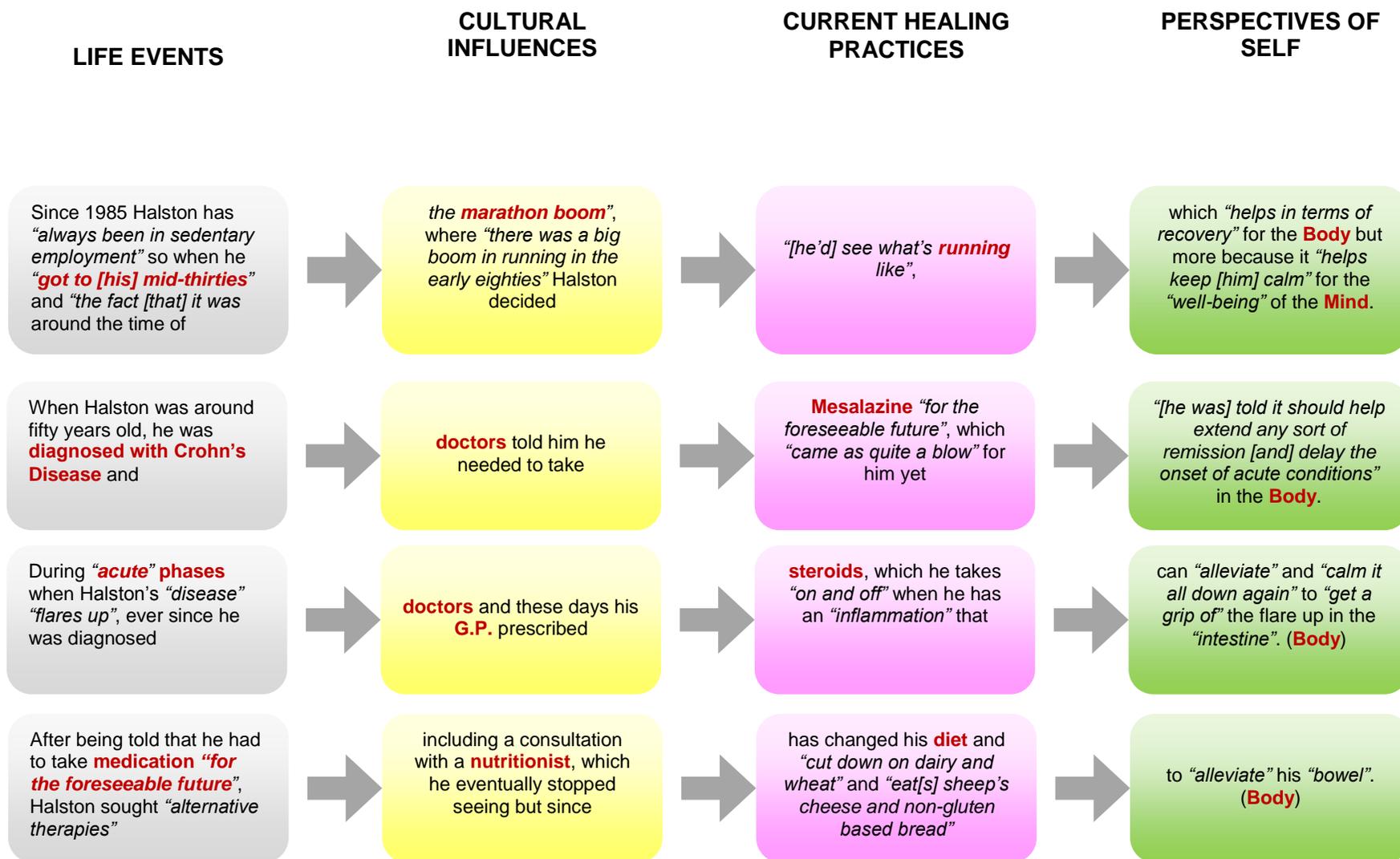
When comparing different healing practices’ approach to illness and healing, Halston commented that “*the medical professional is geared up to treating the body, isn’t it?... [I don’t] think they have time to treat the whole person*” and that “*if you have got a physical illness then their aim is to treat the physical causes with medication of some sort*”. Furthermore, while perceiving healthcare staff as “*all caring people but they don’t have the time to treat you as a person; all they can do is treat you as a patient*”. In contrast “*alternative medicine doesn’t; it comes at it from a different angle [and] it’s just a different approach altogether*”. For instance, TCAM practitioners are “*treating the whole person, looking at your physical and mental state, trying to understand what you are and then treat it from that angle rather than looking at it from, in a crude term, as a piece of meat and how do we make it better*”.

#### **5.9.4 Section Four: Halston's Explanatory Model and Current Healing Practices**

The following explanatory model presented in Table 5.16 shows a flow of ideas based on significant life events within the context of the thesis's underlying conceptual framework as a lens through which to interpret and make sense of how and why people with UC use particular healing practices including TCAM. The first column shows the relevant life event, the second shows the cultural influence at the time of a particular life event described, the third column displays the recommended healing practice that the participant is currently using and the fourth column is the interpretation of how the choice of that treatment relates to perspectives of Self.

Table 5.17 presents the main types of healing practices and their current use by Halston, divided into those that are more preventively or more curatively. It is important to note that, although Halston had stopped using Acupuncture, he indicated that, as he had found it helpful when he was in pain, *"if [he] deteriorate[s] again then [he'll] look at going back, particularly as a method of pain relief"*. The current healing strategies presented below are not exclusively preventive or curative but only represent a tendency of ways of coping expressed by Halston during his interviews.

Table 5-16: Explanatory Model for Halston



**Table 5-17: Preventive and Curative Strategies for Halston**

Preventive	Going running	Halston said that “ <i>running can be <b>very relaxing and very therapeutic</b></i> ” adding that he thinks “ <i>it <b>helps [his] mental health</b></i> ” as “ <i>it <b>keep[s] [him] calm</b> and it <b>helps you cope with all the stuff that’s going on.</b></i> ”
	Taking Mesalazine	He was told that Mesalazine “ <b>help[s] extend any remission [and] delay the onset of acute conditions</b> ”. Halston explained that he “ <i>tend[s] to increase a dose if [he’s] going to the toilet a lot and that seems to help a little</i> ”.
	Making diet changes	Halston expressed that “ <b>cutting down on dairy and wheat</b> ” as well as eating “ <b>non-gluten based bread</b> ” probably “ <b>might help</b> ” but “might not be ‘the cause’” of his “attacks”. He added that “ <i>the difference here is the general condition of how many times you go to the loo, which is probably affected by the things you have eaten</i> ”. Yet Halston is unsure if the “ <i>things [he does] may stop [him] going to the loo quite so much</i> ” or “ <i>have an impact on whether the Crohn’s comes back or not</i> ” since “ <b>[his] digestive system is such that it’s susceptible</b> ” to illness.
Curative	Taking steroids	When Halston starts to get “ <b>abdominal pain</b> ” indicating that he has a “ <b>flare up</b> ”, he said he “ <i>usually takes [steroids] <b>for a couple of weeks</b></i> ” and has taken them “ <i>probably 4 or 5 times</i> ” since his diagnosis. He explained that “ <i>you build up and down</i> ” when taking steroids “ <i>so you can’t drop them off</i> ” but that seems to “ <b>calm it all down again</b> ”.

## Conclusion

This chapter set out to provide insight into the diverse and distinctive journeys that each participant took in living with IBD. In particular, it applied the conceptual framework outlined in Chapter Three as a way of interpreting and organising the participants' stories, linking it to supportive evidence for each narrative. Its evident applicability demonstrated in the chapter suggests its potential value as an analytical, conceptual framework, a mode for understanding the significance of treatment and perspectives of healing practices in coping with long-standing illness.

Through the processes of data analysis and interpretation, three main points emerged in the individual analyses. The first can be seen in the use of the list of life events to get an overview of the chronology of participants' life stories. This helped in constructing the bio-summaries presented at the beginning of each individual case, which highlighted the context of life events in coping with IBD where periods of 'crisis' played a big part in guiding sufferers' choice of treatments. For example, in Halston's individual case, after describing his crisis period being in hospital, needing surgery and being told he would need to take "*conventional medicine for the rest of [his] days*", he said he "*wanted to take some control back*", which is why he started looking for "*alternative*" ways of healing.

The second point coming from looking at the selected data was how cultural influences led to turning points in using multiple healing practices other than medical treatments in living with IBD. Participants talked in detail about what they thought and how they felt about cultural influences. Further detailed exploration of cultural influences was made possible by focusing on at least two life events leading up to Decision Point Two, at which point participants had decided to use non-medical healing practices. Looking at the data in this way illustrated the factors and properties of cultural influences necessary for sufferers to become receptive to suggestions and recommendations leading to their decision making to use particular non-medical healing practices like TCAMs. For example, in Venezia's individual case, she mentioned her brother sending her "*a photocopy of a chapter from a book called 'When The Body Says No'*", which seemed to confirm curiosities that sprung from looking at herself (Self) and deciding how she perceived illness and healing. This book helped her develop an interest in looking at other books on similar ways of healing and understanding the Self.

The third point emerging from selected data was IBD sufferers' use of particular healing practices for specific parts of the Self. This was effectively portrayed through looking at participants' individual current healing practice strategies, both preventive and curative.

Using this method of sorting and analysing data made it possible to see in an almost step-by-step way how participants used healing practices in both an acute and/or remission phase of the illness. For example, in Isa's individual case, she explained how if her UC "*flares up a little bit*" she would "*rest up and take things a bit easier until it settles down itself*". Using resting in this way after a 'flare up' has already started seems more curative to 'calm things down'. This use of resting was presented as the first step Isa would take to make herself feel better. If this did not work, she described the next step of going to "*see the homeopath*" as what she would do next if resting did not help.

These ways of looking at the narrative data and the associated key points (crisis life events, receptivity to cultural influences and re-evaluating the Self) seemed to link very well to the conceptual framework highlighting the importance of cultural influences and perspectives of Self of individual sufferers in their 'quest' for appropriate healing practices with specific functions in healing particular parts of the Self whilst living with long-standing illness. The analysis is taken a step further in the next chapter (Chapter Six) which adopts a cross-case perspective. It identifies the types of cultural influences mentioned by the participants and compares the eight cases using two analytical strategies by looking at the life events leading up to Decision Point Two and explores participants' use of their current healing strategies.

## ***CHAPTER SIX: Cultural Influences & Current Healing Practice Strategies in Regaining Control of illness whilst Coping with Embarrassment***

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### **6.1 Introduction**

This chapter explores four dimensions (divided into four sections), which are central to the aim of the thesis and address the first three research objectives. Firstly, it elucidates how participants dealt with some of the stigma attached to living with IBD. Secondly, it points out some of the ways of coping sufferers used to regain control of their lives affected by this long-standing illness. Thirdly, it explores participants' perspectives of the healing practices (current healing practice strategies) used that 'suit' their perspectives with regard to treating their ailments in the context of recommended treatments (by a range of cultural influences) and their application. Lastly it looks at the way participants used healing practices (current healing practice strategies) to preventively avoid and curatively take care of issues and symptoms in living with IBD in order to uncover how sufferers used particular healing practices to manage their illness.

The first two dimensions set a dynamic context of suffering within which cultural influences and perspectives of Self 'live', and focus on the 'Stimmung' [equivalent in English to ambience, mood or disposition with the sense of the feeling of suffering from a person's lived experience] of living with IBD. 'Culture' is perceived here as dynamic, influencing the individual and their behaviour or perceptions of how others might view them, and also as being reflected back out from the individual into society to (re)produce culture through what they do and interactions with others. The last two dimensions are explored in relation to the life events leading up to the second decision-point, that is, factors affecting their search for, access and use of alternative healing practices to Medicine. Exploration of the fourth dimension, current healing practice strategies, is in addition situated within the underlying conceptual model of the thesis and the notion of Self as Body, Mind, Spirit and Vitality within culture. In contrast to the previous chapter where the focus lay on each participant separately, in this chapter the analysis adopts a cross-participant approach.

### **6.2 Living with a 'dirty disease'**

In Chapter 2 on Perspectives of IBD, the section subtitled 'Contextualising symptoms and signs of IBD' provided a brief insight into the stigma attached to living and coping with a 'dirty disease'. In particular, sufferers experienced frequent embarrassment and

humiliation from the symptoms of IBD as well as the loss of control of the bowels or complications of using stoma bags resulting in ‘accidents’, sometimes in public. These unfortunate issues were also connected to the difficulties participants faced in being able to talk to others about their experiences with an illness of this nature. This seemed mainly because participants expressed that handling or talking about excrement was taboo and generally not acceptable in most social circumstances. It is precisely these stigma and perspectives that participants expressed that are presented in this section of Chapter 6, together with the ways of coping they determined might be useful in helping them live with IBD. In particular, participants’ descriptions of coping with: unpredictable and messy IBD symptoms for example living with stoma bags, going through intrusive diagnostic and treatment procedures and awkward social circumstances involving living with IBD. Whilst looking across cases, all eight participants mentioned embarrassing situations connected to having a ‘dirty disease’ with five using the term ‘embarrassing’ itself and the other three using other terms like: “*desperate*” (Eden), “*paranoid*” (Calvin) and “*awful*” (Charlie). Table 6.1 provides an insight (including examples) into these situations and of how participants said they used ways of coping to prevent and/or deal with embarrassment in living with IBD.

In terms of understanding ways of life involving living with embarrassment, it is useful to perceive the concept of culture as something that is dynamic and ever-changing reflected outwards into society by IBD sufferers’ perspectives of Self and translated inwards from a context, as an attitude or way of doing something an IBD sufferer may adopt. This inward and outward juxtapositioning is interpreted throughout this section whilst describing the three main points identified across all eight cases listed in Table 6.1: 1) public and 2) private situations involving disgust or awkwardness and 3) medical examinations, treatments and/or care perceived by participants as intrusive and/or shameful. While the points and issues listed and briefly described in Table 6.1 present a simple view of participants’ suffering, they clarify particular circumstances participants’ recalled that exemplified the embarrassment of living with IBD.

Table 6.1 is split into three parts divided over five columns. The first part consists of the first column which lists the three main points seen across cases regarding how participants coped with embarrassing situations in living with IBD. The second and third parts are split into two columns each representing issues mentioned in participants’ narratives involving embarrassment linked to the stigma of having a ‘dirty’ disease and how they coped with these scenarios respectively with one example provided for one issue listed in the adjacent columns (both in red font).

**Table 6-1: Points identified across cases related to coping with embarrassing situations in living with IBD**

POINTS IDENTIFIED ACROSS CASES	EMBARRASSMENT		COPING WITH EMBARRASSMENT	
		An example of an embarrassing situation	Ways of coping	An example of coping with embarrassment
Public situations involving disgust or awkwardness	<ul style="list-style-type: none"> <li>• <b>Soiling oneself</b></li> <li>• Dealing with IBD symptoms like smelly or noisy stools</li> <li>• Un-aesthetic perspectives of Self-image like showing one's stoma bag</li> <li>• Talking about suffering and 'dirty' IBD symptoms like bloody stools</li> </ul>	<p><i>"I was away on holiday and I went to a place [on the west coast] and I stayed in a hotel there. And I went for a little walk in the morning and I'd already been to the toilet and I walked to the front there and I felt: I just gotta go, and I couldn't [hold it]. And when you experience something like that, there's nowhere to go. I was in a bit of a state actually."</i> (Charlie)</p>	<p>Being prepared as much as possible like:</p> <ul style="list-style-type: none"> <li>• Knowing where the toilets are before arriving at a location</li> <li>• Having extra stoma bags or wet wipes handy</li> <li>• Knowing what to say if IBD comes into conversation</li> <li>• <b>Finding the most efficient route to get out of sight of others</b></li> </ul>	<p><i>"So I managed to get myself back to the hotel and I were bladdered, you know, and had to, well I washed me clothes and I washed myself down in the shower and stuff like that. And then I stopped in for that weekend, you know, but that isn't the first time that it's happened. It can just happen out the blue. And, you know, I need to use the toilet, if you understand, it's an urgency."</i> (Charlie)</p>
Private	<ul style="list-style-type: none"> <li>• <b>Un-aesthetic</b></li> </ul>	<p><i>"[...] if you can do the different pinks; cause obviously</i></p>	<ul style="list-style-type: none"> <li>• <b>Learning to accept</b></li> </ul>	<p><i>"It is something you take a while to get used</i></p>

<p>situations involving disgust or awkwardness</p>	<p><b>perspectives of Self-image</b> like showing one's stoma bag</p> <ul style="list-style-type: none"> <li>• Handling excrement</li> <li>• Talking about suffering and 'dirty' IBD symptoms like bloody stools</li> </ul>	<p>again [stoma bags are] a new thing for non-whites and the world is always generally on a white basis as the norm. [...] I suppose it's better than nothing but, you know, you're not telling me that for the sake of, even pre-orders now, that there is [...] a higher incidence of Black and Asian people with Crohn's, that you can't do a bag that suits them in the same way that you can do a bag that suits white people. Cause obviously they've got the same thing as well so the better you can blend it in; you're not going to get it so it's invisible but just any other colour would be better. And it's just <b>for a body image, mental aspect cause it is a shock</b>. For me, it's cause it's just this pink thing on me [...]" (Celine)</p>	<p><b>the new Self</b> like a stoma bag or having a changed lifestyle</p> <ul style="list-style-type: none"> <li>• Being prepared for unexpected situations by being expeditious and hygienic</li> <li>• Finding someone to talk to about suffering and IBD symptoms like family, friends or a counsellor</li> </ul>	<p>to, to actually sink in that it's there. You know, you're getting dressed and you look in the mirror and it's just there." (Celine)</p>
<p>Medical examinations and/or treatments or care that feel intrusive or shameful</p>	<ul style="list-style-type: none"> <li>• Physical examination especially to do with the anal region or handling excrement for tests</li> <li>• <b>Application of</b></li> </ul>	<p>"[...] they'd prescribed some steroids to take topically, which I couldn't do because I was just like really 'I can't do that', 'that's just not', 'I don't wanna do that', because it was <b>the administering of an enema which was obviously something I'd had no experience of and I was just really; couldn't do it.</b>" (Venezia)</p>	<ul style="list-style-type: none"> <li>• Going numb</li> <li>• <b>Negotiating treatment options</b></li> <li>• Expressing feelings and opinions about examination, treatment or care</li> </ul>	<p>"So then the prescription was changed. I think my <b>GP changed the prescription to oral steroids</b> and then I started to get a little bit better." (Venezia)</p>

	<p>some medical treatments like enemas</p> <ul style="list-style-type: none"><li>• Receiving care when incapacitated</li></ul>			
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Four issues came up when looking across the eight cases that involved feeling disgust or awkwardness in public situations linked to embarrassment: soiling oneself, dealing with uncomfortable symptoms in the vicinity of others like having smelly stools, feeling self-conscious about oneself like needing to hide a stoma bag from public view and feeling unable to talk about suffering or symptoms of IBD such as flatulence with others. The example provided reflects an embarrassing situation that all participants either had experienced or feared might happen to them. The chosen extract was described by Charlie when he soiled himself accidentally, whilst in public on holiday. The shocking embarrassment felt in a public situation like this reflects perspectives of society on the taboo and 'dirtiness' of excreting in public or being in contact with excrement. These perspectives were clearly shared by Charlie as he hurried back to his hotel as fast as he could to get out of sight and clean himself. Not so dissimilarly, while someone who might have split food on themselves with food (and thus 'soiled' themselves) in public might react in a similar way, the stigma attached to food dirtying garments in public is sometimes still acceptable and commonly does not warrant the same expeditious reaction to get away from public view whereas excrement does.

Public and private embarrassment seemed to have different meanings in what they were connected to but still shared some similarity as can be seen in the second point in Table 6.1. Here private embarrassment involved less people and was more introspective in terms of feeling embarrassed about oneself, sometimes without other people being around. Most participants described this kind of embarrassment as more connected to feeling self-conscious about the Self-image. The example described by Celine about wanting a darker stoma bag demonstrated this self-embarrassment as she expressed her struggles in living with a pink stoma bag. Although her way of coping with having to wear a stoma bag for most likely the rest of her life might not seem a solution to her problem, finding a darker stoma bag was clearly something she intended to do whilst learning how to accept being an "ostomist" (Celine). Again with regard to shared societal perspectives, the idea that the bowels are 'normally' inside the body and out of view is a perspective that is shared by most non-ostomists and perhaps also by most ostomists. As an ostomist and sometimes people living with or around ostomists (for example, family or ostomy nurses) might change their perspective of Self to accept part of the bowels (particularly the excreting part) as hanging outside of the body, this could be accepted by others as well. In this way the stigma of dirty disease changes as it is morphed between the Self and society.

Looking at the final categorisation in Table 6.1, all participants talked about intrusive medical examinations, treatments and/or care they received for IBD and linked these from feelings of mild discomfort to "traumatic" embarrassment. The example presented by Venezia in having

to use medicated enemas was something mentioned by most participants who used different ways of coping to deal with the awkwardness of needing to have contact with the inside of their bowels. In this situation, negotiating with medical professionals in order to find a more suitable method of treatment was one way of coping with an intrusively embarrassing medical treatment. In contrast, the use of enemas applied by sufferers themselves, although unpleasant, seemed one of the methods used by some participants when they felt their flare ups going a little too much out of control, thereby changing the perspective of the stigma of a dirty disease depending on the acute imperative of the state of health.

In this section of Chapter 6, the main points identified that had to do with the stigma attached to living with a 'dirty' disease highlighted recollections of participants' experiences of embarrassing situations encountered in living with IBD. It was difficult to firmly delineate the different points in Table 6.1 into three parts as each overlapped another and were more complex, dynamic and interwoven in lived reality. These retrospective recollections also interlinked with issues about how participants talked about regaining control of their illness and lives. The following section explores precisely this, examining participants' ways of coping in order to regain control.

### **6.3 Regaining Control**

In the previous section participants talked about issues around embarrassing circumstances particularly connected to the stigma of having a 'dirty disease'. This is very much connected to the concept of control whether it is bowel control, controlling a situation or state of health so as to be able to live more comfortably on a physical, mental and social level. This concept of 'control' came up with eight participants, with seven directly used the term itself. For example, "[...] I'm not in control of my bowel in the way that I'd like to be [...]" (Isa), "[...] that wasn't really about getting control over the illness. It was around getting control over my own emotional health really." (Venezia) or "[...] I wanted to take some sort of control over it [...]" (Halston). Participants' perceptions of this concept are explored in this section, drawing on their expressions of losing and regaining control in living with IBD. In looking across the eight cases to find similarities and differences between participants' ways of life, this section includes examples of ways of coping which they adopted to regain control.

Five main points were seen across cases: 1) issues about support or the lack thereof, 2) identified personality traits affecting how sufferers lived with IBD, 3) particular emotions affecting illness, 4) several life events concerned with coping with suffering or the lack thereof and 5) making sense of how to perceive or behave in living with IBD related to social interactions and/or physical and mental capacities from being self-aware. The following Table 6.2 lists these five points, using one participant as an example for each. Although

these points may appear as an oversimplification of suffering, they have been presented in this way in order to more clearly see the types of issues participants were concerned with in living with IBD.

This table is split into three parts divided over five columns. The first part consists of the first column which lists the five main points seen across cases regarding how participants coped with illness by regaining control. The second and third parts are split into two columns each representing issues mentioned in participants' narratives involving losing or regaining control respectively with one example provided for one issue listed in the adjacent columns (both in red font).

**Table 6-2: Points identified across cases related to loss and regaining control of illness using various ways of coping**

POINTS IDENTIFIED ACROSS CASES	LOSING CONTROL		REGAINING CONTROL	
		An example of losing control	Ways of coping	An example of regaining control
Getting Support	<p>Not receiving enough:</p> <ul style="list-style-type: none"> <li>Care</li> <li>Understanding</li> <li>Information on IBD</li> <li>Choice of treatments</li> </ul>	<p><i>"[...] my meat manager, manager of the department, he wasn't too sure what [my illness] was about and it took a little while for him to understand I think. [...] I wasn't really telling him what was going on really, I'd get ill and I'd try to get through it and I have to have time off work."</i> (Calvin)</p>	<ul style="list-style-type: none"> <li>Receiving care from those close to sufferers</li> <li>Communicating suffering with others</li> <li>Getting information about IBD</li> <li>Being informed about treatment options</li> </ul>	<p><i>"[...] we've come to an agreement that if I do start to feel a bit dodgy then I will let him know, and perhaps we could talk about it and maybe reduce my hours or something [or] go part-time. Yeah, so there isn't really a problem at work, I mean, I am quite good mates with my manager; we get on really well. So there is no boundaries, [...] I feel comfortable telling him about anything really, I talk to him like my dad really. So yeah, work's cool really."</i> (Calvin)</p>
Identifying Personality traits	<ul style="list-style-type: none"> <li>Over-worrying about things</li> </ul> <p>Being:</p> <ul style="list-style-type: none"> <li>Too sensitive</li> <li>Self-reliant</li> <li>A "high achiever"</li> </ul>	<p><i>"I'm an only child and I'd been used to working things out for myself, being quite self-reliant and it's funny really because that's how I was with the Ulcerative Colitis. I didn't particularly discuss it with anybody. I kind of coped myself"</i> (Isa)</p>	<ul style="list-style-type: none"> <li>Being more laid back or relaxed about things</li> <li>Keeping calm</li> <li>Accepting help from others</li> <li>Pacing oneself</li> </ul>	<p><i>"[my husband] would be quite supportive with the Ulcerative Colitis in the sense that, say I was having an off day and didn't feel very well; in the past I would've probably just tried to keep going and exhausted myself and if I'd not been able to, I would've felt guilty that I was having an off day and just given myself a hard time about it. Whereas he'd be much more</i></p>

				<p>'You don't feel well, fair enough, just accept that and have a day out' or 'Take the time to recover and just lie on the sofa, do nothing, whatever, that's OK' you know, <b>he'd give permission to be ill or just not to perform at such a high level.</b>" (Isa)</p>
<p>Emotions affecting illness/health</p>	<p>Not dealing with negative emotions like:</p> <ul style="list-style-type: none"> <li>• Grief/sadness</li> <li>• Worry (stress)</li> <li>• <b>Anger/frustration</b></li> <li>• Self-pity</li> <li>• Guilt</li> </ul>	<p>"[...] I was just starting to come around to the idea that there was an emotional component to when I had flare ups. [...] I didn't get angry about anything. <b>It was repressed anger and so that's why I would get flare ups</b> because something would happen, I wouldn't deal with it, I'd pretend I was fine about something or pretend that I was OK or pretend I wasn't bothered or upset or annoyed and then I'd have a flare up about a week later." (Venezia)</p>	<ul style="list-style-type: none"> <li>• <b>Expressing emotions as they occur</b> to avoid pent up feelings</li> <li>• Giving oneself time to process emotions fully</li> </ul>	<p><b>"I've learnt to express emotions as they actually happen rather than weeks later.</b> So that's been the preventative thing, I think, that's been, the thing that's been going on for me is that because I've been learning how to do that, I haven't really had a need psychosomatically, I haven't had a need to have a flare up because it's already been processed in the here and now." (Venezia)</p>
<p>Life events affecting illness/health</p>	<p>Experiencing life events that were somewhat out of the control of the sufferer like:</p> <ul style="list-style-type: none"> <li>• Death of a family member</li> <li>• <b>Unemployment</b></li> </ul>	<p>"I think [the Crohn's came from] <b>the added problems regarding the divorce and the work problem and health problem</b>". "I haven't talked with me ex-wife for 3 years now but I still communicate with [my daughter]. No we are not [close], [...] that's my fault and [pause] [my daughter's] gay. She has a partner and in fact I went down to see her that was about 5/6 years ago and she had a civil wedding and I went</p>	<ul style="list-style-type: none"> <li>• <b>Settling unresolved issues</b> to move on from negative circumstances</li> <li>• Avoiding/changing situations that cause negative emotions</li> </ul>	<p>"I was kind of pleased with meself the way I reacted with it. [That it had taken] <b>that long and come out, I says, I said does it matter.</b> I still love you and err, yeah." (Charlie)</p>

	<ul style="list-style-type: none"> <li>• Stress at work</li> <li>• <b>Going through a divorce</b></li> </ul>	<p><i>down, it was fine.” (Charlie)</i></p>		
Self-awareness of perspectives and behaviour	<p>Not paying attention to things that happen that aggravate illness like:</p> <ul style="list-style-type: none"> <li>• Feeling responsible for others</li> <li>• <b>Lack of observing oneself</b> and one’s physical and mental limits</li> </ul>	<p><i>“[...] my life just stopped for about nearly 8 to 10 years and it was just really depressing; really, really depressing cause on top of that you can’t do anything, you can’t go anywhere [...]. I realised that I had to slow down and sometimes I still have this battle with wanting to get up and run around and do everything and <b>for short moments in time I forget I’ve got a stoma and then I’m shattered at the end of the day</b> or I’m falling asleep and then I realise that no, I can’t really, I can’t really do as much as I’d want to do and I have to slow down, kind of thing.” (Celine)</i></p>	<ul style="list-style-type: none"> <li>• Being self-aware/<b>regularly ‘checking’ the state of the Self</b></li> <li>• Developing courage and acceptance of one’s limitations in order to change old patterns of behaviour</li> <li>• Learning to say ‘no’ to others who encourage obligation or life pressures in moments of recognition of one’s limits</li> </ul>	<p><i>“I mean <b>I still probably do a bit too much but I try [...] and be aware of that</b> so. And basically just work it into my new life, which is, you know, I want to do stuff during the day. So you have to incorporate a new life style, which fits me cause, then I still manage to do things I want to do. Maybe not all of them, all of the time but most of the time, which helps mentally really [...].” (Celine)</i></p>

When looking at the first point, 'Getting Support', participants described this when talking about not receiving enough care, understanding, and information about IBD or a lack of treatment choices, which seemed to make them feel that they were losing control of their life situations. The example provided in the third column demonstrates the lack of understanding by others (in this case Calvin's boss) about IBD, which made circumstances unnecessarily stressful thereby giving sufferers a sense of a lack of control of their lives or illness. The ways of coping with these issues mentioned by the participants included: receiving care from people close to sufferers, communicating suffering with others whether they were sufferers or not, getting information about IBD or being informed about a variety of treatment options.

The second point, 'Identifying Personality traits' emerged from looking across cases where participants described having or adopting personality traits that affected the health of their bowels. The traits that appeared to prompt a loss of control in the sufferer's life were when they were: over-worrying about things, being too sensitive, self-reliant or a "high achiever" (Isa). The ways of coping mentioned by the participants were both methods of thinking as well as patterns of behaviour that made it possible to either avoid or deal with 'illness aggravating traits', for instance: being more laid back or relaxed about things, keeping calm, accepting help from others or pacing oneself in life. These traits enabled participants to regain control of their illness and cope better with life situations.

All participants mentioned a connection between emotions and illness (the third element in Table 6.2), in particular the loss of control of the Self or illness from negative emotions aggravating their IBD. There was a range of emotions including: feeling grief or sadness from the loss of someone close (for example, death of a family member); worry, anxiety or stress, for example, felt at work or during academic studies; anger or frustration, for example, from repeated efforts to try and heal or "storing" and not dealing with anger (Venezia); and feeling sorry for oneself (self-pity) connected for example, to the helplessness of their suffering and feeling guilty about, for example, how their lives were affecting others around them because of their illness. While all participants described their own individualised ways of coping depending on their life situations and perspective of the Self, the main ways they explained would help them regain control of their illness and lives were by expressing their emotions as they occurred and/or giving themselves more time to process emotions fully.

The fourth element in Table 6.2, 'Life events affecting illness/health', emphasises that certain unforeseen circumstances happen in life and they can take people by surprise in terms of how suddenly they come on and how there is a sense of loss of control of situations in which IBD sufferers are immersed. This characteristic "unpredictability" or "uncertainty" was talked about by all participants with regard to losing control of situations and their illness precisely

because of coping with untimely events such as: death of a family member; unemployment; stressful circumstances (for example at work or at home) connected to feeling responsible or obligated to others; or going through a divorce (as described in the example presented by Charlie in Table 6.2). The main ways of coping mentioned by participants in dealing with these types of circumstances were to settle unresolved issues or avoid/change situations that caused negative emotions.

The fifth and final element in Table 6.2, 'Self-awareness of perspectives and behaviour', is something all participants mentioned as important in regaining control of their lives and illness. Participants expressed that not paying attention to things might aggravate their bowels (see Celine's example in Table 6.2) such as: feeling depended upon by others (for example, financially or doing too many favours for others) or not observing themselves when they might, for example, be feeling tired or unwell meant a loss of control of their illness and lives. Most participants found that being self-aware, regularly checking the Self, having courage and accepting their own limitations as well as learning to say 'no' to others who made them feel pressured or obligated to perform tasks, particularly during times when they felt unwell, were all ways of coping that helped them regain control of their illness and lives.

This section outlined the main points identified where participants talked about losing and regain control of illness with various ways of coping. Although these points may seem straightforward and oversimplified, they are all interrelated and happen in a messier way in real life. It is also important to note that this making sense of what happened through re-telling of life stories happened after participants had some time to make sense of their circumstances and illness. Hence their analysis in giving meaning to actions was retrospective and may not have fully represented what they may have felt, thought or reacted to including ways of coping, during these life events. Nevertheless, this retrospective making sense of illness and reporting of the use of various ways of coping provides insight into how participants re-presented their journeys in living with IBD particularly with regard to losing and regaining control of the Self, illness and the way they lived. The following section moves on to present a detailed analysis of particular cultural influences participants' stories drew attention to and the ways in which these influenced their choice of treatments.

#### **6.4 Cultural Influences**

As mentioned in Chapter Three, cultural influences are defined as 'factors' which influence people's day-to-day lives by shaping or guiding their way of life within the context of living with a long-standing illness. In particular, it involves the receptivity towards cultural influences which makes sufferers more open to recommendations on TCAM treatments over other more conventional healing practices. In order to examine why sufferers adopt

particular healing practices it is important to examine the life events leading up to those decisions. The following section looks at the types of cultural influences and the factors considered in the process of making decisions on TCAM treatments (Decision Point 2).

#### **6.4.1 Considering Context**

Although issues around cultural influences were the most prominent data that emerged from looking at the life events leading up to decision points, these should be recognised as part of a complex, ever-changing process immersed within a context. Analysis of the interviews identified two main ways in which participants considered the context they were in when talking about cultural influences and thus whilst being potentially guided by the cultural influences. Firstly, there is context in the sense of an unfolding illness experience whilst making attitude and/or lifestyle changes. Secondly, there is context in the sense of spatial environment and/or characteristic ambience.

An example of the first sense (unfolding life experience) is taken from Isa. By the time she reached thirty five years old, she described making “*big lifestyle changes*”. Isa explained in her narrative that she had met a number of people who guided her towards using Homeopathy *before* making these changes. However, she seems to have only taken the decision to try out this modality *after* experiencing, and thus in her interviews expressing, her discontent with situations in her life. Perhaps if Isa had been more satisfied, she may not have been influenced to try Homeopathy even if the cultural influences recommended she did so.

An example of the second sense (context as a spatial environment which contributed to deciding on a healing practice) was presented in Eden’s case. She had described going with her mother to visit a “*herbalist*” when she was a child. Eden enthusiastically described the shop, its smells, the containers in which herbs were stored, the bell that sounded when she walked into the shop and the liquorice twigs her mother bought her. She seemed to connect this physical environment from her childhood with the characteristic ambience and paraphernalia of her Chinese Medicine clinic by saying “*I suppose it was our equivalent of the Chinese herbs you saw when you went to the Chinese doctor*”.

#### **6.4.2 Types of Cultural Influences**

Participants mentioned several cultural influences in the life events leading up to their using non-medical healing practices. Table 6.3 displays four groups of cultural influences: people, media, Medicine and miscellaneous.

‘People’ was the most mentioned significant cultural influence, indicated by all the participants. For all but Celine and Halston, ‘family members’ were mentioned. For Isa,

Celine, Eden and Cristalle 'friends' also were noted, and Isa, Venezia, Celine, Cristalle and Charlie pointed to the role of 'professionals'. In contrast, the 'media' was least mentioned (by three participants, Venezia, Celine and Calvin). All the participants except Isa, Calvin and Cristalle, spoke of having cultural influences in the 'Medicine' category. The 'miscellaneous' category covers a range of influences, including a particular therapy or programme (Venezia and Charlie), locations (Celine and Charlie), a national system (Charlie), a cultural trend and illness-related concepts (Halston). Finally, looking down each column in relation to each of the participants, Venezia, Celine and Charlie noted cultural influences under each of the main types.

It is important to emphasise that all participants mentioned several cultural influences in their narratives, but only the ones evident in the data selected for focussed analysis of life events leading up to Decision Point Two were included in this Table 6.3. For example, Eden did not mention being affected by a cultural influence listed in the 'media' category; however, she talked about her husband "*hav[ing] a look on the computer to find out more about [her] condition [“anaemia of chronic disease”]*". So even though she did not use the computer (that is, media as cultural influence) to find out about a non-medical healing practice, she showed that she used it in order to get information that might help her in living with her illness.

**Table 6-3: Types of cultural influences guiding participants towards using non-medical treatments**

Categories		Isa	Venezia	Celine	Calvin	Eden	Cristalle	Charlie	Halston
People	Family	parents	brother ----- kids		mother ----- family	mother	father ----- mother	wife ----- sister	
	Friends	osteopath friend from university ----- other friends		bohemian school friend & her parents		a fellow Samaritan	friends		
	Professionals	consultant	GP	youth worker ----- homeopath			mediums	gastroenterologist ----- neurologist at another hospital pain clinic	
Media		book	the net ----- alternative medicines sites ----- TV	dalai lama autobiography					
Medicine		surgery	medication		drug therapy		antidepressants ----- hospital	being in hospital	
Miscellaneous		psycho- therapy	community centre				living with pain program ----- house ----- benefits system	age, health ----- marathon boom	

### 6.4.3 How Did Cultural Influences Affect Participants?

There are eight key factors evident in the data that directly or indirectly guided participants towards choosing non-medical healing practices, which are examined below. The eight factors are listed and their meaning illustrated in Table 6.4; the illustrations represent one 'typical' and one 'atypical' example, where applicable, of how these factors were considered whilst being guided by cultural influences (highlighted in bold font).

**Table 6-4: Factors raised by participants when being guided by cultural influences**

Factors	Typical and atypical examples of each factor
Doing things differently	<p>"After four years of lots of <b>chemical stuff</b>, anything that's naturally helpful, I'd like some alternative just for longevity of me really." (Celine)</p> <p>"I got to my mid-thirties and start[ed] to think about [my] condition, how healthy [I was], how fit [I was] and what impact [age is] going to have on all that. When you were younger you could knock off for two or three weeks and go back and everything was fine. Now you knock off for two or three weeks and it takes you a while to get back and that's just an <b>age thing</b> I think." (Halston)</p>
Having a connection	<p>"One of [my] <b>friends</b> had been to a homoeopath here, so that's what I did, I went, on a personal recommendation." (Isa)</p> <p>"It was around the time of the <b>marathon boom</b> [when] there was a big boom in running in the early eighties. I thought 'I need to do something so I'll see what's running like'." (Halston)</p>
Openness to TCAM	<p>"A <b>fellow Samaritan</b> had a daughter who had one of those terrible situations; she was born with eczema [...] when she heard of this Chinese doctor [in town] and they went to see him. He took her care in hand and with remarkable results; with diet and with his herbs he completely cleared this problem for her." (Eden)</p> <p>"I look it up on the net and see if it can help, well just do a search really, even health food sites sometimes give you a bit of information. Then there are horticultural sites, homeopathy sites and <b>alternative medicines sites</b> that can give you a bit of information on different herbs and stuff." (Celine)</p>
Trusting	<p>"I think it's just proving to you that they have got your relative there by telling you things. They're fascinating! Some [<b>mediums</b>] can be good but some can be rubbish." (Cristalle)</p> <p>"I knew the [<b>community</b>] centre, it wasn't a new place [so] went into the centre and did courses from there [...] and then [left] the kids at [their] crèche." (Celine)</p>
Death of a family member	<p>"In 1992 my <b>father</b> passed away and I think that was a trigger for my condition of Ulcerative Colitis. I tried to remain strong [...] and not break down [but] maybe I [should] have broken down, been more emotional, cried more [and] let it out that way instead of it coming out in [my] colon." (Cristalle)</p> <p>"[<b>mediums</b> have] told me [my father's] always around me so that's why I always think 'oh, he's looking after me' or [with] my mum now, they're both up there." (Cristalle)</p>
Loss of a safe environment	<p>"When I came out of hospital, I couldn't work, I was reliant on <b>benefit</b> and [...] I used to sit in my flat in the dark because I had no money. I couldn't take any stress and if I had a little bit of stress, just say a household bill,</p>

	<i>I'd have to run to the toilet." (Charlie)</i>
	<i>"I was in [<b>hospital</b>] for four months [and] what it did to me was it made me institutionalised. I didn't want to come out because it was a safe house." (Charlie)</i>
Convenience	<i>"I'd just had surgery and I was trying to get out and about again and [...] there's the <b>local community centre</b> near me [... where ...] basically you took the kids to the crèche and then you did [a] course." (Celine)</i>
Divorce	<i>"I think [my Crohn's] is the [accumulation of] problems regarding the <b>divorce</b>, the work problem and health problem." (Charlie)</i>

For the first factor '*Doing things differently*', Celine is a typical example of how many of the participants expressed their need to use less medical treatments; participants commonly spoke in terms of *trying alternatives*. In contrast, Halston is more atypical; his emphasis lies on getting older, and by implication the length of time he has lived problematically with IBD. Only few participants expressed reflections of the Self as getting older in relation to their decision to use non-medical treatments.

The second factor, '*Having a connection*', shows something that seems to have been preferred by most participants, that is, their being introduced to non-medical healing practices through personal recommendations. Halston, on the other hand, presented another way of demonstrating how having a connection with a cultural trend, in this case the marathon boom in the mid-eighties in the UK, can guide someone to using non-medical healing practices.

The third factor '*openness to TCAM*' was the next most prevalent factor considered by participants. Eden's quote conveys a typical example of how a cultural influence's own' openness to TCAM, in this case a colleague/friend's daughter's successful use of Chinese Medicine, contributes to guiding participants in their choice of non-medical healing practices. In contrast, Celine's quote demonstrates a less typical example; she, and others, talked about their use of Alternative Medicine sites, from which she gets information that would probably be pro-TCAM.

The next factor, '*trusting*', showed a need for some participants to trust the cultural influence and thus to consider and then act on their cultural influences' suggestions. Cristalle's quote expresses her way of validating the skill of mediums; she goes to for readings, commenting on how some are better than others in accurately being able to tell her things about her life. Celine's quote presents a less typical example. Being familiar with her local community centre and having already come to know the staff, she implies having trust in using it to learn more about non-medical healing practices.

The following four factors: '*Death of a family member*', '*Loss of a safe environment*', '*Convenience*' and '*Divorce*', were factors that reflected cultural influences for three participants (Cristalle, Charlie and Celine). These influences seemed to apply less to the other participants.

The cultural influence of '*Death of a family member*' was pointed to by Cristalle and Charlie. Cristalle expressed how the loss of her father and later her mother, "*trigger[ed]*" her UC. She explains how the internalising of emotions, which should have been externalised, caused her to be unwell. In this case Cristalle might have been searching for a healing practice that enabled her to externalise her "*grief*" about losing her parents. The second quote, again from Cristalle, is more atypical example; it, demonstrates how wanting to keep connected to a family member who has passed away may be something considered by participants when looking for a healing practice.

The factor '*Loss of a safe environment*' emerged only from Charlie's narrative. The first quote is a typical example of this factor for Charlie, as it has to do with his welfare and security, which had an effect on his health. He talks about his insecurity of not being able to work and therefore being dependent on the UK benefit system. In particular, he describes the stress of claiming benefits in combination with having no money to pay utilities as directly affecting his bowels. In this case, Charlie might have been searching for a healing practice context, which he could access at low cost that allowed him to interact on a more social level with people who might have similar issues and health problems. The second quote expresses how Charlie 'lost' a safe environment by leaving the hospital he was in for four months. He describes his life, mostly alone, outside the hospital as less secure, with less social interaction and care. This may be an important reason why he was more receptive to the free skills for life programme he attended.

Similarly, only one participant, Celine, mentioned issues that implied '*Convenience*' as a factor as guiding her choices about healing practices. The extract shows two aspects of convenience in using her local community centre: firstly, having convenient access to this centre, which she described as 'near'; and secondly, being able to multi-task by leaving her children at the centre's crèche whilst simultaneously attending a course on Homeopathy. This demonstrates how the convenience of this cultural influence made it more receptive to her finding a non-medical healing practice in living with CD.

Similarly, the last factor '*Divorce*' applies only to one participant, Charlie. The way he talks about no longer having a family with his wife and daughter suggests its significance as a cultural influence on his decision-making. He "*blame[d] [him]self*" for the divorce and consequently described this cultural influence as part of an "*accumulation*" towards "a

*nervous reaction*”; Charlie mentioned wanting to “*talk about problems*” and “*getting it out*” rather than “*bottling it up*” as something that “*helps [him] to keep on looking for things that [enable him to] get [on with his] life*”. Perhaps looking for a healing practice and/or environment that made it possible for him to do this was what Charlie seemed to be doing when deciding on non-medical healing practices.

#### **6.4.4 Analysis of the Eight Factors**

The following section provides further and more detailed insight into the issues that participants described leading up to these eight factors all of which are considered as being guided by cultural influences in choosing non-medical healing practices.

##### ***Doing things differently (using replacement and/or compensatory activities)***

This factor can be further sub-divided into ‘*doing things differently*’ as a replacement and/or as a compensatory activity. A replacement activity is defined as where a participant stops an old pattern of thinking and/or behaviour and replaces it with another. A compensatory activity is where a participant introduces another pattern of thinking and/or behaviour and combines it with an old pattern of behaviour in order to compensate for something not achieved with the latter way of thinking and/or behaviour. These ways of doing things differently can happen either directly or indirectly because of cultural influences. Seven of the eight participants (Isa, Venezia, Celine, Calvin, Eden, Charlie and Halston) described using replacement activities, and just one (Halston) talked about using a compensatory activity whilst doing things differently. Cristalle did not mention this factor.

For the seven participants who found replacement activities, reasons covered six factors.

- *Negative experiences using Medicine* – three participants (Venezia, Celine and Charlie) described having negative experiences in using medical drugs due to their negative effects with Celine adding problems she had with addiction to painkillers. Venezia also mentioned the lack of support from the NHS system. Furthermore, she described her dislike of surgery as a method of treatment for UC adding that she thought Medicine to be a “*cold*” and “*faceless*” healing practice.
- *Experiences of Medicine not working* – two participants (Eden and Charlie) explained how they had used surgery but had unfortunately not seen many benefits or change from this healing practice. Eden also emphasised her necessary yet unsuccessful use of medication and supplements in attempting to alleviate her “*attacks of flux*”.
- *Opposing encultured ideas* – two participants (Isa and Calvin) mentioned wanting to do things differently from the enculturation of beliefs and ways of coping practised by their

families with regard to living with illness. In Isa's case it concerned her family's use of medical treatments and in Calvin's case it was his disinterest in his family's religious beliefs as "*Christians*".

- *Considering emotions* – one participant, Venezia, talked about how her role as a mother encouraged her to make some "*changes of attitude*" towards her illness in order to deal with her emotions, avoid getting flare ups and therefore gain greater energy to be with her sons more.
- *Considering aging* – one participant, Halston, spoke about age related to being fit and healthy. He described how age also affected how long he took to build up muscle again to go running, after a period of being ill.
- *Considering inactivity* – one participant, Halston, mentioned his "*sedentary employment*" implying the need for movement, which he described when talking about commuting to work from home and back by running instead of using a car. This is regarded as Halston finding a compensatory activity, rather than as a replacement activity, for the following reason. Halston started running instead of using a car to go to work. He could have chosen to change the way he worked at his job by standing at a raised desk but the fact that he continued to work sitting down shows that he also used running as a compensatory activity to move the stagnation of sitting at his desk during working hours.

### ***Having a connection***

As the second most mentioned factor, '*having a connection*' with cultural influences was present in all the participants' narratives. The following six issues were linked with this factor.

- *Likeability* – three participants (Isa, Celine and Eden) described their relationships to their cultural influences with regard to how likeable they were. All three talked about being friends with their cultural influences except in the case of Isa's consultant who she liked because of his "*quirky personality*". This 'trait' in a cultural influence infers a sympathetic connection to participants that could make them more receptive suggestions of using non-medical healing practices.
- *Networking* – three participants (Isa, Cristalle and Celine) talked about getting to know about a healing practice through networking either via word-of-mouth or, like Isa, by "*personal recommendation*".
- *Getting support* – two participants (Venezia and Halston) pointed out the importance of the need for support by healing practice professionals by describing the *lack* of support

they felt, Isa by her GP and Halston when he was hospitalised saying he found hospital a “*strange place*” and that “*you become a bit numb*” with “*people do[ing] things to you*”.

- *Being referred* – one participant, Charlie, talked about getting a referral from his neurologist to the ‘Living With Pain’ program, which helped him learn “*about living with pain*”. He was later recommended to attend the ‘Skills For Life’ program in order to help him cope with his illness with regard to using non-medical healing practices.
- *Ideological familiarity* – one participant, Calvin, described himself as “*always [having] had the ability to cope with problems without too much grief*” and “*not being affected so emotionally*” by his illness. He expressed being interested in meditation as practised by Tibetan monks implying a connection between his and their way of controlling emotions explaining that through their way of meditating he “*might be able to control [his] illness*”.
- *Interest in cultural trends* – one participant, Halston, described having an interest in running during the “*marathon boom*” in the 1980’s in the UK as a potential way of getting fit linked with his need for movement from his “*sedentary employment*”.

### **Openness to TCAM**

The following factor was one that emerged from four participants who talked about their cultural influences’ openness to TCAM. Participants talked about three issues leading up to this factor:

- *Experience in using TCAM* – For three participants (Isa, Celine and Eden), they mentioned friends having knowledge of, or having tried a TCAM healing practice. Aside from friends, Isa said her consultant “*used regularly a hypnotist as part of his clinic*” in treating IBD patients. Eden might have been more open to Chinese Medicine because of associations she made when comparing it to the herbalist her mother used to visit, when she was a child.
- *Finding familiarity* – two participants (Venezia and Celine) talked about their familiarity with their cultural influences. Venezia seemed to relate to something she read in the chapter of a book her brother gave her about “*a deeper, psychological issue at play*” linked with the manifestation of symptoms in IBD. Similarly, Celine talked about what she had learnt at the Homeopathy course she attended at her local community centre. She described this healing practice and how she related to it because of its “*use of natural elements to create remedies to work alongside and enhance the body’s own abilities to heal itself*”. Celine also mentioned her interest in TV documentaries and that she had seen one on Homeopathy before attending her course, which she implied, made her more open to doing the course at her community centre.

- *Getting information on TCAM* – one participant, Celine, described how when she is interested in finding out more about a particular homeopathic remedy or “*a bit of information on different herbs and stuff*”, she goes on “*horticultural sites, homeopathy sites and alternative medicines sites*”.

### **Trusting**

Trusting a cultural influence was something mentioned directly or indirectly by four participants. The following issues show why participants trusted their cultural influences.

- *Knowledge of professions* – four participants (Isa, Celine, Cristalle and Charlie) spoke enthusiastically about the knowledge their cultural influences had in their professions. Isa and Charlie seemed more open to suggestions about non-medical healing practices by their medical professionals because of their knowledge of IBD. Celine described being similarly impressed with her homeopath’s knowledge of her profession and Cristalle said that “*more often than not there is some part of a reading that gives [her] proof that [her parents] are around, with things that have been mentioned*” by mediums.
- *Feeling safe* – one participant, Celine, mentioned being able to leave her kids at the crèche of the community centre whilst she attended courses which implied her trust in the community centre staff as she had “*done ‘mums and tots’ with the older two*” children.

### **Death of a family member**

This factor came up in this study with only two participants (Cristalle and Charlie) as they expressed the following issues around coping with the loss of a relative in relation to IBD.

- *Externalising Emotions* – the need to externalise emotions was something that both Cristalle and Charlie expressed, particularly with regard to losing their relatives. They both spoke of not “*bottling it up*” emotions like anger and sadness and “*let[ting] it out instead of it coming out in the colon*”.
- *Staying Connected* – both Cristalle and Charlie described feeling connected to their deceased relatives with Cristalle saying her parents are “*both up there*” and are “*looking after [her]*” and Charlie describing he “*felt like [his] sister had sent*” the “*new minister for the church*” to console him.

### **Loss of a safe environment**

The following two issues that came up from analysing this factor were both expressed only by Charlie.

- *Less company and care* – After four months in hospital, Charlie said he felt “institutionalised” as he had tried going home for a weekend before he was discharged but said he “was so scared” of the traffic on his way home that he wanted to “get back to the hospital”. He talked about his experience living alone at home and the care and company he got in hospital, which might have contributed to his fear of leaving after being discharged even though he “used to have a CPN [Community Practice Nurse] come to see [him]” at home.
- *Feeling trapped and dependent* – Charlie talked about two situations in his life that contributed to his illness because of cultural influences. After leaving hospital, he said he could not work due to his illness and was therefore “reliant on benefit”. Later he pointed out the “rigmarole” of claiming affected his bowel as well as the occasional discomfort of “sit[ting] in [his] flat in the dark because [he] had no money”.

### **Convenience**

This factor was mentioned only by Celine with reference to the following two issues.

- *Accessibility* – Celine talked about the fact that “there was a community centre near [her]”, so she could access it easily with her four children to be able to attend the Homeopathy course there.
- *Doing simultaneous activities* – Celine talked appreciatively about being able to leave her kids at the community centre crèche at the same time as attend the Homeopathy course.

### **Divorce**

After getting divorced, Charlie described being alone and retrospectively “blamed [him]self for things” saying he “was really selfish up to before [he] went into hospital with Crohn’s” and added that he thought “things happened to make you think differently”.

## **6.4.5 Summary of Cultural Influences**

This section has presented the range and types of cultural influences which affected participants in making decisions on TCAM treatments and the ways that cultural influences affected them. All the issues leading up to these eight factors drawn out in the analysis and interpreted as the ways cultural influences affected participants, seem to be motivators towards their decision-making within different contexts. Aside from the last four factors, which are more pertinent to only three of the participants (Celine, Cristalle and Charlie), it is possible to view the issues in all eight factors as informative to the other participants as well as perceiving them as concepts preceding making decisions on non-medical healing practices such as TCAMs. Having examined the issues and factors motivating participants to

decide to use TCAMs as suggested by cultural influences, the next section explores how participants used healing strategies to, firstly, preventively avoid and, secondly, curatively take care of issues and symptoms in living with IBD.

## **6.5 Current Healing Practice Strategies**

Participants described an extensive range and variety of issues and symptoms including: pain, diarrhoea, watery stools, trapped wind, blood in the stools, losing water and body salts, having too firm stools, loss of appetite, losing weight, feeling tired, feeling or bottling up negative emotions (anger, grief) and wanting to go out for fun. By examining participants' preventive or curative use of their current healing practices, it was possible to analyse the strategies they used to heal these symptoms and take care of these issues.

A key question to ask is: how can participants have healing strategies without knowing what they need or dislike? The descriptions of how and why the participants used their current healing practices provide insight into this and the way that their current healing strategies can be considered a reflection of their perspectives of themselves. The following section of the cross-case analysis explores the parts of the Self involved when using their current healing practices and their applying healing strategies more mechanistically or more holistically. As explored in Chapter Five, parts of the Self may include: the Self as Body, the Self as Mind, the Self as a Social being and the Self as Mind, a Spiritual & Social being. The analysis builds on the individual case analysis in the section 'Perspectives of Self' in Chapter Six. For example, Isa described using Mesalazine "*foam enemas*" during a "*flare up*" she could not "*control*" since her "*disease*" affects her "*rectal end*". The description of the anatomical location of her disease as well as the acute severity of the flare up pertain to a more mechanistic view of illness involving the Self as Body, which can be linked to a more mechanistic healing practice like a Mesalazine foam enema.

This section mirrors the structure of the previous section looking at cultural influences. It begins by enumerating the types and range of *preventive* and *curative* healing practices that the participants used. It continues by exploring their use overall in relation to different parts of the Self. The final section examines the parts of the Self that linked to *current* healing strategies, which participants described when using healing practices more preventively and curatively.

### **6.5.1 Preventive and Curative Healing Practices**

The following tables present the healing practices participants used more preventively (Table 6.5) or curatively (Table 6.6) in trying to avoid flare ups or control them in considering what they liked and disliked, that is, their perspectives of the Self. The following tables display the

healing practices used to heal different parts of the Self. The parts of the Self in each of the tables are ordered in relation to, firstly, the more singular parts of the Self and then, secondly, onto the more 'multi-part' Self perspective.

In both tables, the first column on the left-hand side represents the parts of the Self interpreted from data analysed as part of the individual case analysis. These labels are not definitive but provide loose categories in order to better understand how and why participants used healing practices. The first category is the Self as Body, which is concerned with anatomical and/or physiological characteristics. The next category, Body and Mind, includes characteristics involved with the mind such as emotions or stress. The Body and Vitality category concerns more than just the physical in terms of the Body having energy but also vigour. The category after that looks at the Self as Body and as being a Mother, looking at the connection between feeling physically tired and wanting to be a better mother. The following two categories look at the Body and Mind in combination with the Self as a Social Being needing to be healthy enough to socialise with other people; the former is more concerned with body image in a social realm and the latter with being able to have fun in a social environment. The last category in both tables includes the Mind and the Self as a Spiritual Being (concerned with connection to ethereal entities).

Looking at Table 6.5, the healing practices participants used more preventively, it is evident that most participants used healing practices linked to the Self as Body. Five of the participants watched their diets and three were using medical drugs. All participants except Eden, Cristalle and Charlie used healing practices linked to the Body and Mind parts of the Self. Of these, Isa and Venezia used listening therapies (Counselling and Psychotherapy) with Isa also using Swedish massage, Halston using running and Celine and Calvin using resting. While Venezia and Eden also used resting as a healing practice, this was linked to, and is located in, the Self as Body and Being a Mother category and the Body and Vitality parts of the Self for these participants respectively. Only Calvin used a healing practice (doing exercise) linked to the Body and Social Being parts of the Self as well as Mind and Social Being (listening to music). Charlie also used positive thinking as a healing practice for this category, as well as going to mediums, receiving "*some nice messages*" connected to healing the Mind, Spiritual and Social Being parts of the Self.

Table 6.6 displays the healing practices that were used more curatively linked with parts of the Self. All participants except Venezia used healing practices (medication, resting, not eating, and drinking more water) linked to the Self as Body. Isa, Venezia and Celine used healing practices linked to the Self as Body and Mind with all three participants using Homeopathy as well as Celine taking Co-codamol. Only Eden used Dioralyte as a healing

practice for the Body and Vitality parts of the Self and Cristalle was the only participant going for readings linked to the Mind and Spiritual parts of the Self.

**Table 6-5: Types of healing practices used more *preventively* reflecting participants' perspectives of Self**

PERSPECTIVES OF SELF AS:	Isa	Venezia	Celine	Calvin	Eden	Cristalle	Charlie	Halston
BODY				Having healthy food & drink	Taking bulking agents	Watching her portions	Taking Mesalazine	Taking Mesalazine
					Having to watch what she eats & drinks		Watching what he ate	Making diet changes
BODY & MIND	Having Swedish Massages ----- Having counselling	Psychotherapy	Resting	Resting				Going running
BODY & A MOTHER		Resting						
BODY & A SOCIAL BEING				Doing exercise				
MIND & A SOCIAL BEING				Listening to music			Thinking positive	
MIND, A SPIRITUAL & SOCIAL BEING							Getting nice messages & meeting nice people	

**Table 6-6: Types of healing practices used *more curatively* reflecting participants' perspectives of Self**

PERSPECTIVES OF SELF AS:	Isa	Venezia	Celine	Calvin	Eden	Cristalle	Charlie	Halston
BODY	Using Mesalazine foam enemas		Using clip-on stoma bags	Taking medical drugs: steroids, anti-inflammatories & immuno-suppressants	Taking steroids ----- Taking Omeprazole ----- Taking Metronidazole	Drinking more water	Resting ----- Taking steroids ----- Not eating	Taking steroids
BODY & MIND	Resting ----- Using Homeopathy	Using Homeopathy	Taking Co-codamol ----- Using Homeopathy					
BODY & VITALITY					Resting ----- Dioralyte			
MIND & A SPIRITUAL BEING						Going for readings		

### 6.5.2 Parts of the Self linked to healing practices

The following section presents the more specific parts of the Self that current healing strategies are taking care of. Tables 6.7 and 6.8 respectively show the way participants described using healing practices more preventively and more curatively linked to parts of the Self that they described or elicited. The 'Perspectives of Self' column has been split into two columns: the first contains the main categories similarly presented in Tables 6.5 and 6.6; the second has more specific labels looking at particular parts of the Self linked to the adjacent columns displaying healing practices and their descriptions.

In Table 6.7 the majority of participants used preventive healing practices linked to healing the Body. Of these, five described their bowels with regard to functionality and how to keep healthy through diet including Eden's use of bulking agents in order to give her body "*time to absorb the goodness*" of her food and drink intake. Only Charlie and Halston talked about their bowels more anatomically, with regard to avoiding inflammation by taking Mesalazine, thereby healing the Body more as a pure object.

All participants except Eden, Cristalle and Charlie used preventive healing practices to heal the Body and Mind. Four out of five of these mentioned using healing practices (Swedish massage, counselling, resting, psychotherapy and going running) dealing with the emotional aspects of their illness. Venezia and Halston described using Psychotherapy and running respectively in order to help the Body part of the Self. For Venezia, the therapy was used to interact with cellular change and for Halston to help his "*digestive system*" better function. Celine and Charlie elicited using resting for stress as well as Isa having Swedish massages and counselling to help her relax.

The next two main categories, 'Body & Vitality' and 'Body and Being a Mother', are linked to resting. In Eden's case, this was to help her body's "*well-being*" as well as regaining vigour. In Venezia's case it was to trigger her body's "*self-healing*" in order to have enough energy to be with her children.

The last three main categories consider the Self as a Social Being. Calvin mentioned doing exercise to also improve his body image and described how "*chilling out*" whilst listening to music helped the Mind part of the Self as well. Charlie explained how thinking about nice things and "*talking about his issues*" helped his mental well-being. He was the only participant who mentioned using psychic messages preventively, which is linked to the Self as a Spiritual Being.

**Table 6-7: Preventive healing practices and strategies linked to parts of the Self**

PERSPECTIVES OF SELF		HEALING STRATEGIES	PARTICIPANTS DESCRIBING USE OF HEALING PRACTICES
BODY	Controlling the bowel	Taking Mesalazine	<i>"[...] finally they discharged me and they told me what had happened, that [CD] had <b>blown my bowel up</b> and they were <b>frightened of it bursting</b>. [...] he said 'you'd be on these <b>tablets for the rest of your life</b>', which was <b>Mesalazine</b> [... which has been] [...] prescribed since I came out of hospital [...]" (Charlie)</i>
		Taking Mesalazine	<i>"[a flare up is] mainly pain and you do tend to get the <b>diarrhoea</b> and things of that nature. You don't have any [appetite] [...] and then you <b>don't want to eat</b> anyway because, then you need to go to the toilet all the time [...] and that's when you then [...] get <b>abdominal pains</b> as well. I take the Mesalazine because they said that would <b>help [...]</b> <b>extend any remission</b> [and] <b>delay the onset of acute conditions</b> [...]. I think it probably does, I think it maybe helps. I do tend to <b>increase a dose if am going to the toilet a lot</b> and that seems to help a little [...]" (Halston)</i>
	Helping the digestive system	Having healthy food and drink	<i>"Obviously I wasn't taking that much care of myself really that well until recently but now I [eat] healthy foods, clean foods, I don't really eat sweets or drink fizzy drinks [...and drink] plenty of water. [I] make sure I eat plenty of fruit and vegetables; no artificial stuff and no sweets. Yeah just wholesome food. [Just] plenty of food, plenty of rest, having three meals a day and having a little fourth meal before I go to bed. I do eat plenty of meat and I just notice that I never go hungry. I'm not into spicy food." (Calvin)</i>
		Having to watch what she eats and drinks	<i>"I think it's important that people do eat as well as they can; <b>proper food</b>; proper things that we're supposed to eat. I'm not talking about people with less plumbing like myself cause we <b>have to watch what we eat</b> because of it causing <b>undue problems</b>. I know my <b>husband's passion</b> [is eating] <b>fruit, vegetables, salad</b> and anything like that so I'm so used to producing those sort of things for meals." [...] if you have diarrhoea and sickness you're <b>not supposed to take milk for at least two days</b> [as] <b>lactose isn't a good thing</b> to have apparently." (Eden)</i>
		Watching her portions	<i>"I was told I had to drink more because I wasn't reabsorbing with not having a colon. [...] you can eat anything. I watch my portions cause sometimes if I eat too much it is uncomfortable where the old scar is but it could be for any scar. I don't drink coffee. At that time I wasn't a big alcohol drinker. I think I drink more now really. I don't eat any spicy food. I don't like curries; I am not a curry person. So I am very basic, plain food eater. I think I eat red meat more now but I do like white meat and fish." (Cristalle)</i>
		Watching what he ate	<i>"[...] what I know now is [milk's] the worst thing they could've given me because milk has lactose in it. I had to watch what I ate because I had to avoid all pulses like beans, peas [...] cause I used to get wind. (Charlie)</i>

		Making diet changes	<p>“[...] more recently, I have been <b>cutting down on dairy and wheat</b>. So if I eat cheese, it’s <b>sheep’s cheese</b> and I <b>eat non-wheat, non-gluten based bread</b>. Well, we thought that might help [but] might not be ‘the cause’. So I think it helps probably <b>helps my not having a lot of cheese, milk and bread</b>. I’m not convinced that any food has any particular impact [...] but I just think it probably <b>helps my digestive system if I don’t eat as much cheese and [...] bread</b> and things like that. [...] it might just be my digestive system is such that it’s susceptible. [I] am really [cutting down on dairy] to <b>control the amount of times [I go to the] toilet [...]</b>. That may have an impact on the Crohn’s but the prime motivation is more to do [with] trying to <b>stabilize my insides</b>. (Halston)</p>
		Taking bulking agents	<p>“Obviously <b>food went through me at a hell of a rate</b> that [I had] got to <b>slow that down</b> because this was like eating a meal and it <b>not having the time to absorb the goodness</b> that you’re going to need. So for some time I’d been <b>taking a great many bulking agents</b>, which I still do. And at the time it was: ‘try fibre sachets and Celevac tablets and Imodium.’ I’m still taking the <b>Celevac</b> and the <b>Imodium</b> but it’s now <b>Fibre-gel</b> that I have to take. I mean I take <b>enormous quantities</b> per day. You’d think I’d be set like concrete but that’s far from the case.” (Eden)</p>
BODY & MIND	Dealing with stress & emotions	Having Swedish massages	<p>“well actually I feel that <b>having massage</b> helps me cause it <b>helps me relax</b>”. (Isa)</p>
	Dealing with stress, emotions & attitudes towards herself and others	Having counselling	<p>I’ve had counselling not specifically in relation to the Ulcerative Colitis but just <b>to help me generally</b>. [...] Obviously <b>for my mental health</b> but I feel that everything’s tied in really. I don’t think you can separate off your mental health from your <b>physical well-being</b> and the rest of it. So I feel that the counselling has helped with that as well. Through the counselling I <b>learnt more about relaxation</b> and <b>taking care of myself</b>” (Isa)</p>
	Dealing with stress & slowing down	Resting	<p>“If I want to do stuff on a night, then sometime during that day I’ve got to <b>sit down and have a rest [...]</b> or I <b>have a lay down [...]</b> for an hour then we’ll wake up and then go out. I have to <b>incorporate a new lifestyle</b>, which fits me cause then I still manage <b>to do things I want to do</b>. I can <b>get knocked out</b> if I’m out with the kids [...] or I’m too tired, [...] so for me it’s more an <b>excretion stress</b> as opposed to mental stress, if I <b>overwork myself</b> and over do stuff, that kind of stress [...], I mean <b>kids are stressful</b> situations and they can add to it.” (Celine)</p>
	Dealing with stress & emotions & feeling the intestines	Resting	<p>“If I’d had a good week and hadn’t <b>run myself down physically</b>. It’s just saying that I can’t do this for you because I’ve had a busy day and [am] having to <b>chill out</b>. [...] <b>looking after myself</b> and letting people know that I’ve got to look after myself. I’ll have to <b>be really careful what I do</b> and <b>get plenty of rest [...]</b> and just <b>rest when I need rest</b> and if I feel tired <b>having a quick nap</b> and making sure I <b>have a good night’s kip</b> and <b>get to bed in good time</b>. [With UC] you don’t really feel like doing anything much for it just <b>sitting down</b> or</p>

			even <b>lay down</b> and <b>put your feet up</b> and have a rest. (Calvin)
	Expressing emotions & interacting with cellular change	Psychotherapy	I “started to look at a lot of ways around <b>how I deal with emotional stuff</b> ” in particular, “feeling a lot of <b>anger</b> to do with some of my family relationships and bringing that into more sharp awareness has <b>refocused the energy into a consciousness</b> rather than avoiding it and the anger being turned inwards and coming out in a flare up way.” So “through the process of seeing a homeopath and seeing a psychotherapist over the last few years, I’ve <b>learnt to express emotions as they actually happen</b> rather than weeks later. So that’s been the preventative thing”. (Venezia)
	Helping the digestive system & switching off emotions	Going running	“I mean the <b>running helps dramatically</b> . I’ve always found it useful in times of you going from home to work [... as] a <b>slow transition</b> so by the time you get there, home’s back home and work’s where you are, and on an evening, similarly, you leave work and by the time you get home you’re home, and work’s somewhere else. [...] the fact that you’ve got yourself <b>in a car, you’re getting tense</b> and all that kind of stuff. <b>Running can be very relaxing and very therapeutic</b> in that sense as well. I think it <b>helps my mental health [...]</b> because it <b>keeps me calm and it helps you cope with all the stuff that’s going on</b> . You tend to <b>switch off when you go running [...]</b> . I think that one of the things is that it’s a <b>big relaxing thing</b> . I think mentally, I think <b>mentally</b> going back to that side of stuff it <b>helps on the stability side</b> . I use these terms non-clinically. I feel that it <b>helps my mental state [...]</b> because it helps keep me calm.” (Halston)
BODY & BEING A MOTHER	Triggering self-healing & self-responsibility	Resting	In the past “I’d have to have a <b>rest all the time</b> and was thinking ‘I don’t want to be this kind of mother’ [and] ‘I don’t want to be somebody that’s not able to be with [my kids] all day’. I was conscious [...] that this was my <b>body’s way of saying</b> that I <b>needed</b> something that I wasn’t getting in terms of <b>emotional support, rest or space to express myself</b> ” (Venezia)
BODY & SOCIAL BEING	Helping the digestive system & Not worrying what people think	Doing exercise	“When I first <b>started running</b> I was putting weight on because I wasn’t over doing myself so that I would lose weight. I saw it as <b>building up a bit of muscle</b> . [I] <b>do a few weights</b> . I get up in the morning and do a few <b>press ups</b> and a few <b>pull ups</b> and <b>go for a quick jog [... and...]</b> that’s pretty much my routine [...]. [I] just try to <b>get myself looking good</b> as well <b>so I’m not as skinny</b> as I am.” (Calvin)
MIND & SOCIAL BEING	Chilling out & having fun going out	Listening to music	“I quite like listening to music so I <b>put some music on and chill out</b> and don’t really do anything that is exhausting. [...] it has only been the last two or three years that I have been <b>going out and enjoying myself</b> . I go to see live entertainment, I’m really into music so I <b>go to see live bands</b> . It’s what I like to do really it’s just go out to the local pub just to get out of the house really rather than just sitting in. [...] it’s <b>all about who you’re with, good friends</b> and you’ve got to make sure you go somewhere you enjoy. [...] give me good music and I’m well away. It could be <b>anything from heavy metal to the blues, a bit of jazz, even a little bit of classical</b> really. <b>Music that sets the mood, makes you want to have a dance or makes you smile or makes your hair stand on end</b> really. I like <b>ska and rock steady</b> and stuff like that.” (Calvin)

	Thinking about nice things & sharing issues with others	Thinking positive	<p>"I do use [relaxation and skills for life] to a certain extent regarding relaxing [...]. Like to <b>think about</b> other things; <b>nice things</b>. It's like <b>taking yourself off to a little house by the sea</b> [...]. It's like the <b>rain on the caravan</b> and things like that; it's <b>rain on the roof</b> [...]. The <b>sound of the water</b>; a lot of us are attracted to water for some reason, the little kids. I can't explain it; everyone is different [...]. I think I'm a bit <b>more laid back</b> than what I used to be back then because <b>before I was impulsive</b>. I would get worked up but <b>since I have retired</b> and <b>the stress doesn't happen anymore</b>. It's like <b>getting myself out</b> and <b>getting myself motivated</b> and <b>talking about my issues</b> and if anybody wants me to talk about my issues I will whereas <b>one time I was bottling it up</b> and now it doesn't bother me and <b>I am more relaxed about it now</b> than I was then [...]." (Charlie)</p>
MIND, SOCIAL & SPIRITUAL BEING	Expressing emotions, sharing issues with others & being connected to ethereal entities	Getting nice messages and meeting nice people	<p>"I used to <b>get some nice messages</b> [...] like the messages that people get, you only ever <b>feel that they pertain to yourself</b> [...]. [...] it's like reading the stars in the paper [...]. [...] it <b>made me feel good</b> [...]. It was <b>all nice stuff</b>, it's <b>nothing horrible</b> about it [...]. I go round the ["psychic"] church sometimes [...] <b>every Saturday they have the men's breakfast</b> [...]. I used to <b>go round there and talk about different things</b> and that. Yeah I enjoyed it. Yeah, they're <b>all nice people</b>. Yes, <b>very supportive</b> [...]." (Charlie)</p>

**Table 6-8: Curative healing practices and strategies linked to parts of the Self**

PERSPECTIVES OF SELF		HEALING PRACTICES	PARTICIPANTS DESCRIBING USE OF HEALING PRACTICES
BODY	Controlling the bowel	Taking steroids	<p>“I mean I’m very lucky in that, I got [CD] later in life and I have only had a few flare ups [...]. I have had steroids probably four or fifth times since the first time. Usually <b>when it’s acute I take them</b> for a couple of weeks then a week or so running down as it <b>gets a grip of [the CD]</b>. [...] the symptoms from my perspective were more in terms of the <b>pain</b> that I was getting, which is when you’d <b>end up with the steroids</b>. I get the steroids and that would <b>calm it all down again</b>.” (Halston)</p> <p>“[If I have a flare up] I always take steroids [...]. [my symptoms are] just <b>diarrhoea</b> [as my CD has] gone to colitis and IBS. I only use the steroids [...] <b>if I am that bad</b> [so] I go to the doctor’s [...]. (Charlie)</p> <p>“[...] if it’s a bad, <b>really bad attack</b>, I <b>take high doses of Prednisolone</b> [...] but from time to time they wean me off it because they don’t like you on it on a long-term basis. [there’s] really nothing else that <b>gets it calmed down</b>. [...] the only thing that <b>kept things under control</b> were the high doses of Prednisolone.” (Eden)</p>
		Taking Omeprazole	<p>“now I only have to take that <b>when I have an attack of flux</b>. [...] it covers a wide spectrum of things. [... my doctor] wanted me to have it because it <b>helps to dry out the output</b>. So that’s the only time I take it now.” (Eden)</p>
		Taking Metronidazole	<p>[...] I’d had this <b>gas and bacteria problem</b> for about three months before the medicals took it in hand. My bag was filling up not just with the <b>watery output</b> but it was like <b>having a bag of wind</b> and you’d got to <b>keep emptying it</b>, because there was just so much wind coming away from you [...]. [...] it was a <b>desperate situation</b>, it was <b>noisy</b>. [... a doctor] said ‘right I want you to <b>start taking Metronidazole 400mg</b>, three times a day and I think that should <b>control this bacteria</b>’, which is what was causing the trouble. It’s the <b>bacteria</b> that’s <b>producing all this gas</b>.’ Sometimes I can have an attack of flux and I don’t get the bacteria build up like this and other times I do. It <b>acts really, really quickly</b>. [...] I found that the whole thing was totally controlled by taking ten tablets.” (Eden)</p>
		Using Mesalazine foam enemas	<p>“my <b>disease</b> is <b>confined to the rectal end</b> so it’s quite <b>easy to use a foam enema</b> to reach it so I guess that would be an option if I had a flare up [and] I really <b>couldn’t control it</b>”. (Isa)</p>
		Taking medical	<p>“Hopefully I can come off [the steroids] successfully but I am on two other types of medication as well. Apparently they are ok to take over a long period of time so I suppose I’m not too fussed about them: the</p>

		drugs	<i>anti-inflammatories and immunosuppressants. [...] they just say that the <b>steroids have more long lasting negative effects</b> and I've taken them for a while, than the anti-inflammatories and immunosuppressants; they don't affect the body so much after a long period of time. I tried to explain that I really didn't see the point of [changing the other drugs] seeing that <b>my symptoms had settled</b> and there is actually no problems and I've gone back up on the steroids [...], there didn't seem to be any point in changing this medication if it is just relying on the steroids really." (Calvin)</i>	
		Using 'clip-on' stoma bags	<i>"the new one that's just come out is a click mechanism where you have a plate [...] that you stick permanently around your stoma and then you just click this [plastic ring] round and I'm <b>finding them really, really good</b>. I was a bit dubious cause obviously once you have more than one piece there's always more scope for leakages or whatever but these are really good." (Celine)</i>	
		Helping the digestive system	Resting	<i>"I used to go to the toilet and then I used to <b>lie on my bed</b> and what happened then was like, it was like <b>trapped wind</b> and it just <b>come away from me</b>. I used to <b>relax my bowel</b> and then I'd be alright. [If I had another flare up], well I would <b>go to bed [and] rest [...]</b>, just <b>try and relax</b> really [and] just <b>don't do anything strenuous</b>, [...] <b>watch telly</b> or something [...]" (Charlie)</i>
			Not eating	<i>"[If I get a flare up], I <b>don't eat anything [for] twenty-four hours</b>. It normally lasts for utmost two days. I won't eat, well I <b>might drink fluids</b>, well just <b>water or tea</b> but I <b>have some light toast</b>." (Charlie)</i>
			Drinking more water	<i>"I won't say [my stools are] 'normal' because you're <b>still quite watery</b>. [...] 'how I'm passing and going to the toilet now, I'm <b>happy with its consistency</b>.' I think I'd feel <b>uncomfortable if</b> it were any <b>firmer</b>. If I find that they are firming up, I <b>tend to drink more</b> anyway to <b>make them more passable</b>". (Cristalle)</i>
BODY MIND &	Dealing with stress & controlling the bowel	Taking Co-codamol	<i>"I <b>take Co-codamol</b> and I don't know if that's more to <b>keep [pain] at a level</b> or it's just a <b>placebo effect</b> for me. I don't know why I still take Co-codamol." (Celine)</i>	
	Dealing with stress & helping the digestive system	Resting	<i>"I've been really fortunate in that if [my UC] <b>flares up a little bit</b>, I've been able to just <b>rest up and try and take things a bit easier</b> until it <b>settles down itself</b>." (Isa)</i>	
	Dealing with stress & kick-starting self-healing	Using Homeopathy	<i>"[Homeopathy is...] the use of <b>natural elements</b> to create remedies to <b>work alongside and enhance the body's own abilities to heal itself</b>. [...] if you take an element of an illness, water that element down, you can then use it to treat that illness to <b>kick-start your body</b> into <b>aiding that illness</b> or ailment. [...] it's just the fact that [Homeopathy is] so <b>holistic</b>, you have to <b>get more into the person and the illness</b> to get the right thing that works for you [...]. [...] it seems weird but with the Homeopathy, I seem to find that that <b>seems to sort everything out again</b>. [if I did not have Homeopathy] I don't think I would've coped as well</i>	

			mentally as opposed to physically cause the medical stuff can do the physical stuff but the advantage [is] the Homeopathy <b>deals [...] on a more holistic, mental basis.</b> " (Celine)
	Expressing emotions & interacting with cellular change		"If I started to get proper symptoms like proper <b>diarrhoea</b> or <b>lose any blood significantly</b> that would be an indicator that things were going downhill and I would see [my homeopath]. I'd take some kind of remedy, which would be dependent not just on what the <b>symptoms</b> were but what was happening with me in terms of my <b>emotional state</b> . I'm not necessarily saying that [homeopathic remedies] cured me or made me better but I think the <b>process of having a relationship with a homeopath</b> and just <b>believing that your body has the capacity to heal itself</b> has <b>triggered my physical and psychological capacities for self-healing.</b> " (Venezia)
	Expressing stress & emotions		"I did go and <b>see the homoeopath</b> and I've managed to <b>settle things down reasonably quickly</b> through that. So yeah, if [a flare up] happens again I would go back and see a homeopath again and I'd <b>feel confident that that would help me.</b> " (Isa)
BODY & VITALITY	Helping the digestive system & Regaining vigour	Resting	"I had thirteen trouble-free years, until 1985 when I was forty-eight and then I had occasional, debilitating upsets when I would start churning out the output in a very watery fashion and [having] <b>terrible feelings of lassitude and lack of energy.</b> [...] when I have a whole string of attacks of flux it's <b>very debilitating: drags you down,</b> makes you feel in spite of yourself, <b>extra low in spirits.</b> It's just as if <b>all your vitality goes</b> with it. It really does <b>sap your energy and your well-being in no time at all</b> and the only thing you can do is <b>creep into bed.</b> " (Eden)
		Taking Dioralyte	"I always take Dioralyte for the first two days [of an attack of flux], especially <b>high doses of Dioralyte</b> and I take two sachets of those a week anyway. That's the thinking in that regard, just <b>topping up the electrolytes</b> to <b>help replace lost salts, lost water</b> and body salts." (Eden)
MIND & SPIRITUAL BEING	Expressing emotions & being connected to ethereal entities	Going readings for	"I'm <b>very into spiritualism</b> and when my <b>dad passed away,</b> it was <b>quite sudden</b> and I <b>went for readings</b> and they've told me <b>he's always around me</b> so that's why I always think 'oh, <b>he's looking after me</b> ', or well, my mum now, or they're both up there. I think it's for <b>comfort</b> and <b>reassurance</b> [...]. The statements they gave [...] used to be <b>emotional and funny.</b> [...] it's <b>just a bit of fun,</b> the reading; [...] it's not life or death." (Cristalle)

Table 6.8 looks at the participants' curative healing practices. Seven of the eight participants used healing practices to treat the Body part of the Self. Six of these seven participants talked about using medical practices to control "*flare ups*" by "*calming*" the bowel inflammation, with five also taking medical drugs and Celine using clip-on stoma bags. Charlie and Cristalle also explained how they help the Body part of the Self functionally. For both, it was to facilitate their bowel function; for Charlie through resting and not eating and for Cristalle by drinking more water to loosen firm stools.

Only Isa, Venezia and Celine used three of the curative healing practices to help the 'Body & Mind' part of the Self. All three talked about dealing with stress and emotions by using Homeopathy. Celine also described how it kick-starts "*self-healing*" and Venezia explained how homeopathic remedies can cause cellular change in the body. Aside from dealing with stress, Celine and Isa also described healing the Body part of the Self by controlling pain in the abdomen when taking Co-codamol (Celine) and settling the bowel to help it function better when resting (Isa).

The last two main categories 'Body & Vitality' and 'Mind & a Spiritual Being' were healed by Eden's (taking Dioralyte) and Cristalle's (going for readings) use of curative healing strategies and practices. In Eden's case, she described how the supplement she took was improving her body's function by replacing lost "*body salts*" and water as well as regaining rigour. Cristalle said that visits to mediums enabled her to express emotions (Mind) whilst connecting with her deceased parents (considering the Self as a Spiritual Being).

### **6.5.3 Analysis of the Self in Relation to the Current Healing Strategies**

The following section analyses the parts of the Self that linked to *current* healing strategies, which participants described when using healing practices more preventively and curatively. Some categories that have been made, for example, Body & Vitality, pertain to particular individuals (for example, Eden). At the same time they reflect issues and strategies that were seen in other participants' narratives, but are not included in this analysis as those participants were not *currently* using preventive or curative healing practices involved with those parts of the Self.

In relation to the question of 'what leads up to a flare up?' three different explanations were evident in the participant data. Firstly, there was *physical tiredness and tension*, arising from reasons such as overwork, rushing around doing chores and/or errands and taking care of children. Secondly, there were the factors of *mental stress and emotions*. Stress related to areas including worry about work, health, their children,

money or security. Emotions included sadness, arising from a loss of a relationship (for example, death or relationship / marriage break-up), loneliness, self-pity; it also related to anger, for example, with themselves as they saw themselves as achieving or too ambitious; and frustration about their illness. Thirdly, there was the '*wrong*' food and/or drink. These might not easily be digestible, seen as toxic, taken too much or too little, slowing the processing of food and drink and more positively as getting better nutrition to address perceived nutritional deficiencies.

It must be remembered that the parts of the Self described are not mutually exclusive. There is always overlap and blurred lines between distinguishing exactly what part of the Self is being healed by a particular healing practice. Participants describe tendencies towards particular types of therapies for more specific ailments.

### **6.5.3.1 Preventive Healing Strategies**

By looking at the sub-categories in Table 6.7 for each part of the Self, the strategies connected to avoiding flare ups by using more preventive therapies can be explored.

#### ***The Self as Body***

According to the medical perspective of IBD, when a person experiences a flare up, one of the main things to consider when looking at a 'diseased' bowel is inflammation. Moreover, when the bowel is not in an acute phase of illness, there is always a susceptibility to getting a flare up. Participants taken in two different ways:

- '*Controlling the bowel*'. This anatomical perspective of the bowel as part of an organ system, and specifically the affected bowel, is a more mechanistic way of understanding IBD. This view is demonstrated by participants when describing the bowel "*blow[ing] up like a case ball*" (Charlie) or as a "*leaky intestine*" (Halston). Therefore when avoiding inflammation whilst sharing this perspective of Self, it would be understandable that these two participants used Mesalazine (anti-inflammatory) as a preventive healing practice in order to "*extend any remission*" and "*delay the onset of acute conditions*" (Halston).
- '*Helping the digestive system*' and '*having the wrong food and/or drink*'. Susceptibility to a flare up means being aware not to provoke inflammation as well as assisting the already-ailing digestive system. The perspective of Self as Body in this case is focussed on the movement and function of the entire digestive system on a physiological level as opposed to a solely anatomical view. The use of these terms in describing this perspective of Self is presented in the data when the functionality of the bowels are described. For example, Charlie commented:

*“you’ve got little hairs on your intestines and when they get washed away there’s nothing for the food to cling on to so whatever I was taking in was just going straight through”*. In such situations, eating little but often (Cristalle), ingesting food and drink that is easier to digest (less fibre, *“cutting down on dairy and wheat”* (Halston)) and avoiding irritant or toxic foods and drink (no or little alcohol as it *“ruin[s the] stomach or intestine”* (Calvin), *“avoid spicy foods”* (Charlie)) were the preventive strategies used by most participants to improve digestion. Another strategy to take, as diarrhoea and watery stools are two of the main symptoms in IBD, is to try and slow down the movement of food through the digestive system in order to help reabsorb water and nutrients. Eden is one example, through her taking bulking agents.

### ***The Self as Body & Mind***

This combination of parts of the Self was linked to the majority of participants when using preventive healing practices. Dealing with stress and emotions and alleviating physical tiredness and tension seemed the most relevant to participants using healing practices to heal the Body and Mind together.

In talking about *‘dealing with stress & emotions’*, most participants described how stress (worry) and emotions (sadness/grief and anger) either *“triggered”* a flare up or contributed to aggravating the bowel. In other words, these participants made a link between the Body and Mind parts of the Self and so their explanations for the use of certain healing practices seem to follow. Isa and Venezia, for instance, used similar therapies (counselling and psychotherapy) to help them learn how to *“express emotions”* and *“take care of [themselves]”* with Venezia further connecting the Mind to the Body through *“interaction with [cellular change]”*.

The strategy of *‘alleviating physical tiredness & tension’* is linked to dealing with stress and emotions. At the same time, it is important to emphasise that physical tiredness and tension was something all participants talked about needing to alleviate in order to prevent having a flare up. Resting was a way that helped Celine and Calvin manage to regain strength and energy as well as take time out for themselves. Halston and Isa, on the other hand, talked about *“relaxing”* and *“keep[ing] calm”* by going running (Halston) and having a Swedish massage (Isa).

### ***The Self as Body & Being a Mother***

All female participants except Cristalle talked about how being a mother affected their IBD either as a motivation to become better mothers by interacting more with their

children or as something that contributed to their stress and tiredness. Whilst examining preventive healing strategies across cases, Venezia spoke of needing to “*rest all the time*” preventing her from being with her sons, which is something that motivated her to take better care of herself in order to fulfil her role as a mother.

### ***The Self as Body & Social Being***

All participants mentioned how disruptive IBD can be on their lives especially when it comes to going to the toilet. This as well as other symptoms and issues that these IBD sufferers have to live with have been talked about when it came to their social lives. Although the age of onset for all participants varied, Calvin was the participant with the earliest onset of illness being only aged nineteen. Calvin talked about doing exercise not only as a means to being “*healthy*” but also with the intention of “*building up a bit of muscle*” in order to help his body image. This he said enabled him to feel more “*confident*” whilst socialising and “*battl[ing]*” with “*what people think*” especially when finding a “*girlfriend*”.

### ***The Self as Mind & Social Being***

Following on from the points made above, most participants described how they “*incorporated life change[s]*” (Celine) in order to be able to work around IBD symptoms and issues preventively. In this category, the Social Being is more connected to the Mind part of the Self where participants described needing to “*chill out*” (Calvin) whilst going out with friends and listening to music or “*think[ing] about nice things*” and “*talking about [their] issues*” (Charlie) with others in a socialising realm.

### ***The Self as Mind, Social & Spiritual Being***

Almost all participants except Halston, talked about the stress and emotions involved in having problems with relationships, either with family members or intimate partners. In particular, the emotions felt after the loss of a family member exacerbating the bowels towards a flare up (Isa, Calvin, Eden and Charlie). Charlie described being connected with his sister after her passing away with colon cancer through expressing emotions (sadness and grief) to a “*minister for [a “spiritualist church”]*” whom he “*felt his] sister had sent*” to comfort him. This type of experience as well as “*go[ing] round the church sometimes*” at the end of each month when “*they have the men’s breakfast*” to be around “*nice*”, “*very supportive*” people, is something that Charlie said he does in link with not “*bottling up*” emotions that may harm his bowels.

### 6.5.3.2 Curative Healing Strategies

In examining the sub-categories shown in Table 6.6, it is possible to see a link between specific parts of the Self and healing practice strategies that participants used *more curatively*. This section looks at how participants treated themselves using therapies dealing more with an acute phase of illness, after a flare up or having already experienced unwanted symptoms leading up to an acute condition.

#### ***The Self as Body***

Aside from inflammation, another main consideration in treating a flare up, according to Medicine, is pathological autoimmunity. Participants talked about two areas.

- *Controlling the bowel.* In this sub-category, the anatomical, more mechanistic perspective of the Self as Body was expressed using terms like *“plumbing”* (Eden) or *“the rectal end”* (Isa) when talking about *“control[ling]”* inflammation or *“calm[ing] down”* an acute phase of illness. Most participants seemed to use medical treatments (mostly drugs) to control symptoms like *“gas”* (Eden), *“pain”* (Halston) and *“diarrhoea”* (Charlie) curatively.
- *Helping the digestive system.* When perceiving the Self as Body with regard to helping the digestive system function, two participants (Charlie and Cristalle) mentioned eating less food and drinking more water in order for the movement of food to pass more comfortably through the digestive tract. Charlie also talked about resting up to a maximum of two days before his flare up gets really *“bad [that he has to] go to the doctors”* to ask for steroids.

#### ***The Self as Body & Mind***

With this sub-category, participants mentioned the connection between Mind and Body after getting a flare up or preceding symptoms and the curative strategies they would apply to help themselves. Particular attention was drawn to *dealing with stress & emotions and physical tension*. In particular, participants mentioned looking at their *“emotional state”* (Venezia) and encouraging their body’s *“self-healing”* (Venezia and Celine) abilities when using Homeopathy (remedies and consultation) curatively. In considering the Mind part of the Self in having to deal with *“keeping [pain] at a level”* (Celine) as well as other symptoms of a flare up (Isa), Co-codamol and resting were used in order to *“settle [things] down”* (Isa).

### ***The Self as Body & Vitality***

Although this category was created from analysing Eden's curative use of resting and Dioralyte, her strategic approach in trying to regain physical strength by ingesting electrolytes and resting when tired can be seen in other participants' narratives with regard to replenishing energy. The added characteristic of the Self mentioned by Eden is vitality.

### ***The Self as Mind & a Spiritual Being***

As previously described when mentioning other participants who suffered negative symptoms after losing a family member, Cristalle was another participant who went to mediums to connect with her parents who has passed away. Cristalle got comfort and reassurance from "*getting readings*" also enabling her to express her grief whilst reflecting the view that her parents were still around her.

#### **6.5.4 Summary of Current Healing Practice Strategies**

This section on current healing practice strategies explored both preventive (remission phase of illness) and curative (acute phase of illness) uses of healing practices in relation to the Self. It described various ways in which participants linked parts of the Self such as Body and Mind in relation to healing their illness. It also addressed perspectives of Self as a social and spiritual being, in some cases including vitality, in the context of living with IBD. It demonstrates a range of diverse approaches used by the participants in general and in relation to the parts of the Self being addressed or linked to.

It is important to remember that the way the material has been presented provides a way of seeing how perspectives of Self are reflected outwards into society through behaviour but also how perspectives in society translate into attitudes and ways of life within the Self by acculturation. Hence 'culture' is shaped dynamically as it shifts between and through individuals and society as a whole in an ever-changing state. In this way healing practices are adopted and discarded as ways of life depending on the context in which an IBD sufferer lives as well as the state of the Self an individual transfers to the outside world.

#### **6.6 Concluding Comments**

This chapter presented four sections illuminating how participants said they coped with the stigma of living with a dirty disease, how they said they regained control of their illness and lives, how they expressed how cultural influences affected their choice of

treatments as well as participants' use of current healing practices (preventively and curatively). The first section listed the issues participants recalled when talking about coping with embarrassing situations whether public or private as well as dealing with intrusive medical examinations, treatments and/or care. It presented the diverse ways in which participants transformed the stigma of having a 'dirty' disease using various ways of coping with societal norms. The second section, strongly linked with the first, explored the ways in which participants managed their lives with IBD in order to regain control of their illness and somehow stabilise a sense of unpredictability and uncertainty in living with IBD. The third section presented a range of cultural influences seen across cases that participants described facilitated their use of a variety of healing practices used preventively and/or curatively. The last section demonstrated the ways in which participants used healing practices in particular, by highlighting the parts of the Self intended for treatment. The first two sections showed how participants talked about (and/or understood) their ways of coping whilst the last two sections focussed more on current healing strategies in order to heal.

One of the difficulties encountered during this chapter was to delineate points and issues that arose across the eight cases and not to oversimplify, whilst also aiding analysis, interpretation and presentation. Many of the issues and points addressed did not seem to take on necessarily similar aspects; their multiple expressions, both within and across cases, seemed more chaotically and dynamically linked to ever-changing ways of life within a society and context. Focus now turns in Chapter Seven to provide an overview and discussion of the concepts and points that came up during this cross-case analysis as well as the arguments expounded in the thesis in relation to the guiding research questions.

## **CHAPTER SEVEN: DISCUSSION AND CONCLUSION**

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### **7.1 Introduction**

This thesis set out to explore how and why the participants of this study did things differently than what is considered mainstream perspective and treatment of IBD. The inspiration for the thesis came from the researcher's personal experience in living with IBD. In particular, the people and things that influenced her use of mainly non-medical healing practices was the springboard to developing curiosities about how *other* IBD sufferers lived. These curiosities morphed into specific objectives to answer the research question of how these IBD sufferers lived with this long-standing illness and used several non-medical as well as medical healing practices together (healing practice pluralism). This exploration of the way these IBD sufferers lived with their illness and used healing practices came with the understanding that, firstly, nothing happens without context and that, secondly, within this context, sufferers constantly interact with cultural influences that have major impact on their choice of treatments.

In wanting to implement the objectives and answer the research question, it was necessary in Chapter Two to set the scene and explain what IBD is as well as present two vantage points: how the mainstream medical practice perceives and treats IBD and how this illness and its treatment could be seen through a different lens (Chinese Medicine). With the comparison between these two healing practices, the viewpoints on how to manage and treat IBD still came from the perspective of the healing practice and not individual sufferers. It became apparent from initial literature searches that there were three major gaps: (i) there were very few qualitative studies looking at the use of non-medical healing practices in the treatment of IBD; (ii) most research on self-care involved monitoring sufferers' use of guidebooks, advice given and prescriptions of treatment from medical practitioners; and (iii) there were a limited number of studies looking at the complexity of decision-making of healing practices with regard to the impact from cultural influences.

Alongside this evolution of ideas was the hunch that cultural influences have a huge impact on sufferers' decision making on healing practice use as sufferers are exposed to ideas and through interactions with various sources of information develop their knowledge about healing practices. The initial hunch was built upon from academic education and ideas, explored in Chapter Three, drawn from previous research around different ways of healing, for instance, Helman's (1985, 1995, 2007) descriptions of popular medicine with people using mostly self-care, or folk medicine including

alternative and complementary ways of healing to allopathic medicine, which is normally considered mainstream practice. Both Helman (ibid) and Kleinman (1981, 1995, 1997) looked at the individual sufferer and their plight to finding better care and services in a world of growing availability of non-medical healing practices in particular, TCAMs. Helman (2007) also mentioned in great detail the broad types of influencing factors one might find in the context of living with long-standing illness and how those factors guided or drove sufferers to make decisions on which healing practices they would use. It was the development of these concepts from the initial hunch that brought forth the components identified as necessary in understanding how IBD sufferers culturally construct perspectives of illness and healing. Most importantly, this chapter expounded a conceptual framework, built around different constituent parts of the self, to explore cultural constructions of illness and healing.

After having outlined inspirations, curiosities, hunches and developed the research interest, objectives, concepts and a plausible conceptual framework, it was necessary to understand how the research objectives would be met and how the study would need to be conducted in order to answer the research question (Chapter Four). The methodological ideas and concepts along with the qualitative research tools were described and justified along with emphasising the way in which the research was conducted taking into account the rigour of going through and recording the process of collecting and analysing information from participants including awareness of ethical issues that needed to be implemented.

Having explained how the study was conducted and how data was processed, the outcomes of these undertakings started to emerge from interpretation of information participants presented. The first stage, presented in Chapter Five, was to focus on each participant one by one. Through the selected structure of how data was processed and analysed, it was possible to see four main points across cases, subsequently presented in Chapter Six: (i) how participants used diverse ways of coping with embarrassing situations in living with the stigma of having a 'dirty' disease, (ii) how participants managed their lives by regaining control of their illness, (iii) factors and properties of cultural influences necessary for sufferers to become receptive to suggestions and recommendations leading to their use of particular non-medical healing practices like TCAMs; and (iv) the detailed ways in which individuals perceived themselves and the parts of the Self that healing practices were intended to treat. The analysis was guided, informed by, and began to demonstrate the importance of the conceptual framework highlighting the importance of cultural influences and perspectives of Self of individual sufferers in their 'quest' to finding appropriate healing

practices with specific functions in healing particular parts of the Self whilst living with long-standing illness.

Against this background, this final chapter aims to draw out the empirical and theoretical contributions made in addressing the four research objectives in order to: discuss the research findings, examine the usefulness of the conceptual framework, point out the main strengths and limitations of the study, describe personal experiences felt whilst conducting the research and finally suggest possible areas for future research. Two key outcomes (of four) seen in the findings are highlighted as they make particularly unique contributions to this area of research. The first is the emergence of features of cultural influences that make sufferers receptive to their recommendations for non-medical healing practices including TCAMs. The second outcome is the constant re-evaluation of the Self in juxtaposition to these cultural influences.

## **7.2 Empirical and Theoretical Contributions**

Looking back at Chapter Three, it is noticeable that the four components of the conceptual framework (cultural influences, perspectives of Self, perspectives of illness and healing and healing practice pluralism, all informed by Helman (1985, 2007) and Kleinman's (1981) work) clearly appear in the findings of the study. The following text demonstrates how these components link with the four objectives posed in Chapter One, which have each been addressed by the research findings.

### **7.2.1 Find out how individual sufferers perceive living with IBD relative to their cultural or ethnic background**

An overview of the symptoms, diagnostic processes and procedures as well as the various medical treatments of IBD was introduced in Chapter Two giving a more generalised glimpse into what it might be like to live with IBD in the abstract. The basic understanding of 'culture' as a 'way of life' is explained in Chapter Three along with the building blocks that make up the conceptual framework. The inclusion of context, cultural influences, the Self and healing practice pluralism starts to build up a more realistic perspective on living with IBD within a social, cultural and to some extent political milieu. It is only with the findings and presentation of individual cases in Chapter Five that one can see a more individualistic experience of living with IBD in relation to cultural or ethnic matters. Examples include when participants clearly linked living with IBD to: 'rebellious' from encultured inherited methods of care (Isa), their ethnicity (Celine) or accultured ways of coping (Charlie).

### **7.2.2 Explore participants' perceptions of the healing practices they have used, which 'suit' their perceptions with regard to treating their ailments in the context of recommended treatments and their application**

This objective looks at three aspects of decision-making with respect to finding treatments in living with IBD. The first has to do with participants' perspectives of healing practices, in particular, the features of therapies they 'connected' with, which led to their use. The first mention of the connection between the features of healing practices and what participants were looking for was made in Chapter Three with the hypothetical example of Aziz using various healing practices in connection to ways of life he encultured or accultured. Chapter Five explores this connection (see 'current healing practice strategies' tables at the end of each individual case analysis) in more detail in relation to the function of healing practices more preventively or curatively intended to heal different ailments experienced in living with IBD. Participants' opinions about what they liked or 'got' from a healing practice including the life event they were living, were analysed and presented in more detail in life events leading up to decision points one and two in the individual case analyses. For example, Celine described wanting to treat her illness in a more "*holistic way*". (See Chapter Five, Celine's individual case, Decision Point 2, 'Knowing her "*Bohemian*" school friend')

The second aspect of this objective looks at the concept of the Self, where sufferers consider what they like and dislike from previous or current experiences of treatments. This concept is introduced in Chapter Three explaining the parts that make up the Self along with the other components of the conceptual framework. It is explored in more detail with more specific sub-categories (like the 'big bowel' as a pure object – see Eden) of parts of the Self intended for healing by participants in Chapter Five. The connection between the part of the Self needing healing and the treatment intended with a particular function is introduced in the 'current healing practice strategies' tables at the end of each individual case in Chapter Five and explored in more detail in the cross case analysis of the eight participants in Chapter Six, briefly illustrated in Tables 6.5 to 6.8. For example, Isa described "*taking things a bit easier*" and resting "*to relax*" and "*keep calm*" in order to avoid a 'flare up'. (See Chapter Six, Table 6.8, Body & Mind, 'Dealing with stress & helping the digestive system')

The third aspect of this objective, and the least looked at or explored in the broader literature, is the cultural influences that exist in the context of living with IBD, which participants described being receptive to for various reasons. These reasons came about not only because of the urgency of a life situation (crisis period) but also had a lot to do with the features of cultural influences (for example, their 'openness to TCAM' –

see Table 6.4 in Chapter Six), which made sufferers more receptive towards recommended treatments. This can be contextualised against the concept of urgent life situations which is presented in Chapter Two in descriptions of emergency and non-emergency situations IBD sufferers experience from a medical perspective. A more personalised view of crisis periods can be seen in Chapter Five in participants' bio-summaries as well as in the life events leading up to some decision points. The features of cultural influences expressed by participants of the study are listed and analysed in detail in Chapter Six (section 6.3.2).

### **7.2.3 Uncover the reasons why sufferers use particular healing practices to manage their illness**

Similarly to the points made about features of cultural influences (see Chapter Six) in the previous two objectives, this third objective focusses more on these in connection to their practical and functional use as shown in Chapter Five 'current healing practice strategies' tables. This chapter elaborates on other reasons why participants used particular healing practices more with regard to the constant re-evaluation of the Self including sufferers' need to 'take control', be more self-responsible in their self-management of illness and mixing and matching healing practices whilst considering the Self.

### **7.2.4 Gain insight into the TCAM healing practice settings in which IBD sufferers are situated**

This fourth objective focusses on the environment, objects and people that exist in the settings of IBD sufferers' lives whilst receiving TCAMs. Since there was no first-hand observation of IBD sufferers' TCAMs settings, this information was gathered as reported by participants when recalling their experiences of using TCAMs. This included the therapeutic rapport they had with practitioners (see Venezia in Chapter Five), the spatial environment they were comforted by (see Decision Point Two of Eden in Chapter Five) and the use of TCAM paraphernalia in self-care (see Celine's use of homeopathic remedies in self-care of CD, Chapter Five).

## **7.3 Discussions Emerging from Research Findings**

Notwithstanding the fact that the research objectives have been linked above to specific chapters in the thesis, the concepts and issues that arose in the findings overlap throughout, since all aspects of living with IBD are interrelated. The key messages transpiring from IBD sufferers' narratives that address the four objectives in order to answer the research question are: receptivity to cultural influences, on-going

re-evaluation of the Self with emphasis on self-management and self-care, the context of living with embarrassment and ways of regaining control of illness; and the multiplicity of healing practices (including, for example, home remedies and other ways of coping such as finding public toilets prior to arriving at a location) used simultaneously (healing practice pluralism). Each is discussed in turn below.

### **7.3.1 Receptivity to Cultural Influences in Choosing Healing Practices**

This point has emerged as one of the most important findings of this research and thus is a major contributor to the existing literature. As previously defined in Chapter Three, cultural influences are *‘factors which influence people’s day-to-day lives by shaping or guiding each individual’s way of life within the context of living with a long-standing illness’*. Table 6.3 in Chapter Six presented types of cultural influences mentioned by participants, which were found to be information sources in the case where the cultural influence was a person guiding IBD sufferers. Another example of a cultural influence that emerged from this study was a disruption in a sufferer’s life like a divorce or death of a family member. Although these examples of findings show difference in types of cultural influences, the main point is that participants in this study were receptive to them for various reasons explained in Chapter Six. This ‘receptivity’ towards cultural influences played a big part in guiding sufferers to use non-medical healing practices like TCAMs.

Previous studies looking at cultural influences and their impact on sufferers’ use of TCAMs examined the rapport between practitioners and patients with the former representing the cultural influence. In a study by Chatwin (2008: 254), as part of a Department of Health project, forty recordings of homeopathic consultations (involving professional and medically trained homeopaths) demonstrated the use of conversational analysis, focussing on *“the linguistic motifs [...] evident during the initial stages of ‘first-time’ homoeopathic consultations”*. His work showed that homeopathic practitioners (cultural influences) took *“control of the way in which the information [was] presented, and [...] gave] accounts”* during consultations with first time sufferers that were *“essentially favourable to their position”* of power in guiding the sufferer’s choice of treatment. (ibid: 255) Although power play and transfer of information in communication between cultural influences and sufferers play a part in this study, there remain additional points for discussion.

Aside from studies on the influence of practitioners on patients, there have also been several studies looking at the vantage point of caregivers caring for people with long-standing illness. A qualitative study by De la Cuesta (2005), conducted in Columbia,

focussed on observing and interviewing eighteen primary caregivers (for example, daughters and wives) of people within their families with dementia. This qualitative study was based on symbolic interactionism and grounded theory principles and methods. De la Cuesta (ibid: 885) described the core category emerging from her study as the “*inventiveness*” caregivers improvised in the care of their relatives under adverse circumstances. She explained that due to the pressing needs of sufferers’ dementia and the irrational process of care, caregivers developed a “*craft of care*” (ibid: 885). They did this by “[*inventing*] care not only for practical reasons but also as a craft that transforms the relative with dementia, the material world and the caregiver” as the sufferer’s condition evolved (ibid: 885). In so doing, “*the idea of caregivers as makers began to emerge*” where these strove to get their relatives to “*accept being taken care of and to accept them as their caregivers*”. (ibid: 886) De la Cuesta’s (2005) study focused on the interpretation of suffering by a cultural influence (caregivers) on people with long-standing illness utilising inventiveness and ruses to ameliorate their standard of living.

These two studies have essentially focussed on one type of cultural influence whereas the participants of this PhD study mentioned several cultural influences that guided their choice of healing practices. The interest in other studies in the literature has been to gather information from the point of view of the cultural influence. The PhD research endeavoured to accumulate information from the perspective of the sufferer; in particular the sufferers’ perspectives of the cultural influences, the features of the latter and how they impact on sufferers’ receptivity to recommendations on TCAM use. The studies described in literature indicated the use of one type of healing practice whereas this research made it possible to capture the complexity of using a variety of healing practices concurrently. Many previous studies do not take the context of living with illness into consideration in the way they conduct qualitative research to collect information about guiding sufferers on how to choose healing practices. In the PhD study, two key life events were elaborated and explored, each chosen in relation to the particular individual and their context in living with IBD, in particular, the disruptive periods of crisis in participants’ lives.

The key emergent category from De la Cuesta’s (2005) study pointed out the inventiveness of the caregiver in alleviating suffering in long-standing illness. ‘Inventiveness’ has relevance and resonance with the findings presented in the PhD research. Here inventiveness is practised by sufferers, and not their cultural influences (see Chapters Five and Six). Another key point that studies on cultural influences explored was the transfer of ideas and information (as in Chatwin’s (2008) work) on

perspectives of illness and healing from the point of view of the cultural influence to the sufferer; yet the use of that transferred information by sufferers is not explicit. This thesis denotes the sufferers' perspectives of illness and healing conveyed in narratives describing their healing practice strategies for particular parts of the Self, whilst being guided by the cultural influences within their life events.

### **7.3.2 Sufferers' Constant Reference to and On-going Re-evaluation of the Self**

The points that came through from having interpreted the data findings that are concerned with the Self are: 1) the constant re-evaluation of the Self and 2) identifying parts that make up the Self in sufferers with a long-standing illness. This is whilst keeping in mind that the Self is not void of context and is strongly linked to each individual's culture. Culture is not only a movement of ideas and ways of life from a context adopted by an individual but is also created within an individual and reflected outwards into society from the Self. 'Knowing' the Self whilst taking context and culture into account made it possible to recognise participants' likes and dislikes in order to find healing practices that suited their wants and needs. For example, Isa had initially followed her parents 'conventional' way of treating illness by taking medication for fourteen years but then stopped after considering what she wanted; her "*system to be as free of drugs as possible*".

#### **7.3.2.1 Re-evaluation of the Self**

The process of re-evaluating their likes and dislikes closely related to the way IBD sufferers lived their lives (culture) in the context of life events was something that was repeatedly conveyed in narratives throughout this study. This can be linked to Bury's (1982:3) description of biographical disruption where sufferers' lives underwent major unexpected changes "*where the structures of everyday life and the forms of knowledge which underpin them [were] disrupted*" by chronic illness. Although IBD sufferers clearly expressed negative experiences during and after initial symptoms and diagnosis as presented in their bio-summaries, this was "*followed by a period of reorganisation and reconstruction of the self and [their] place in the world*" (Hunt, 2000: 88) within varying time frames. This was particularly relevant when looking at how IBD sufferers made radical re-evaluations of the Self with regard to using non-medical healing practices like TCAMs. For example, Halston said he started using Acupuncture and Homeopathy soon after diagnosis yet Eden only started using Chinese Medicine around forty years after her diagnosis. Moreover, IBD sufferers' changes in perspectives of Self were closely linked to being guided by cultural influences thereby contributing to sufferers' cultural constructions of illness and healing. This is best explained by Garro (2000)

who wrote that “[t]hrough such interactions, a person seeking care may come into contact with an essentially new framework or a new application of an existing framework, with this new knowledge playing a constitutive role in the reorganisation and interpretation of past experiences”. (ibid: 73, 74)

### **7.3.2.2 Identifying parts of the Self**

When IBD sufferers described their use of various healing practices, this was always related to which part of the Self they were treating. By identifying the part of the Self needing healing especially the characteristics of that part, it was easier to understand how and why IBD sufferers used particular healing practices. Encultured ideas learnt during one’s upbringing about the Self as well as accultured perspectives adopted from *other* cultures through cultural influences in participants’ ways of life seemed to constantly change through time and space. This notion of more individualistic and detailed characteristics of parts of the Self as expressed by participants of this study does not seem to be reflected in TCAM literature commonly portrayed in popular culture and the media.

The usual properties of using TCAMs as characterised in the media are that they are used on the ‘Body, Mind and Spirit’ of sufferers. These terms are frequently used and typically have a taken-for-granted, assumed definition that the Body refers to the physical body, the Mind to the mental state and the Spirit to something that perhaps includes an ethereal soul but also involves some sort of energetics. There is also the idea that there is a connection between Body, Mind and Spirit, probably with energy that may spread throughout the physical body, mind and is taken from or given to the surrounding environment. An example of this common use of these terms in describing characteristic concepts of TCAM use is described by O’Connor (2003). She presents the following description under the heading “*Interrelation of Body, Mind and Spirit*”:

*“Bodies do not (in fact, cannot) ‘stand alone’. A complex interconnectedness is posited among body, mind, and spirit; health and illness incorporate all of these aspects of persons. True healing must likewise take into account all of these aspects and their interconnections with each other and with their wider environments (e.g. society, nature, cosmos).” (ibid: 50, 51)*

Even though these parts of the Self are described as connected and part of the environment or even the universe, this generalisation of using the terms ‘Body, Mind and Spirit’ says nothing of their qualities or characteristics neither their relationship with/to the Self. The common use of these terms in popular culture and media also insinuates the idea that medical healing practices or non-TCAMs do not involve or heal

these parts of the Self which is one of the distinctions usually made between using medical and non-medical TCAM healing practices. According to participants' narratives, sufferers had specific ideas of what they wanted and needed which reflected how they identified and perceived parts of themselves. Once this was accomplished, the task of finding healing practices that suited those parts was more concerned with being receptive to cultural influences that recommended treatments. Hence the generalised portrayal of parts of the Self in popular culture and media is inaccurate and in some cases misleading both with reference to using TCAMs as well as medical treatments.

In understanding how the findings of the study answered the first objective on how IBD sufferers live with long-standing illness relative to their cultural backgrounds, it seemed relevant to present how participants 'saw' the Self in the context of culture. From looking across Chapters Five and Six there seem to be various ways in which participants perceived the Self that extended beyond their physical bodies to the outside world. This extension of the Self was first presented by Hall (1963: 1003) in his study of proxemics, "*the study of how man unconsciously structures microspace – the distance between men in the conduct of daily transactions, the organization of space in his houses and buildings and ultimately the layout of his towns*". This is easily relatable to the ways of coping described by participants of this study when looking for toilets whilst visiting public spaces to accommodate the 'inconveniences' of their illness.

Moreover, the way people in society view and react to those suffering with IBD particularly with regard to the negative associations connected to it being a 'dirty' illness can also be related to an extension of the Self which others see as too personal. Examples include humiliating circumstances (soiling oneself in public) or the embarrassment of not being able to talk about private parts of the body linked with excrement (see section 6.1 in Chapter Six).

With regard to body image, the bowels as part of the 'Body' part of the Self presented by participants in this study was perceived in different ways. For example, Isa talked about her gut 'guiding' her in making decisions, expressing the bowels as somehow 'communicating' with the Self. Another perspective of the bowels that was described by participants as a more mechanical 'object' was presented by Helman (2007) when describing the 'plumbing' model of the body where "*the body is conceived of as a series of hollow cavities or chambers, connected with one another and with the body's orifices by a series of pipes or tubes*". (ibid: 30, 31)

With these concepts in mind, living with 'defective' plumbing (Eden) in a culture where conversation about excrement is taboo, not to mention coping with the loss of control of the Self, could be associated with the mechanical (surgery) removal of that part of the Self. This reinforces the importance and value of exploring the connection between living with IBD in a culture, considering the part of the Self needing 'healing' and finding a healing practice that 'suits' that perspective of Self, that is, using the conceptual framework as an analytical tool.

### **7.3.3 Importance of Context in the Decision-Making Process of Finding Treatments**

The main interest in this section is to understand how IBD sufferers used healing practices connected with the settings in which they were experienced. The settings or context could include any space in which sufferers were living and interacting with cultural influences. This is particularly important as IBD sufferers described how they remembered being directly affected by societal 'norms' including experiencing a variety of embarrassing situations both private and public due to the unpredictability and uncertainty of their illness (see section 6.1 'Living with a 'dirty' disease' in Chapter Six). From what can be inferred from the data analysis, participants expressed the fact that healing practices used could not and were not divorced from the context in which they occurred. In other words people did not just 'buy' or 'absorb' just the treatment but also the atmosphere (context) of the therapy including and in some cases in particular the interaction with the practitioners (cultural influences). This need to experience the 'wholeness' of the experience seemed to be more associated with the use of TCAMs rather than when participants used medical treatments although their experiences encompassed the settings in which they received those treatments too.

This experience of 'feeling' the context of healing practices can be related to Helman's (2007) description of the micro and macro-context of the total drug effect. He explained that people using medical drugs experience "*the whole social, cultural, political and economic milieu in which use of the drug takes place*". (ibid: 196) Similarly IBD sufferers in this study spoke of getting therapy not just from the herbs or homeopathic pills they consumed but also the therapeutic relationship they had with their practitioners in particular related to the comfortable, 'safe' settings in which healing took place.

### **7.3.4 Sufferers Wanting to be More Involved in the Management of Their Illness**

Looking across the data analysed in Chapters Five and Six there seemed to be many instances of participants wanting 'control' back (see section 6.2 'Regaining Control' in

Chapter Six) with regard to both their physical bodies as well as the management of their illness. In particular, participants seemed to want more autonomy in coping with suffering and ‘exercised’ this autonomy by experimenting with trial and error to find healing practices that ‘suited’ them.

#### **7.3.4.1 Wanting more autonomy in healing**

One of the main disruptions in living with IBD as expressed by participants in this study was the loss of control firstly of the bowel and then of the following consequences of feeling ill over a long period of time. With having to be diagnosed by medicine whilst being exposed to embarrassing diagnostic procedures and prescribed treatments, IBD sufferers expressed a need to gain control and be more autonomous in the decision-making process of using healing practices. This issue was particularly well explained by Furnham and Vincent (2003) in their discussions on the attractiveness of using TCAMs in a growing market of consumerist patients. The authors pointed out that “[w]hat the modern Western patient wants, and appears not to be getting, is to be treated with individual respect; not to have to endure crowded waiting rooms, or being patronised”. (ibid: 67) In a context where cultural influences, such as growing trends in the use of TCAMs or sufferers not wanting to put up with the lack of medical service in healthcare exist, sufferers are taking into account what they want (Self) and being more confident in their decisions to choose particular healing practices medical and non-medical that suit their needs.

#### **7.3.4.2 Experimenting using trial and error**

Participants’ processes of trial and error in trying out healing practices sprang from figuring out what they liked and disliked (Self) as well as their encounters with various cultural influences who/which suggested different healing practices at particularly difficult points in their lives (crisis periods) when they also might have been more receptive to recommendations. In order for sufferers to gain experience to establish healing practices strategies, it was necessary for them to: 1) consider other people’s experiences through familiarity, something Sevcik (2004) looked at in understanding how IBD sufferers live with their illness; and 2) through self-discovery sometimes by rebelling against inherited methods of care encultured by family members through upbringing. For example, Isa no longer uses medication after fourteen years of taking maintenance doses of Mesalazine and no longer follows the ‘conventional’ route of healing her family practised. Unlike the ‘rebellion’ that Paterson and Thorne (2000: 411) described that was “*characterized by denial*” of long-standing illness especially “*in the presence of others*”, the ‘rebellion’ happening to participants in this study was

characterised by an acceptance and acknowledgement of 'the way their illness needs to be lived with' after having used encultured methods of care (see example with Isa above) for a period of time. This subsequently predisposed participants towards openness to other cultural influences recommending other types of healing practices.

### **7.3.5 Sufferers Wanting More Individualistic Treatment**

There are a lot of views about the use of medical versus TCAM healing practices in popular culture and media, closely linked to cultural trends as well as legislation of practice that people are exposed to and often guided by when deciding on which therapies to use. It is the cultural influences that reside in this context which provide the platform and sometimes the fuel to motivate sufferers to try different therapies and create more individualistic treatment strategies from healing practices available to them. This mixing and matching of healing practices described by participants in this PhD study did not seem to provoke confusion or conflict from using several therapies together for specific purposes.

#### **7.3.5.1 Mixing and matching healing practices**

Whether medical or not, a major point conveyed by participants in this study was their 'non-conflicting' use of different healing practices alongside one another. Similarly to Furnham and Vincent (2003), Cant and Sharma (1999) and Helman (2007) have described their understanding of medical pluralism with the core concept being that, in the Western world, medicine is the mainstream healing practice and all other practices are complementary or alternative to that. It was their pointing out of the dominance of medicine that serves as the base standard for other practices that might have contributed to the term 'medical' pluralism. Their descriptions on the increasing pluralistic use of different therapies were based on two driving components: 1) the antagonistic and occasional co-operative engagement between medical and non-medical (mostly TCAMs) healing practices; and 2) the powerful role of the consumers of TCAMs "*in an increasingly consumerist society*". (Sharma, 2003: 211, 212)

Although these views and debates about medical dominance or antagonism between healing practices were described in IBD sufferers' narratives, there was a very subtle but strong attitude and practice that was described in participants' behaviour that needs to be emphasised. Participants may have thought negatively about healing practices (notably medical treatments) and, for instance, clearly described their dislike of the practice of medicine, but this did not stop them using various types of medical treatment options alongside other non-medical healing practices in a non-conflicting

way (healing practice pluralism). The general 'vibe' felt in the way IBD sufferers lived their lives was the ability to use several healing practices together without conveying the dominance of any particular practice but more its usefulness in a particular situation or for a specific purpose. This is well explained by Thorne et al (2002) who conducted a qualitative secondary analysis of twenty-one people (seven each) with HIV/AIDS, multiple sclerosis and Type 2 diabetes looking at their self-care decision making in using both conventional medical and health care services as part of their disease management with all but three regularly using one or more CAM approaches. Similarly to the IBD sufferers in this study, Thorne et al (2002: 675) described their participants use of healing practice pluralism in a non-conflicting way; *“recognizing that conventional and CAM approaches each offered different possibilities in the process of working toward the best level of health possible under the circumstances, these individuals with chronic illness saw no inherent contradiction between the two therapeutic strategies.”*

Self-care and self-management seem to have been frequently used in other studies as synonyms as mentioned in Chapter Three (section 3.3.3). Some studies such as Kennedy et al. (2003) used the term self-care where participants were given a guidebook about how to care for themselves with IBD. In this study self-care was defined (in Chapter Three) as the use of any healing practice (usually but not exclusively non-medical) that *nurtures* the Self for example by self-prescribing homeopathic remedies. Self-management is interpreted slightly differently where any healing practice (usually but not exclusively non-medical) or way of life that somehow relieves or mends the Self is used to *organise* the Self and context in order to bring about preventive measures to reduce or avoid embarrassing situations, for example, finding out where the toilets are before arriving at a location or maintain what a sufferer would consider a healthy disposition.

There were two main points for discussion, in relation to the third research objective, that were interpreted from data analysed in individual and across cases. Firstly, participants went through experimentation processes to discover what works and what does not when choosing healing practices, which ended up, secondly, serving a specific, useful purpose in treating particular parts of the Self. These ways of coping and analytical considerations took into account what they were looking for (parts of the Self) in a healing practice (medical, non-medical and/or applied by a professional or in self-care or self-management) as well as the often opportunistic circumstances in which participants were exposed to suggestions and recommendations from cultural influences in their life events (context).

### 7.3.5.2 Establishing the usefulness of healing practices

The current healing practice strategies described by IBD sufferers in this study centred on two main circumstances: 1) acute imperative phases of illness when symptoms experienced were considered intense needing urgent care and treatment and 2) non-urgent (preventive) periods associated with maintaining remission of inflammation and avoiding aggravating factors of illness. The constant swings from acute imperative (and use of multiple healing practices, though often prioritising the medical (Gordon, 1996)) to preventive phases of illness are characteristic of the lived experience of this affliction. These contexts direct attention at different patterns of healing practice use from a singular medical model to varying combinations of TCAM therapies and lifestyles changes as antithesis to or in combination with medical treatments. The general attitudes projected by participants during these two types of phases of living with IBD are pragmatism and keeping calm. Although not always the case, as seen in this research, most healing practices used by IBD sufferers looking for a pragmatic and fast-acting treatment for their acute phase of illness were medical. On the other hand, when sufferers experienced a period of remission of symptoms, they tended to use less intrusive healing practices that focussed on being tender and 'kinder' to the Self. As Mitchell and Cormack (1998: 5) pointed out, this attitude was key to the use of TCAMs *"on promoting the person's own self-healing"*.

This strong association between the context of urgency in the phases of illness associated with usefulness of healing practices is also dependent on sufferers' individual preferences (Self) in determining which therapies to use, when and how. These explanations of being pragmatic or keeping calm in different situations have been described as 'pragmatic acculturation' by Quah (2005, 2008). She lists three categories of pragmatic acculturation based on a sufferer's illness trajectory: *"preventive health behaviour (the behaviour of people who consider themselves healthy and wish to avoid illness); illness behaviour (the activities of a person who feels ill for the purpose of defining the illness and finding a solution); and sick role behaviour which refers to the activities of a person diagnosed with a disease for the purpose of recovering"* (Quah, 2005) This pragmatic approach to illness situations and behaviour connected to avoiding illness are similarly expressed in this study (see Chapters Five and Six).

An additional point needing some clarification is that labels used to categorise healing practices as either preventive or curative only served to point out the purpose of using particular healing practices. In reality, participants did not delineate healing practices into these categories but stuck to describing them according to their function.

Moreover participants did not label or name healing practices as traditional, complementary or alternative instead using the name of the practice in their descriptions of their use. Yet when IBD sufferers described using medical healing practices, these were often referred to as 'orthodox', 'conventional', 'mainstream' or 'allopathic' practices. This point contributes to comments made previously about the non-conflicting use of healing practices whilst still embracing strong opinions about those healing practices reflecting the complex nuances of using therapies whilst living with long-standing illness in an ever-changing context of culture.

#### **7.4 Benefits of the Conceptual Framework**

This section examines the value and usefulness of the conceptual framework for the research and how it may benefit other research. The key points for discussion about the conceptual framework are: 1) whether it works in terms of usefulness, 2) how it is beneficial in understanding IBD or use of healing practices, 3) whether it is transferable in terms of being applied to other illnesses and other research. It is clear from the discussions posed in the first section of this chapter that the cultural construction of illness and healing in the understanding of how and why healing practices are used involves the Self, cultural influences and happens in the context of life events. The four interconnected components of the conceptual framework do not seem to be able to exist without one another, which is something this framework offers in capturing the complexity of living life and using a mixture of different therapies.

##### **7.4.1 Is the Conceptual Framework Useful?**

As mentioned in Chapter Three, the initial ideas that inspired the inclusion of the four components of the conceptual framework mostly came from Helman's (2007) descriptions on the importance of understanding the context of culture in medical anthropology as well as the interconnected sectors in health care: popular, folk and professional. These components seem to reflect the aspects of real life in living with long-standing illness as they take into account the complexity of how things work in reality; the 'messiness' of figuring out how to help oneself and use treatments. The fact that the framework works in a cultural context makes the interpretation of meaning in understanding the use of healing practices diverse and individualistic considering a multitude of ways of living. This flexibility, yet simplistic organisation of the components that co-exist make the framework easily applicable and user friendly.

#### **7.4.2 Does the Conceptual Framework help in Understanding IBD and Healing Practices?**

Having thought about the necessity of each of the four components, there was a need to move the conceptual framework from being a descriptive theory to something presented in a more functional way. This is where Kleinman's (1980) work on explanatory models helped in constructing an explanatory model of the conceptual framework including the four components thereby giving it 'movement' and functionality in the cyclical flow of change between components. For example, when an individual changes their perspectives of Self, this inevitably has an effect on changing the other three components, like exposing oneself to a new healing practice setting (life event) in order to communicate with the cultural influences associated with that setting and therefore coming into contact with therapies. The fact that the components of the conceptual framework co-exist and take time and space into account with regard to changes in people's ways of life makes it possible to mirror, to a certain extent, to see what happens in real life. In particular, capturing the nuances situated in the four components makes it possible to encompass the complexity of life. By understanding the nuances and functions of mechanisms and systems, it is possible to explore the meaning behind use of healing practices as well as making explicit the consequences and coping mechanisms of living with a long-standing illness.

#### **7.4.3 Can the Conceptual Framework be Applied to Other Illnesses?**

The conceptual framework already pre-conceives that any sufferers of illness will be living in a context, that they will be interacting with things and other individuals, that they will want to be following their own interests in striving to feel more comfortable and experiencing less suffering and that they will be using some form of healing in order to achieve a more content state of health. With these ideas potentially familiar to anyone experiencing long-term illness, this conceptual framework can be applied to most if not all illnesses so long as the goal of the research is to understand meaning behind use of healing practices. In other words, this framework and model focus on the epistemological 'making sense of illness' and use of healing practices. A point that needs to be added to this discussion is that this framework can also be used to look at any form of healing, not necessarily just TCAMs (for example, use of home remedies or ways of healing like resting). In fact one of the literature sources that similarly considered most of the aspects studied in this research was work done by Soivio (1999) using an anthropological approach and the use of explanatory models to understand how sufferers make sense of IBD whilst using medical treatments.

## 7.5 Outlining the Study's Main Strengths and Limitations

In research not everything is necessarily straight forward. The main strengths of having done this research including the way the study was conducted are as follows:

- *Capturing complexity* – the research interest and particularly the use of qualitative methods in recording and analysing how and why IBD sufferers used particular healing practices made it possible to capture the complexity of real life situations, in particular, with regard to the interrelatedness of the four components that make up the conceptual framework. The fact that this study used an interpretive lens focussing on concepts found in medical anthropology also contributed to this strength.
- *Presenting other ways of healing* – because of the research interest in understanding non-conventional ways of healing an illness that is commonly healed using mainly allopathic treatments in medicine, the provision of other perspectives on illness and healing presented by other types of healing practices like Chinese Medicine made it possible to see life with a long-standing illness and its healing from a very different vantage point (yin yang theory as opposed to anatomical/physiological understandings of the Self, illness and healing).
- *Providing different vantage points* – this study, being centred on the stories as expressed from a sufferer's point of view, provides readers of this research with a different way of seeing illness and getting healing which may benefit other sufferers not to mention practitioners or policy makers in considering other ways of coping and healing.
- *Providing a therapeutic opportunity within the interview process* – this point comes chiefly from feedback gathered from participants of the study who expressed (most participants) the therapeutic experience of: 1) exteriorising their views and having the opportunity to tell their stories as well as 2) hoping to contribute to helping others with similar illness.
- *Clarifying interpretation of data* – this was possible because of the use of multiple interviews in order to probe further and have a second opportunity during second interviews to get more information on certain points mentioned in previous interviews or written diaries. The use of life events lists as a brief list of chronological facts summarised into usually one page for participants to revise at the start of their second interviews also made it possible to check on the researcher's understandings of the data.

The main limitations highlighting what this research lacked are as follows:

- *Having few participants* – due to: 1) the research interest in finding people who used non-conventional treatments in healing IBD, particularly when the mainstream healing practice is still medicine and 2) the amount of data needing processing in doing qualitative research, making it difficult to recruit many more people to the study. For instance, in an exchange of emails with Cristalle during recruitment, she expressed her concern as to whether her inclusion in the study would be useful given that she no longer was using a TCAM healing practice and considered herself “normal” since having her surgery. She said, in general but especially, concerning doing the diary that she felt it was “a bit irrelevant to [her]” as she “no longer [had] the disease”. After some explanation of the research interest, she accepted to be in the study since her story seemed particularly relevant in terms of how she came to use Chinese Medicine or any other healing practices whilst she *did* have the “condition”. This relevance also included why she decided *not* to use Chinese Medicine any longer, in the context of changing life events and cultural influences. This made the outcomes more suited as empirical findings that provided ideas for future research with many more individuals in order to make any significant conclusions applicable to the general population of people suffering with IBD let alone other illnesses.
- *Not covering certain topics* – in the reality of living with illness and using healing practices, this research left out a large section of important topics that were not covered by this study, in particular, access, safety of and cost of using TCAMs. These issues were mentioned by a few participants but were not delved into particularly during the analytical processing of data although they would have definitely given another dimension to the availability of TCAMs. The reason for this was that the research question and interest lay with understanding perspectives and mechanisms of use of TCAMs rather than the process of accessing, affording and considering the safety of TCAM healing practices.
- *Providing only snapshots of experiences* – unlike many other qualitative studies, especially those adopting a qualitative approach, these accounts of IBD sufferers were ‘limited’ to the fact that they were situated in a short time frame in comparison to the reality of experiencing long-term illness and changes occurring within life events in the span of years rather than a few months. The main reason for this is the fact that funding, time and purpose of the research experience was more about learning how to do research rather than actually doing research as an established researcher with more time and funding.

- *Oversimplifying lived experience* – the way the data has been interpreted and presented can be seen as an oversimplification of complex, multi-dimensional patterns of occurrences and intricacies experienced by sufferers taking part in this study. Although themes and concepts emerging from the data were clearly laid out, this made the ‘messiness’ and dynamic nature of ‘real life’ with IBD less obvious and to some extent misinformed. In particular, using the conceptual framework as a guiding tool for the analysis and also the presentation of the findings within the thesis implied a ‘tidiness’ of participants’ thinking and decision making. This is both potentially misleading (their narratives clearly demonstrated shifts and changes over time and at particular points in time) and potentially leading the researcher to take a narrower lens over the data, its analysis and interpretation, thus inhibiting the researcher in searching for or seeing other potentially important nuances and emerging concepts. Nevertheless, as has been pointed in section 7.4, the conceptual framework was valuable and useful in helping the researcher both understand IBD and the use of healing practice pluralism in the context of mainstream medical practice and to communicate the complexity of participants’ approaches.

Aside from the main strengths and limitations of the study, further reflection on the approach adopted suggests the potential of two particular ways the data could have been analysed and interpreted differently, and thus of potential in future research. The first comes from recognising that the narrative accounts, the primary data sources in this thesis, were analysed and interpreted more as ‘actual’ and potential ‘real’ or ‘true’ (within the context of Frank’s (1995) comment on any account has a current rather than complete truth value) rather than retrospective accounts of participants. An approach that sought to explore this, both in the data collection process and in the analytical strategy could have been explored. The second approach would be to explore the similarities and differences between participants’ illness trajectories (a concept developed in the work of Corbin and Strauss (1992) and Strauss and Glaser (1970)). This was at least partially undertaken in Chapter Five within each participant’s brief biosummary of their lives at the beginning of each individual case analysis. An alternative approach to the data analysis, therefore, could have focused on a comparative illness trajectory analysis. An example of such an approach is evident in Godfrey and Townsend’s (2008) exploration of older people’s ‘transition from illness to health’ and their depiction of four (illness) recovery trajectories. However, while using this method of analysis could have contributed to answering the question *how*

participants lived their journeys differently, it would not have fully answered the current PhD research question and interest in *why* they would use specific healing practices for particular purposes.

Yet another possibility for a future research study in this area to attempt related to the data collection process would be the undertaking of participant observation at, for instance, times of crisis. Although this method would have divulged a very different sort of lived experience and detailed insight into the actual lived decision-making experience, getting access to sufferers at times of crisis would be problematic (ethically or morally) as well as being highly resource intensive.

## **7.6 Revealing Personal Experiences during the Research Process**

In keeping with my strong personal views of the need for researchers to be honest about their opinions and experiences in doing research, this section is a personal reflection on my experiences of doing this research whilst considering two main roles: being a student learning research and being an IBD sufferer. These two roles are discussed in the same vein as Lofland and Lofland's (1995) descriptions of insider/outsider roles of the researcher in conducting research and maximising rigour.

### **7.6.1 Learning How to Do Research**

The learning experience of doing this research, in general, was a very challenging but fulfilling life experience, in particular with regard to improving my skills of using qualitative methods, expressing concepts and ideas concisely and building confidence in my capabilities of processing and representing other people's stories. The original time frame envisaged for doing this PhD was a maximum of four years. This did not happen due to mainly personal commitments to helping my parents with my father's ill health as well as recovering from my own exacerbated states of ill health as a consequence. Nevertheless, the process having taken double as much time to complete, provided me with the opportunity to see my work (usually in the form of working documents) at different points in time, which allowed for certain ideas and ways of doing research to 'sink in' and be applied over time; this is something that might not have been possible had I finished the PhD in four years. Another important point seen in retrospect of having done this research is the need to be disciplined and organised about recording as many thoughts and experiences as possible as these only enrich the quality of the research as well as make it easier for things to be

remembered and more accurately portrayed thereby achieving the goal of being as 'true' and honest as possible to participants stories.

### **7.6.2 Living with IBD**

I have had extensive experience (fifteen years) at different life stages in living with IBD. I was brought up in a family where my own father had IBD and my parents promoted the use of TCAMs and other non-medical healing practices and had strong aversions to medical treatments. My familiarity with having to take care of someone, who had suffered with IBD for forty years including other diseases associated with this illness, as well as have to deal with my own suffering with a lived example of what might happen to me in the future ever-present, made it was easier for me to understand meanings behind behaviour and empathise with participants of the study. Probably due to my upbringing as well as my character, the uniqueness of individual experience was instilled in me from a very young age. This also made it easier for me to be able to remind myself frequently during this research that any pre-conceived notions I might have about suffering with IBD might not be shared or experienced by others. I also had studied Chinese Medicine at university in the UK for five years with one semester's clinical experience in two major hospitals in Beijing leading to my clinical qualifications, which I have not used since 2003. I was also invited to do a three-month work-internship at the Traditional Medicine Unit of the WHO in Geneva. These aspects of my personal knowledge and experience were the things that facilitated as well as made me particularly cautious when collecting, sorting and interpreting data.

During the experience of collecting life stories and interacting with other IBD sufferers, I decided to tell only half of the participants that I have IBD as I was not sure if this was going to affect the interview experience. Participants whom I told I had IBD seemed more open about talking about their illness.

However it was my experience just after interviews and during playback of voice recordings that I found most difficult, with some life stories reducing me to tears from the amount of suffering participants had experienced linked with the helplessness of their situations as well as the possibility of similar mal experiences happening to me. I found myself sometimes jumping from one healing practice to another after hearing about it from participants whilst thinking 'this might work for me'. Another thing I seemed to experience was all the stages of participants' lives embodied in a faster and more intense way than was being presented by participants in their life spans. These distressing situations affected my health on many an occasion but also drove me to

continue my research in order to provide some sort of contribution to the improvement of their as well as other IBD sufferers' lives.

### **7.7 Recommendations for Future Research**

Considering the points outlined above, the study findings can serve as eye-openers to different ways of living with long-standing illness as well as presenting reasons and meanings behind how and why sufferers use particular healing practices. This information being empirical in nature may only have a small yet marked impact on how practitioners of both medical and non-medical healing practices perceive and understand sufferers. These implications might also add insight into how policy makers could consider supporting the use of different healing practices in a more pluralistic, non-conflicting way rather than underlining the differences between healing practices.

Further research employing the conceptual framework of cultural perspectives of illness and healing, and undertaken using qualitative methods, is needed, as well as conducting other studies more focussed on collecting information about the specific use of TCAMs would contribute to the lives of people suffering with and practitioners treating long-standing illness. In addition, the variables not looked at in this study (access, safety and cost of using TCAMs) are options for further study. Possibly after several studies in different academic fields will have been conducted to answer research questions dealing with gaps that exist in this area of interest, a more flexible approach to the provision of healing practices and services to people living with long-standing illness will emerge.

### **7.8 Concluding Comments**

The thesis set out to explore how and why cultural influences affect the way in which IBD sufferers look after themselves using particular healing practices, including TCAMs. Of the several ways healing practices perceive IBD (symptoms, diagnosis and treatments), this research focussed on the viewpoint of participants living with IBD and coping with suffering. A number of major contributions to existing literature are evident.

At a theoretical and analytical level, the conceptual framework has been demonstrated to aid understanding of the way participants with IBD live their lives and cultural dimensions of this.

At an analytical and empirical level, through the use of qualitative methods, an anthropological approach to gathering and selecting data from participants' narratives, using inductive analysis and applying the conceptual framework, the following outcomes and contributions to wider understanding were produced:

1. Enhanced receptivity to cultural influences
2. On-going re-evaluation of Self with emphasis on self-care and self-management
3. The use of a multitude of healing practices both preventively or curatively
4. Coping with long-standing illness in the context of life events including crisis periods, embarrassing situations and recurring loss of control

These addressed the four objectives, thus answering the research question.

The first two key messages coming out of the research are:

1. Features of cultural influences which make people more receptive to suggestions for using TCAMs and
2. Constant re-evaluation of Self in understanding which parts need healing

Both of the above guided sufferers in their choice of treatments, in particular, use of non-medical (for example TCAMs) ones. This choice to use non-mainstream therapies is characteristic of participants' in this study who did things differently. This way of life was made possible by the availability of a multitude of non-medical healing practices in a country with a diversity of ethnic groups and a cultural readiness for change bolstered by factors such as globalisation, migratory fluxes and an increase in TCAM consumerism.

The two last key messages that amplified the use of particular healing practices are:

1. The stigma of living with a 'dirty' disease for example in embarrassing situations and
2. The need to regain control of the Self and illness

These contributed directly to the ways in which participants cope with the lived experience of the unpredictable and uncertain nature of a life with this illness. These ways of coping manifested into using healing practices to either nurture or organise the Self and one's surroundings in order to live more comfortably and compromisingly with IBD.

The outcomes contribute new perspectives to existing empirical and methodological scholarship, highlight strengths, identify limitations and propose avenues for future research. Together with the broader literature examining this area of interest, the discussions and recommendations of this study may prove useful as a possible explanatory model for other long-standing illness research as well as the combining of various healing practices in the context of healing practice pluralism.

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## **APPENDIX A**

Ethical Approval Letter

School of Healthcare

Baines Wing  
University of Leeds  
PO Box 214  
Leeds LS2 9UT

Dr Janet Holt  
0113 343 1296  
hcsjh@leeds.ac.uk



UNIVERSITY OF LEEDS

11 August, 2008

Mrs Lynn Morra Philipp  
Room 3.35  
School of Healthcare  
Baines Wing  
University of Leeds  
LS2 9UT

Dear Mrs. Morra Philipp,

**Research Projects for Ethical Approval (SHREC/RP/142)**

Thank you for submitting further information on your research proposal "*Cultural Influences in Living with Ulcerative Colitis.*"

This has been reviewed and I can confirm that the issues raised by the School of Healthcare Research Ethics Committee (SHREC) have been fully addressed and consequently ethical approval is granted.

The committee wishes you every success with your project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Janet Holt', written over a faint horizontal line.

Dr. Janet Holt  
Chair  
School of Healthcare Research Ethics Committee

Professor Dawn Freshwater  
Head of School of Healthcare



Dr Janet Holt

0113 343 1296  
hcsjh@leeds.ac.uk

19 December, 2008

Mrs Lynn Morra Philipp  
Room 3.35  
School of Healthcare  
Baines Wing  
University of Leeds  
LS2 9UT

Dear Mrs. Morra Phillipp,

**Research Projects for Ethical Approval (SHREC/RP/142)**

Thank you for submitting the amended documents to your research proposal. I have reviewed the amended documents and I am pleased to confirm that ethical approval has now been granted.

The committee wishes you every success with your project.

Yours sincerely

Dr. Janet Holt  
Chair  
School of Healthcare Research Ethics Committee

## **APPENDIX B**

### Participant Recruitment Pack



UNIVERSITY OF LEEDS

Date

Dear Client,

**RE: A PhD research study on Cultural Influences In Living with Inflammatory Bowel Disease**

I would like to invite you, on behalf of Lynn Morra Philipp (a PhD student researcher), to take part in a research study that is being carried out at the University of Leeds.

The overall aim of the study is to explore the views of people who live with Inflammatory Bowel Disease (IBD), which includes Ulcerative Colitis and Crohn's Disease, about how their culture influences their choice of treatment.

Lynn would like to interview you about your use of Complementary Medicine in living with IBD. In the interview, Lynn will ask about: yourself and how you identify yourself ethnically within your culture; your experience in living with IBD, from when you discovered your first symptoms to how you came to be treated at your Complementary Medicine clinic; and the sorts of treatments you have used and things that influence the way you manage the signs and symptoms of the condition. The interview could last around an hour or so depending on how much you would like to say. If you feel you would like to, Lynn would also like to invite you to keep a written diary of any thoughts or memories you have in living with IBD.

Please read the enclosed *Information Sheet* carefully. This tells you more about the study and what happens if you agree to take part. Please note that I will not know if you agree to take part in the study. Furthermore, taking part, or not, will not affect your treatment within the clinic in any way.

If after reading the information sheet attached, you are unclear and would like more information about the research then please email Lynn at [l.n.morra05@leeds.ac.uk](mailto:l.n.morra05@leeds.ac.uk) or call her on 0113 343 3202. Lynn will be happy to call you back and discuss any questions you may like to ask about the study.

If you would like to take part, please complete the two consent forms and return *one* form back to Lynn using the FREEPOST envelope provided, keeping the other for yourself. Lynn will then contact you by telephone or email within the following week to arrange a time and place to interview you, at your convenience.

Yours sincerely,

[practitioner insert name]



## **CLIENT INFORMATION SHEET**

### **Study title: Cultural Influences In Living with Inflammatory Bowel Disease**

- I am hoping to recruit people with Inflammatory Bowel Disease (IBD), which includes Ulcerative Colitis and Crohn's Disease, to take part in my PhD research study.
- Please take the time to read the following information carefully and understand why I am doing this research and what it will involve before you decide to take part.
- You might like to discuss it with others before making any decisions.
- Please feel free to ask me if there is anything that is unclear or if you would like more information about the study.

## **PART 1**

### **What is the study about?**

The overall aim of the study is to explore the views of people who live with IBD about how their culture influences their choice of treatment.

### **Who is doing the research?**

I am doing this study as part of my PhD in the School of Healthcare at the University of Leeds with guidance from my supervisors: Professor Kate Thomas and Professor Andrew Long.

### **Why have I been chosen?**

I have asked practitioners in Complementary Medicine clinics and the National Association for Colitis and Crohn's Disease (NACC) to help me find people with Ulcerative Colitis or Crohn's Disease who use Complementary Medicine as part of their treatment. I would like to recruit up to 20 people with IBD who attend Complementary Medicine clinics to participate in the study. I would like to speak to as wide a range of men and women from different ethnic backgrounds and ages as possible.

### **What happens if I take part?**

You will be asked to have two interviews and keep a written diary over a 4-week period. The first interview will take place either at your Complementary Medicine clinic or at a place more convenient for you. In this interview I will ask you some questions about how you identify yourself ethnically within your culture. You will also be asked to describe your life from when you discovered your first symptoms of IBD, to how you came to be treated at your Complementary Medicine clinic. The first interview can take up to an hour or so but this will vary depending on how much you would like to say.

After the first interview, I will ask you if you would like to keep a written diary for a 4-week period asking you about any daily activities, thoughts and memories of your experience in living with IBD in your culture. You can write as much or as little as you like in the diary. If you prefer, I can send you an electronic (Microsoft Word) version of the diary, which you can email me at the end of the 4-week period.

After you have returned the diary, I will make an appointment with you for a second interview at your convenience. The second interview can also take up to 1 hour, again depending on how much you would like to say. In this interview I might ask you to clarify things you mentioned in your first interview or things you wrote in your diary.

The clinic and settings in which the interviews take place will be observed and recorded to provide context to information you present. The researcher will not be participating in any consultations or clinical interactions between you and any staff at your clinic.

### **Do I have to take part?**

No. Participation is entirely voluntary. Not taking part will not affect your treatment within the Complementary Medicine clinic in any way. Indeed, the practitioner will not know whether or not you have agreed to take part in the study. If you decide to participate you can change your mind at any time without giving a reason. If you decide you no longer want to take part, the information you have provided me until that time would remain in the study.

### **What are the advantages and disadvantages of taking part?**

Please be aware that there are both benefits and disadvantages to being involved in research. For example, you may find it interesting and helpful to talk through some of the issues that come up in the interview. However there may be topics that you find distressing to discuss. In the case of the latter the interview will be stopped immediately and will only progress once again, if at all, once you are ready. If I ask you any questions that you do not wish to answer, you do not need to answer them.

If you take part, you will be helping me understand the way people with IBD look after themselves within their cultures. This knowledge will help contribute to more appropriate ways of helping people with IBD in managing their symptoms and signs.

### **What do I do now?**

- If you are unclear about any information provided in this document or would like to ask questions about the study, please feel free to contact me via email: [l.n.morra05@leeds.ac.uk](mailto:l.n.morra05@leeds.ac.uk) or call me on 0113 323 3202. I will be happy to call you back.
- If you would like to take part please complete the two consent forms and return *one* form back to me using the FREEPOST envelope provided, keeping the other for yourself.

## **Who can I talk to for more information or advice about the study?**

I will do my best to answer any questions you may have so please feel free to contact me (Lynn Morra Philipp) via telephone: 0113 323 3202, via email: [l.n.morra05@leeds.ac.uk](mailto:l.n.morra05@leeds.ac.uk) or via my postal address: School of Healthcare, Room 3.35, Baines Wing, University of Leeds, LEEDS, LS2 9JT.

## **PART 2**

### **What if there is a problem?**

If you have a concern about any aspect of this study you can ask to speak with one of my PhD supervisors who will do their best to answer your questions (Prof Kate Thomas – Tel. 0113 343 1335, [k.thomas@leeds.ac.uk](mailto:k.thomas@leeds.ac.uk) or Professor Andrew Long – Tel. 0113 343 6250, [a.f.long@leeds.ac.uk](mailto:a.f.long@leeds.ac.uk)). If you remain unhappy and wish to complain formally you can do this through Clare Skinner, Faculty Research Manager, Faculty of Medicine and Health, University of Leeds, email: [c.e.skinner@leeds.ac.uk](mailto:c.e.skinner@leeds.ac.uk) or via telephone on 0113 343 4897.

### **Will the information I give be kept confidential?**

The information that you give me will be kept *strictly confidential*. Neither your name nor identifying features will be mentioned in any spoken or written reports; instead you will be given a pseudonym. Only I will have access to information identifying you including your contact details. Your interviews will be recorded for transcription purposes and transcriptions will be anonymised and retained for 5 years after the end of the study (this is a requirement of my PhD study). Your personal details and all hard copies of the information you provide will be stored in locked filing cabinets. All electronic copies, including databases of participants (practitioners and clients), and anonymised data sets arising from the interviews and written diaries will be stored on password-protected computers and on the University of Leeds server in order to prevent access to data should an individual computer be stolen. The procedures for processing, storing and destroying your data comply with the Data Protection Act 1998.

### **What will happen to the results of the research study?**

Talks will be given to academics, health care and complementary therapy practitioners during the study period and afterwards. Results from the study will be published in journals during the study period and afterwards.

People who take part in this study will be offered a summary of the final report. If you would like a copy you can mention this in the consent form or let me know later.

### **Who has reviewed this study?**

The overall study has been reviewed (and approved) by the School of Healthcare Research Ethics Committee (SHREC) at the University of Leeds. The PhD study is being funded by the University of Leeds, School of Healthcare.

### **Thanks very much for your time!**

Lynn Morra Philipp (PhD Student)

## CLIENT CONSENT FORM

Name of Centre: School of Healthcare, University of Leeds

Title of Study: Cultural Influences In Living with Inflammatory Bowel Disease

The participant should complete the whole of this sheet himself/herself

Please  
insert your  
Initials in  
each box.

- I have read and understood the participant information sheet.
- I have had the opportunity to ask questions and discuss this study.
- I have received satisfactory answers to all of my questions.
- I have received enough information about the study.
- I understand that I am free to withdraw from the study:  
  1. At any time
  2. Without having to give a reason for withdrawing
- I understand that any information I provide, including personal details, will be confidential, stored securely and only accessed by those carrying out the study.
- I understand that any information I give may be included in published documents but my identity will be protected by the use of pseudonyms.

### I consent to:

- Being interviewed by the researcher.
- Keeping a written diary for the period for one month.

P.T.O. →

Thank you for agreeing to take part in this study.

I agree to take part in this study

Participant Signature..... Date.....

Name of Participant.....

Daytime Telephone..... Evening Telephone.....

Email.....

- Please confirm that you are aged 18 or over

- Please indicate whether you are:

Male

OR

Female

## School of Healthcare

Lynn Morra Philipp  
Room 3.35, Baines Wing  
University of Leeds  
Leeds LS2 9JT  
**Tel:** 0113 343 3202  
**Email:** [l.n.morra05@leeds.ac.uk](mailto:l.n.morra05@leeds.ac.uk)



**UNIVERSITY OF LEEDS**

Date

Dear Practitioner,

**RE: A PhD research study on Cultural Influences In Living with Inflammatory Bowel Disease**

I would like to invite you to take part in a research study that is being carried out at the University of Leeds.

The overall aim of the study is to explore the views of people who live with Inflammatory Bowel Disease, which includes Ulcerative Colitis and Crohn's Disease, about how their culture influences their choice of treatment. Please look at the attached *Information Sheet*, which outlines the study and provides an overview of what taking part in the study will mean for you.

In particular, I am writing to ask you to assist me in selecting participants for the study from the clients whom you treat at your clinic. I would also like to interview you for around 30 minutes about things like: your clinic, what types of clients you treat, why you think your clients have chosen to be treated at your clinic and the rationale behind why you may not include some clients from taking part in the study.

If after reading the information sheet attached, you think that you might be interested in taking part then please email me at [l.n.morra05@leeds.ac.uk](mailto:l.n.morra05@leeds.ac.uk), call me on 0113 343 3202 or write to me at the School of Healthcare, Room 3.35, Baines Wing, University of Leeds, LEEDS, LS2 9JT. I will be happy to call you back and discuss any questions you may like to ask about the research.

I look forward to hearing from you.

Yours faithfully,

Lynn Morra Philipp (PhD Student)

## PRACTITIONER CONSENT FORM

Name of Centre: School of Healthcare, University of Leeds

Title of Study: Cultural Influences In Living with Inflammatory Bowel Disease

The participant should complete the whole of this sheet himself/herself

Please  
insert your  
Initials in  
each box.

- I have read and understood the participant information sheet.
- I have had the opportunity to ask questions and discuss this study.
- I have received satisfactory answers to all of my questions.
- I have received enough information about the study.
- I understand that I am free to withdraw from the study:  
  1. At any time
  2. Without having to give a reason for withdrawing
- I understand that any information I provide, including personal details, will be confidential, stored securely and only accessed by those carrying out the study.
- I understand that any information I give may be included in published documents but my identity will be protected by the use of pseudonyms.

### I consent to:

- Assisting in selecting clients from my clinic to participate in this research study.
- Being interviewed by the researcher.
- The researcher conducting and recording non-participant observation of my clinic and the settings of interviews.

P.T.O. →

Thank you for agreeing to take part in this study.

I agree to take part in this study

Participant Signature..... Date.....

Name of Participant.....

Researcher Signature..... Date.....

Name of Researcher      **Lynn Morra Philipp**

Daytime Telephone..... Evening Telephone.....

Email.....



**PRACTITIONER INFORMATION SHEET**

**Study title: Cultural Influences In Living with Inflammatory Bowel Disease**

- I am hoping to recruit up to 20 people with Inflammatory Bowel Disease (IBD), which includes Ulcerative Colitis and Crohn's Disease, to take part in my PhD research study.
- Please take the time to read the following information carefully and understand why I am doing this research and what it will involve before you decide to take part.
- You might like to discuss it with others before making any decisions.
- Please feel free to ask me if there is anything that is unclear or if you would like more information about the study.

**PART 1**

**What is the study about?**

The overall aim of the study is to explore the views of people who live with IBD about how their culture influences their choice of treatment.

**Who is doing the research?**

I am doing this study as part of my PhD in the School of Healthcare at the University of Leeds with guidance from my supervisors: Professor Kate Thomas and Professor Andrew Long.

**Why have I been chosen?**

Following discussions with my supervisors and other practitioners, I am seeking to recruit clients with Ulcerative Colitis or Crohn's Disease from Complementary Medicine clinics. The sort of people I am looking to access are men and women aged 18 or over from as wide a range of ethnic backgrounds as possible, who have been biomedically diagnosed with Ulcerative Colitis or Crohn's Disease, at any stage of illness, receiving Complementary Medicine treatments.

I will be interviewing clients about things like: how they identify themselves ethnically within their culture, describing their life from when they discovered their first symptoms of IBD, to how they came to be treated at your Complementary Medicine clinic. Clients have been informed that their withdrawal from the study will not affect their ongoing or future treatment at your clinic in any way.

### **What will happen to me if I do take part?**

I would like to ask if you would be interested in assisting me select participants for the study.

I would also like to interview you about things like: your clinic, what types of clients you treat, why you think your clients have chosen to be treated at your clinic and the rationale behind why you may not have included some clients from taking part in the study. An interview will last approximately 20 to 30 minutes but this will vary depending on how much you have to say. Depending on the number of clients selected and how many you decide to exclude, you might be asked for more than one interview during the course of the study. The settings in which the interviews take place as well as the general settings in the clinic will be observed during non-participant observation, and recorded to provide general descriptive information about the clinic setting.

If you would like some clarification about the study, please send me an email on [l.n.morra05@leeds.ac.uk](mailto:l.n.morra05@leeds.ac.uk), call me on 0113 343 3202 or write to me at the School of Healthcare, Room 3.35, Baines Wing, University of Leeds, LEEDS, LS2 9JT to discuss any questions you may have about the research. I will be happy to call you back.

### **Do I have to take part?**

No, it is up to you to decide. If you do decide to participate you can change your mind at any time without giving a reason.

### **What are the advantages and disadvantages of taking part?**

There will be some demands on your time as described above. If any question is asked that you do not wish to answer, please do not feel obligated to do so.

If you take part you will be helping me understand the way people with IBD look after themselves within their cultures. This knowledge will help contribute to more appropriate ways of helping people with IBD in managing their symptoms and signs.

### **What do I do now?**

- If you would like to take part, please let me know if you are interested via email, telephone or you can write to my address at the University of Leeds.
- If you are unclear about any information provided in this document or would like to ask questions about the study, please feel free to contact me on my email: [l.n.morra05@leeds.ac.uk](mailto:l.n.morra05@leeds.ac.uk) or by telephone on 0113 323 3202. I will be happy to call you back.

### **Who can I talk to for more information or advice about the study?**

I will do my best to answer any questions you may have so please feel free to contact me (Lynn Morra Philipp) via telephone: 0113 323 3202, via email: [l.n.morra05@leeds.ac.uk](mailto:l.n.morra05@leeds.ac.uk) or via my postal address: School of Healthcare, Room 3.35, Baines Wing, University of Leeds, LEEDS, LS2 9JT.

## PART 2

### **What if there is a problem?**

If you have a concern about any aspect of this study you can ask to speak with one of my PhD supervisors who will do their best to answer your questions (Prof Kate Thomas – Tel. 0113 343 1335, [k.thomas@leeds.ac.uk](mailto:k.thomas@leeds.ac.uk) or Professor Andrew Long – Tel. 0113 343 6250, [a.f.long@leeds.ac.uk](mailto:a.f.long@leeds.ac.uk)). If you remain unhappy and wish to complain formally you can do this through Clare Skinner, Faculty Research Manager, Faculty of Medicine and Health, University of Leeds, email: [c.e.skinner@leeds.ac.uk](mailto:c.e.skinner@leeds.ac.uk) or via telephone on 0113 343 4897.

### **Will the information I give be kept confidential?**

The information that you give me will be kept *strictly confidential*. Neither your name nor identifying features will be mentioned in any spoken or written reports; instead you will be given a pseudonym. Only I will have access to information identifying you, including your contact details. Your interview will be recorded for transcription purposes and the transcription will be anonymised and retained for 5 years after the end of the study (this is a requirement for my PhD study). Your personal details and all hard copies of the information you provide will be stored in locked filing cabinets. All electronic copies, including databases of participants (practitioners and clients), and anonymised data sets arising from the interviews will be stored on password-protected computers and on the University of Leeds server in order to prevent access to data should an individual computer be stolen. The procedures for processing, storing and destroying your data comply with the Data Protection Act 1998.

### **What will happen to the results of the research study?**

Talks will be given to academics, health care and complementary therapy practitioners during the study period and afterwards. Results from the study will be published in journals during the study period and afterwards.

People who take part in this study will be offered a summary of the final report. If you would like a copy you can mention this in the consent form or let me know later.

### **Who has reviewed this study?**

The overall study has been reviewed (and approved) by the School of Healthcare Research Ethics Committee (SHREC) at the University of Leeds. The PhD study is being funded by the University of Leeds, School of Healthcare.

**Thanks very much for your time!**

Lynn Morra Philipp

## **APPENDIX C**

### Interview Topic Guide

## TOPIC GUIDES FOR CLIENT INTERVIEWS

### Cultural Background

**Tell me a little bit about where you're from.**

*With this open question I am intending to get some information on the client's cultural background. I need to keep in mind that at some point in the interview I need to ask about each client's family (kinship networks), spouses or close friends (hierarchical relationships) or main carers. This is because they might affect the decisions the client makes on types of treatment chosen.*

### Ulcerative Colitis

**Tell me a little bit about when you were first diagnosed with Ulcerative Colitis.**

This question is about asking clients their experience in living with Ulcerative Colitis (UC). It is expected that clients will talk about the process that they went through from the time of first symptoms, biomedical diagnosis, to how they ended up being treated at their Complementary Medicine clinic.

### Healing Practices

**Tell me a bit about the types of treatments you use for your Ulcerative Colitis.**

*In this question, the interest is in any healing practice the client might be using and would like to describe. The intention is to hear their way of managing their symptoms and signs and what influences their decisions within their culture.*

The open questions above will be followed by prompts in order to encourage clients to talk about their perspectives, habits, rituals, belief systems, patterns of behaviour, coping mechanisms etc.

## **APPENDIX D**

Example of a written diary

VENEZIA

**PhD Study 2009**

**University of Leeds**

**DIARY**

I am genuinely interested in how people from different cultural backgrounds live with Inflammatory Bowel Disease and what things in their culture influence the way they care for themselves.

This diary is quite flexible. You can write as much or as little as you like, when you like. If you decide to jot something down, just note the date in the allocated space provided. This diary is about you, so feel free to express yourself in any way you see fit. If there is not enough space to write what you feel, please feel free to add sheets of paper indicating the date next to your writing.

I am happy to collect any information you would like to share, which might include things like: physical or emotional situations you have to deal with in living with Inflammatory Bowel Disease, types of food and drink that you need to consider in your diet, how people in your life affect the way you manage your illness, things you do to make yourself feel better, memories of the past and how things have changed since you got ill, and thoughts, hopes and ideas about the future.

These are just ideas so you don't have to write about any of these if you don't want to.

Things influencing the way I care for myself today.	<p>After the death of my father in June 1992 I start to have runny, mucus + bloody stools. by looking at medical book I have convinced that I have bowel cancer. So I make an appointment with my GP. who examines me and assures me that I don't. He refers me to see a surgeon and to have a colonoscopy. After having the colonoscopy the Dr explained that I had Ulcerative Colitis. I remember feeling very relieved. that it wasn't anything sinister.</p>
Date: Aug 1992	

Things influencing the way I care for myself today.	<p>round about this time I was having a really bad time with my ulcerative colitis I was awaiting a hospital out patient appointment with the surgical Dr. a friend recommended a Chinese Dr that did acupuncture and alternate remedies. My first visit I was asked about what medications I was taking and my past medical history. I was then taken into a small room and asked to lay on a couch where Acupuncture was performed on me. After this session I went back into the waiting area to see a gentleman who put all different twigs, shoots + herbarium. - with an instruction leaflet.</p>
Date: Aug 2001	<p>When I got home we boiled the contents of one of the bags as per instructions. when we had done this (the smell was awful) I got a glass beaker and poured some of the water from the boiled contents and started to drink -!!!</p>

## **APPENDIX E**

Example of a Life Events list

## Life events

- **Birth** - Born in [town] in [county], an only child.
- **Education** - Went to school there until you finished and went to university to study [subject 1].
- **Parents' separation/divorce** – your parents had an acrimonious separation when you were 15/16 years old and divorced when you were 17.
- **First symptoms** - When you were nearly 22, after you'd finished your undergraduate study and was doing a year of work experience before starting your postgraduate study in [subject 2] when you noticed the first symptoms of your illness: passing blood, gradually getting worse with chronic diarrhoea, struggled to eat leading to a large amount of weight loss where your parents thought you were going to die.
- **Stress at home** - You feel the way you were brought up being given too much responsibility as an adult when you were still a child and the way your parents separated that this 'stress' went to your gut.
- **Misdiagnosis** - You mentioned it seemed a long time to get to a diagnosis. After seeing your GP several times, you were misdiagnosed and give Fibre Gel for what they thought was IBS, which pushed things out of your system and made you a lot worse.
- **Conventional Medicine Diagnosis** - You had to wait 3 – 4 months to see a consultant to get a diagnosis and it was in this time that you were really quite ill but they were able to quickly diagnose you after a colonoscopy, stabilise you with steroid medication and put you on a maintenance dose of Mesalazine (anti-inflammatory).
- **Hospital** - You stayed two weeks in hospital and came out delicate but better.
- **Drug treatment** - You took maintenance drugs for 14 years altogether until you were 36 years old.
- **Work** - You mentioned having done 10 years of work as a divorce lawyer (from perhaps 23 to 33 years old?) After this time you re-trained to become a family mediator because you felt that things in your work as a divorce lawyer aggravated your illness.
- **Watershed period** - During this time you also ended your second relationship, moved from where you were in [city 1] and started a new relationship with your now, husband.
- **Stopping maintenance drugs** - It was also around this time (mid-30's) that you decided to reduce the dosage of your conventional drugs and eventually come off them as you wanted to have a baby.
- **Complementary Medicine** - Your osteopath friend (name of her friend) advised you to try Homeopathy. You also used Reiki, Massage and Acupuncture at [the CAM clinic] but also mentioned using Osteopathy, counselling and aromatherapy.
- **Pregnancy** - At around 36 years old you became pregnant and mentioned a good pregnancy with a body free from drugs and gave birth to your son [name of her son], who's now 5 years old.
- **Flare ups** - When you have a flare up now (relapse?), you sometimes use foam enemas, acupuncture, homeopathy and massage to help either treat or prevent your symptoms. In addition, you also take baths, take naps and enjoy relaxing with friends. You also mentioned that coffee, wine, overeating, worry, anxiety, grief, the cold, menstruation and stress aggravate your condition.