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http://hdl.handle.net/10026.1/13078

http://dx.doi.org/10.24382/682
University of Plymouth

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UNIVERSITY OF
PLYMOUTH

INFLAMMATORY BOWEL DISEASE, HEALTH AND WELL-BEING: DEFINITIONS, IDENTITY AND EXPERIENCE

by

SARAH MOLLAND

A thesis submitted to the University of Plymouth
in partial fulfilment for the degree of

DOCTOR OF PHILOSOPHY

School of Law, Criminology and Government

September 2018

Inflammatory Bowel Disease, Health and Well-being: Definitions, Identity and Experience

Sarah Molland

Acknowledgements

I would like to thank the people who have helped me throughout the process of researching and writing my thesis.

I would especially like to thank Professor Gayle Letherby and Dr Mike Sheaff, for their ongoing support. I have learnt a lot from both, and they have provided advice, guidance and kindness. Both my supervisors have given me huge amounts of time and support particularly through the final months of the writing up process - for which I am extremely grateful.

The participants in my research, whom I cannot individually name here, gave me vital insight and understanding, allowing me into their personal lives with special and unique perspectives of IBD. This research could not have taken place without them and I salute their courage and tenacity in dealing with challenging health problems in their everyday lives.

Finally, I would like to give thanks to my family, particularly my husband, and my parents, for their ongoing support throughout my PhD. A lot has happened during this time, including getting married, having two children, and on occasion being unwell. Your unfailing support has meant a lot to me.

Inflammatory Bowel Disease, Health and Well-being: Definitions, Identity and Experience

Sarah Molland

AUTHOR'S DECLARATION

At no time during the registration for the degree of Doctor of Philosophy has the author been registered for any other University award without prior agreement of the Doctoral College Quality Sub-Committee.

Work submitted for this research degree at the University of Plymouth has not formed part of any other degree either at the University of Plymouth or at another establishment.

This study was financed with the aid of a studentship from the Economic and Social Research Council.

Word count of main body of thesis: 74,709

Signed: Sarah Molland

Date: 11/09/2018

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Sarah Molland

ABSTRACT

In this thesis, I explore the meanings and experience of health and well-being in the lives of individuals with Inflammatory Bowel Disease (IBD). Taking an auto/biographical approach and utilising in-depth qualitative online interviews, I draw on the experience and narratives of seventeen individuals with IBD, including myself. The three main themes addressed are 'Living with IBD', 'Becoming a Patient', and 'Coping and Control'. I explore how IBD influences individuals' experience of personal relationships, and their medical encounters and treatments. I reflect on how and why these factors arise and the effect they may have upon the disease and its management and on individuals' feelings of well-being more generally. I look at the resulting illness narratives and the impact of IBD on the daily life experience and the identity of the individual. I interrogate existing research and add to it from my analysis.

Throughout, the research highlights the importance of acknowledging the impact of biographical disruption on the life experience and identity of individuals along with changing illness narratives. There are implications for future research and for policy, including the time taken to reach diagnosis, the use of IBD guidelines in diagnosis and treatment, and patient control and choice as a contributing factor to influence future guidelines and treatment plans.

Inflammatory Bowel Disease, Health and Well-being: Definitions, Identity and Experience

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CHAPTER ONE: Introduction

1.1 The Issue and My Approach

This thesis and the research on which it reports is concerned with living with the experience of the chronic disease of inflammatory bowel disease (IBD) and with individuals' lived experience (both as patients and more generally) of health and well-being, with particular reference to identity, biographical disruption and illness narratives.

Inflammatory bowel disease (IBD) is a chronic condition which is currently not curable but is treated through the use of medication and diet. There are two diseases that fall under the name of IBD. These are Crohn's disease and ulcerative colitis. Crohn's and Colitis UK (2014: 4) describe the differences between the two diseases, saying that ulcerative colitis 'affects the rectum and colon... only the inner lining of the bowel is inflamed', whereas Crohn's disease 'may affect any part of the digestive system from mouth to anus... all layers of the lining of the bowel may be inflamed'. The IBD Standards Group (2014: 6) state that approximately 240,000 people in the UK have IBD. They go on to describe the symptoms:

> The main symptoms are very urgent and frequent diarrhoea, pain, profound fatigue and anaemia, with, for some patients, associated inflammation of the joints, skin, or eyes. Malnutrition and weight loss are common. The disease follows an unpredictable relapsing and remitting course with significant variation in the pattern and complexity of symptoms that may affect each patient.

IBD often causes physical and emotional pain to those diagnosed with it but it is a 'hidden' disease, in that it is not always outwardly noticeable to other people. Individuals may also try and hide or cover the disease which is likely related to

the stigma or possibility of stigma that they feel (Goffman, 1963; Page, 1984; Breakwell, 1986).

My motivation to explore this issue was, and is, auto/biographical. I suffer from IBD and have done so for a number of years. I hope to further knowledge and enhance understanding of the condition and to contribute to an understanding of the different emphases placed on well-being by people who have a chronic condition such as IBD. The research on which this thesis is based explored the factors which contribute towards the feeling of health and well-being for individuals with IBD, and also how biographical disruption might occur along with the associated illness narratives. Thus, the aims of the research were:

- To explore experiences of living with IBD, including diagnosis, the physical and emotional consequences of the disease and the impact on an individual's sense of self and well-being.

- To explore the significance of good and not so good relationships both with health professionals and with significant others for those suffering with IBD.

- To add to sociological understandings of living with chronic illness, specifically IBD, with special reference to biological disruption, identity and illness narratives.

Whilst there is a lot of medically-based knowledge with regard to the physiological aspects and treatment of IBD (e.g. Adamson, 1997; Boumer and

Strober, 2003; Baumgart and Sandborn, 2007; Laass and Roggenbuck, 2014), there appear to be relatively few social science research projects focussing on the experience of living with IBD. Therefore, in this thesis, drawing on my research and on my own experience, I explore, in-depth, the lived experience of living with IBD and thus the sociological understanding of this area. I hope that the knowledge gained through my analysis, and through the subsequent suggestions of further research in the area, will ultimately lead to further research and to changes resulting in an improved treatment experience for individuals with IBD and potentially other chronic diseases. Examples here include general guidelines for the treatment and diagnosis of IBD, and policy changes surrounding the care of these individuals.

My approach is qualitative and I engage with the auto/biographical throughout. I write reflexively of my history and experience with IBD and I draw on my own 'story'/ experiences as well as those of my study participants. I attempt a critical scrutiny of the relationship between the 'self' and 'other' in the research process and reflect on the significance of my 'insider' perspective (Okely, 1992; Stanley, 1993; Letherby, 2000a). Participants were recruited through IBD support groups, and interviews of the participants took place through email. Sixteen participants provided rich and in- depth data of their experiences. Nine participants have Crohn's disease and seven have ulcerative colitis. I asked them a series of questions related to their IBD including questions about diagnosis, impact on daily life, health and well-being, involvement with medical treatment, relationship with health professionals, importance of knowledge and experience and finally their support from others outside of the medical arena.

1.2 Outline of the Thesis

In Chapter Two, I provide a review of the literature where I discuss and explain what IBD is, and the symptoms and problems someone with IBD may face, both physically and socially. I explore meanings of chronic disease, health and well-being and the effect these may have on factors such as work (paid and unpaid) and relationships (both with health professionals and significant others). I also introduce the concepts of fear and stigma, in relation to biographical disruption and illness narratives.

In Chapter Three, I introduce and discuss the methods and methodology of the research. My auto/biographical approach is explored in-depth, and a discussion of the ethics of the research takes place. On a practical level, I describe how I recruited the participants and how the research was carried out. Within this chapter is a short profile / overview of each participant is provided and following this, the method of data collection and analysis is explored.

Chapter Four focuses on 'Sarah's story'. Here I write about my experience of IBD. I reflect on my experience with reference to the literature and attempt to answer the questions posed to my research participants.

Chapter Five is the data chapter, within which I present data from the participant accounts and some detail of my own experience. The main themes here are 'Living with IBD', 'Becoming a Patient', and 'Coping and Control'.

Chapter Six focuses on the discussion and analysis of the data introduced in Chapter Five and thus focuses on the same main themes ('Living with IBD',

‘Becoming a Patient’, and ‘Coping and Control)’. My analysis centres on the concepts of biographical disruption and illness narratives. I refer to Frank’s (1995) description of illness narratives of ‘chaos’, ‘restitution’ and ‘quest’ which I link to ‘biographical disruption’, with particular reference to the work of Bury (1982, 1991, 2001).

Finally, in Chapter Seven, I summarise the main findings and reflection on the experience of doing the research, including suggestions for change if I was to repeat the research and the impact of the research on me auto/biographically. Implications and suggestions for further research, and for policy change, are also discussed.

CHAPTER TWO: Literature Review

2.1 Introduction

My research, reported in this thesis, explores perceptions of health and well-being in individuals with a diagnosis of inflammatory bowel disease (IBD). IBD is a chronic illness. Adopting an auto/biographical qualitative approach I explore the lived experience of a group of individuals living with IBD.

This aim of this chapter is to provide an overview of the sociological and other literature relevant to an understanding of living with IBD. It focuses on three main themes: living with IBD, becoming and being a patient and coping and control. This includes a discussion of core sociological concepts related to my research; such as chronic illness, health and well-being, work, relationships, fear and stigma; and how these factors relate to the ongoing underlying concepts of identity and control which are central to a sociological understanding of IBD. Biographical disruption as discussed by Bury (1982) is a core theme to these concepts and is discussed in relation to them.

2.2 Living with IBD

2.2.1 Health and 'Well-being'

The terms 'well-being' and 'health' are differentially defined. As Danna and Griffin (1999: 361), note:

> Definitions and measures of health and well-being vary, there tend to be two salient person-related concepts that are often combined with a more societal-level perspective. The first is that health and well-being can refer to the actual physical health of workers, as defined by physical

> symptomatology and epidemiological rates of physical illness and diseases. The second is that health and well-being can refer to the mental, psychological, or emotional aspects of workers as indicated by emotional states and epidemiological rates of mental illnesses and diseases.

Many of the definitions of health and well-being describe health as being the lack of ill health. In an early discussion on these themes, Blaxter (1990) for example, connects this to class, and how working women describe health as an absence of illness. It can therefore be seen that health and its perceptions may be linked to other factors, including class and gender.

A sociological definition of well-being is given by Drummond (2000: 235), who relates the concept of well-being to happiness and social relationships and also proposes that well-being depends upon the setting / context of individual circumstances, saying:

> The principal source of value for respondents was described as the experience of happiness in the context of emotionally-significant social relationships. Sources of value appeared to be subject to variation between individuals and through time, implying that quality of life should be considered to be an existential concept.

Another discussion of quality of life is given in an article written by Larsson *et al* (2008) who carried out research examining quality of life in patients suffering from inflammatory bowel disease:

> Ulcerative colitis (UC) and Crohn's disease (CD) are two forms of chronic intestinal diseases which are classified under the main-heading chronic inflammatory bowel diseases (IBD). Both symptoms and treatments influence patients' health related quality of life (HRQoL). The concept *HRQoL* is subjective and multidimensional and incorporates physical, emotional, and social aspects of health perception and health functioning. (Larsson *et al* 2008: 139)

Again, this definition of well-being or quality of life depends on all areas of the life of the patient, and not just the physiological. Larsson *et al* (*ibid*) recognise that not only symptoms influence the patient experience but also the treatments that are prescribed to help alleviate the symptoms. As previously discussed, this is particularly relevant to IBD as many of the medications prescribed to treat it have numerous side effects and risks which may affect the feelings of well-being that a patient experiences.

It is worth considering whether there is a difference between the quality of life and well-being in individuals with Crohn's disease and individuals with ulcerative colitis. This is illustrated by Larsson *et al* (*ibid*: 145) who go on to argue that there is a difference in quality of life between patients suffering Crohn's disease and those suffering from ulcerative colitis, saying:

> Patients with CD had more surgical interventions and more exacerbations than UC patients, which underlines the fact that CD is generally a more complicated and serious condition in medical terms. Patients with UC reported, in this study as well as in previous investigations, better HRQoL and general well-being and less psychological distress than patients with CD. The present study shows that these differences remain during exacerbations in disease.

This shows the way in which the severity of the condition may influence quality of life and well-being alongside the previously mentioned other factors such as the social. It would suggest that the severity of the condition may be the factor that influences the effect of the illness on all the other areas associated with well-being and quality of life as opposed to the simple presence of a chronic illness regardless of severity or presence of symptoms.

De Rooy *et al* (2001: 1816) split the idea of quality of life and the associated concept of well-being into two strands, the quantitative and the qualitative:

> Inflammatory bowel disease (IBD) encompasses ulcerative colitis (UC) and Crohn's disease (CD), two idiopathic chronic inflammatory conditions of the gut. The importance of health-related quality of life is recognized (*sic*), both quantitatively as measure of treatment outcome and qualitatively, where the description of the concerns experienced by people with IBD may deepen the clinician's appreciation of the illness experience and provide focus for the development of relevant psychosocial interventions.

This definition recognises that quality of life and perceived well-being are influenced by both the symptoms and treatment and also the lived experience and feelings of the individual suffering from IBD. The treatment and the effects of treatment are treated as quantitative – something that can be objectively measured and understood from a physiological point of view. The other side of quality of life and well-being is seen as more qualitative. This is about the feelings, emotions, experience, interactions and the perceived self / identity of the patient. In this sense, it can be argued that well-being can be viewed either as a whole, or it can be broken down into separate parts. Breaking the concept down into separate parts is perhaps more useful as it is the sum of all those parts that contribute to the whole, and without separate awareness and/or analysis of the parts it would not be possible to work out the overall levels of well-being. Cloninger (2006: 71) supports this in his research around well-being and mental health, arguing that overall well-being is dependent on several factors, including psychological, biological, spiritual and social.

The study by De Rooy *et al* (2001: 1819) concludes with a list, in order of importance in the view of patients, of what contributes to concerns and worries about their well-being in IBD:

> The top 10 numerically ranked concerns of these outpatients related to energy level, effects of medications, the uncertain nature of the disease, having surgery and / or an ostomy bag, achieving full potential, loss of bowel control, being a burden on others, producing unpleasant odors (*sic*), and feelings about body.

The World Health Organisation (WHO) describe well-being as '... a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (http://www.who.int/about/definition/en/print.html).

All of this supports the need for a multi-faceted understanding of well-being, and the WHO definition of well-being is complicated by the inclusion of the word 'complete' as this suggests that well-being is unobtainable by the majority of people who may indeed consider themselves generally fit, well and healthy. Chronic illness may mean that the individual redefines their own definitions of well-being. What is 'normal' to them may not be normal to people not living with a chronic illness, and therefore the life values and norms of a person with a chronic illness may be altered in order to compensate and fit around with their health status (Beaton *et al*, 2001).

Again, it is important to link back to the concept of identity. It can be argued that well-being is intrinsically linked to identity and placement of self. Changing identity and the way in which an individual may see themselves is likely to have an effect on the factors mentioned above, related to well-being. We can return

to the words of Williams (1999: 812) who argues that there should be a 'commitment to real bodies and real selves, real lives and real worlds'.

2.2.2 Chronic Disease

IBD is a chronic disease. This means that it is not curable (except in the case of ulcerative colitis whereby the entire colon may be removed) and a patient will, once diagnosed, always carry the diagnosis with them. As previously mentioned, the disease may go into remission, in some cases for many years. Individuals have varying levels of symptoms and interference in their lives, but it is a long-term condition with a continuing level of uncertainty and unpredictability regarding if and when symptoms and / or a flare up may occur. This clearly has big implications in terms of the self and the body, self and identity and also self and others. The disease and its associated symptoms may have a significant impact on everyday life and change the way in which individuals live and lead their life. Thus, the identity of an individual may be altered or be adjusted in order to cope with the disease. These concepts are interlinked.

In her award winning blog about living with IBD, Sara Ringer has written about her feelings regarding the diagnosis and the seemingly endless symptoms and treatment. She discusses the feelings of helplessness and not being in control of what happens, alongside the way in which her identity has changed, becoming increasingly isolated from other people because of her illness. Her writing is a very good example of the concepts raised above:

> I was a childhood bride. I had no say you see because this was an arranged marriage. I didn't ask for this.

> At the age of 14 I stood there in my wedding gown, you may know the kind. It opens in the back and is not very modest, some call it a hospital gown. I wore this wedding gown and a hospital bracelet was slid around my wrist to seal the deal. A circle, this hospital band, a symbol of eternity. It has no beginning and it has no end. Round and round in circles this marriage will last forever.
>
> We exchanged our vows. Or I should say my partner rattled off the vows.
>
> *In sickness and in health.*
>
> *Til death do us part.*
>
> I just nodded.
>
> The ceremony went on; "Do you Sara take disease to be your... "Disease? Disease! *No I don't take disease*, but I had no other choice. There was nothing I could do, my arranged marriage that I had no say in. "I do?" What else could I say?
>
> I cannot take the physical abuse much longer. I have been cut, I've bled, and I have the scars to prove it. I have been forced to poison myself because of disease and disease has nearly killed me. The physical abuse that I endure is one thing, but it's the mental abuse that really changed me. Over the years I have been cut off from the world – slowly isolated from my friends, my family, my job, so that I lose my identity. It's a form of control and disease loves to control me. There have been times when the abuse stops and disease is nice for awhile. I am allowed to go back to work and disease allows me to do the things that I love to do but when I start to gain any independence the abuse starts again. I have learned that it's just best to turn off emotion, to not get my hopes up, and to not expect much. It's easier that way.
>
> And so this is my life. I do not work anymore because of disease. I hardly see my friends or my family because of disease. I am here in this house alone, just the way disease likes it. I am isolated and left to the voices in my head that are no longer nice after years of abuse. And just like the hospital band I wear on my wrist, the symbol of our unity, round and round we go in this marriage. Forever.

This account highlights what it is really like to suffer from ongoing and serious chronic health problems. Ringer has suffered from IBD since a young age and has had many hospital admissions. She has had surgery to remove her colon, suffered life threatening complications on many occasions, is on medication that causes serious and potentially life changing side effects, and her life is very

much limited and changed by her chronic illness. Perhaps it is sometimes easy for others to recognise the inconvenience of symptoms and the disruption that a long term condition may cause. But the account given by Ringer very much describes the feelings of lack of control and the helplessness that a sufferer may experience, which perhaps may be more difficult for others who do not suffer in this way to understand. It is an experience which leads to feelings and emotions that many people may not understand or comprehend. Ringer highlights the fact that nobody chooses to suffer from a chronic illness. It is something that is out of an individual's control, leaving only the way that it is dealt with as a choice.

Bury (1982: 169) suggests that chronic illness 'involves a recognition of pain and suffering, possibly even death, which are normally only seen as distant possibilities or the plight of others'. Thus, Bury (*ibid*) considers chronic illness to be a 'disruptive' experience to sufferers that may have long-term and disruptive impacts on lifestyle. This argument is also raised by Kim *et al* (2006: 548) who say '...the lives of chronically ill patients are often complicated by declining functioning, disability, persistent presence of unpleasant, troublesome symptoms, episodes of exacerbation of diseases, or a threat of death'.

A strong theme in the above arguments is a disruption on lifestyle and identity and the ability to live what might be considered a 'normal' life or a life with familiar routines. Indeed, Kelly and Field (1996: 247) argues 'there are few accounts of chronic illness which do not acknowledge that basic to the experience of that illness is the disruption of the normal and usually desired routines of everyday life'. It is important at this point to make the observation

that ‘normal’ life is not just dependent upon treatment of symptoms but also a recognition that the life of an individual encompasses many areas, for example physical, emotional, social and spiritual. This is reinforced by Blanchflower and Oswald (2002:1381) who say:

> Reported well-being is greatest among women, married people, the highly educated, and those whose parents did not divorce. It is low among the unemployed. Second marriages are less happy.

If the focus is only on treating the symptoms and manifestations of an illness along what was traditionally seen as the biomedical model of health, it could lean towards removing or decreasing ‘patient’ control and/or decision making in treating the illness. This could perhaps lead to potential mistrust and alienation as it is not treating the individual in terms of the complete effects of the illness. Indeed, Kralik *et al* (2002) propose that people with a chronic condition who are taking an active role in their healthcare tend to feel empowered and able to have an increased sense of self-identity. As will be noted later increased levels of control by those with IBD can lead to better well-being and compliance in treatment.

An example of the ways in which identity may be affected by chronic illness is highlighted by Gerson (1976: 802) who recognises the many problems that a person suffering from chronic illness may face and writes:

> …chronically ill people must deal with a number of major problems: they must deal with *medical crises* as they occur; the (*sic*) must act to control their *symptoms*; they must carry out their prescribed *regimens* and manage the problems which arise as a result; they must deal with the *social isolation* which often occurs as the result of an illness; they must somehow manage to deal with the impact of the disease on their *families* and on their *work*; and they must deal with the complexities of the

> *organization of medical care* and of *funding*. And they must do all this in the context of an ever-changing medical situation, in which the *course of the disease* may move steadily upward or downward, fluctuate or remain stable.

So, chronic illness involves not only the medical/physiological implications of an illness but a plethora of other factors that require consideration, all of which have an impact on the identity of an individual. An individual with chronic illness has expansive needs that expand far beyond simple medical treatment that health professionals may give, and may consequently not consider themselves as being in a state of good well-being even when treatments alone appear to be working as according to biopsy, blood tests and other physical measures.

More recent research by Williams (2000: 43) appears to support that by Gerson. Williams proposes:

> Illness, particularly chronic illness, is an experience in which, as Bury suggests, the structures of everyday life, its' taken-for-granted features, and the tacit stocks of knowledge upon which they rest are profoundly disrupted.

Gerson (1976: 803-804) has previously argued that chronic illness involves far more than simply a physical ailment that requires treatment saying:

> A measure of quality of life which focuses exclusively on the physical capacities of the patient in such a situation, or which leaves "normal activities" vague and undefined, has largely missed the point. In order to show the value of the approach developed here, I shall simply list some of the questions which might be asked when assessing the impact of chronic illness on sovereignty.

Gerson (*ibid*: 803-804) goes on to discuss the effects of chronic illness and differing ways in which the individual may have their ability to cope with the

illness influenced and goes on to raise the concept of ‘sentiment’ and questions the ways in which the patient may be affected by associates withdrawing from the them because of their illness, asking what the costs to the patient may be in terms of self-esteem, guilt and embarrassment because of the illness. This may be partly due to the effects of stigma or at least perceived stigma, which is discussed below. Link *et al* (2001) support this concept and propose that stigma is a barrier to people and that it lowers self-esteem leading to social withdrawal.

Gerson (1976: 803) also discusses money, and argues that sources of funding may be inadequate to cater for the individual’s needs and that standard of living may suffer. Savings and earning both current and potential may be affected and debt may be suffered as a result of a chronic illness. More recently, Reidpath and Allotey (2012: 2) argue ‘there is, however, little doubt about the financial impact of an increasing chronic disease burden on the individual, the family, and the health system’.

Gerson (1976: 803-804) also raises the question of ‘skill’ and queries whether the patient has adequate knowledge to participate fully in a medical regimen and whether they have sufficient knowledge to recognise adequate from inadequate procedures when they occur. Prior (2003: 45-48) makes a relevant point about the nature of lay expertise as being experiential as opposed to ‘technical’, saying ‘for the most part, lay people are not experts… What lay people recognise and report upon is change, and not disease. Theirs is what might be called experiential knowledge’.

These opinions certainly indicate that a patient's well-being is a multi-faceted concept requiring more skills and knowledge in treatment than a pure 'treatment' viewpoint. Gerson (1976: 804) acknowledges this, and concludes:

> …the treatment of chronic illness requires a very different pattern of skills, emotional involvements, schedules and budgets than those needed for the treatment of acute illnesses. Chronically ill patients require medical staffs to have a much more comprehensive knowledge of the patient's general social circumstances, to devote larger amounts of time to each patient on a continuing basis, to budget for much higher administrative and ancillary services, and to be rather more concerned emotionally with the welfare of each patient.

More recently, Holman and Lorig (2004: 240) support this and propose:

> With acute disease, the patient is inexperienced, the health professionals are knowledgeable, and they apply that knowledge to a passive patient. With chronic disease, these roles are no longer appropriate. The patient should be an active partner, applying his or her knowledge continuously to the care process.... Five categories of outcomes include: physiology, symptoms, physical and emotional function, personal health perceptions, and quality of life.

This statement indicates a need for the recognition of a patient's social background, including emotional, psychological, financial and possibly spiritual factors to provide an overall comprehensive and effective treatment plan.

Indeed, as demonstrated above, chronic illness has far reaching implications and impacts upon the life of the sufferer. This may be in terms of relationships with others, employment, or even the longer-term life choices that an individual makes. This idea is put forward by Bernstein *et al* (2001: 2117), in their research concerning IBD, who propose:

> ... because young adults are typically affected, these diseases may have an impact on patients at a time of their social and physical maturation, as well as at a time of forming their career choices and paths. These diseases can intermittently lead to hospitalizations (*sic*) and frequently to surgery. It is assumed that there are considerable indirect costs to society based on lost productivity time... Although these diseases might affect missed time from school or work, IBD patients have been considered to be more highly educated than the general population and are reported to come from higher socioeconomic sectors of the population.

2.2.3 Chronic Illness and Identity

Issues discussed above will now be applied to the context of IBD, giving particular attention to concepts of identity and self.

It is useful to take the above descriptions and arguments regarding chronic illness and place them specifically in the context of IBD. 'Identity' and 'self' are sociologically important concepts in the consideration of chronic illness and should be included in any definition and discussion of chronic illness. Other concepts such as fear, stigma and relationships may be seen as having a fundamental impact on the concepts of identity and self (Kelly, 1992b; Williams, 1996).

Michael Kelly is a sociologist and researcher who suffers from IBD and has written numerous articles surrounding the area. He raises the concepts of 'self' and 'identity' as important in the understanding of chronic illness related to IBD and its treatment. He relates these concepts to the surgery that is sometimes required for those who suffer from a severe form of IBD. He also links these concepts to the idea that identity and self are altered as a result of IBD. There is

a recognition that the effects of IBD reach further than the simple physiology and medical elements:

> For the people who have this illness there are social and psychological dimensions to the disease far beyond the pathology of the specific lesion. The ability to function socially can be severely undermined. Episodes of unpredictable diarrhoea punctuate all life's activities: from eating, through sleeping, to sex. Life may, at times, literally revolve around going to the toilet, or at least being near a toilet... The unpredictability of the diarrhoea may render even an otherwise innocuous situation terrifying. A simple stroll in the country, a journey on a bus, a weekend away at friends can all be ruined, not only by the diarrhoea but also by the fear that it might overtake the person (Kelly, 1992a: 1).

It is clear then that what many people may consider to be normal, everyday occurrences become a trial and a battle for others. The identity and behaviour of an individual changes as a result. There is a move from being what is perceived as 'normal' through to a person who has to change or modify their behaviour and subsequently their life due to the fear and unpredictability of the IBD.

This sense of change to identity is a form of biographical disruption in terms of an individual changing their life and self. Whitehead (2006: 1023) proposes that this disruption and change takes place over time and has phases depending upon the health situation of the individual:

> A trajectory that describes transitions in identity over time and the range of elements that influence these is proposed. During the acute phase of illness, characterised by total debility, people adopted the traditional sick role. The medium term phase highlighted movement between disability as part of the total self, total debility, and/or the adoption of a supernormal identity. The longer-term phase was defined for the majority of participants as the positive reconstruction of self…. In the longer term people's identity became more static with the development of coping strategies to maintain this.

Adding more emphasis to the concepts of self and identity, Kelly (1992b) writes about self and identity following radical surgery. Kelly (*ibid*: 391) explores the relationship between public identity and self-presentation and argues that there is a tension between 'private self and public identity'. He proposes that an individual who has an ileostomy looks ordinary to the casual observer and that people will not know unless the appliance leaks or the person chooses to tell others about their condition. This could perhaps be extended to anyone with IBD, not necessarily just individuals with an ileostomy. IBD is very much a hidden condition and there is no reason why other people would notice that an individual had it. Thus, there is potentially a cause for conflict between private and public identity. The concept of 'passing', discussed by Goffman (1963) and Breakwell (1986) is relevant to this situation. Whilst an individual may choose to hide their identity in terms of IBD upon the assumption that other people will not notice or automatically realise that they have the condition, there is always the possibility that an individual could be 'discredited'. They live a life in which they are 'discreditable', knowing that their public identity could be inadvertently changed if care is not taken to conceal their condition.

At this point it is important to distinguish between the sociological definitions of 'self' and of 'identity' as two separate and distinct concepts. Kelly contrasts between self and identity and (1992b: 394) recognises self as a phenomenon which relates to experience, subjectivity, knowledge and the way in which an individual interprets the world around them. He goes on to propose that 'self is linked to social context and social relationships by identity… identity is the label imposed by others on self' (*ibid*: 394-395) In a later article, Kelly (1996a: 245) argues that self is:

> ... a cognitive construct that is constantly being reconstructed and which is expressed in the various narrative and autobiographical accounts which are offered by the individual in self-presentation. Self is linked to body in so far as common-sensically (*sic*) self and body are experienced as one and the same thing. However, when bodily demands conflict with desired self-presentation the individual becomes acutely aware of the divergence between body and self.

It can be argued that it is what makes an individual unique. An individual with IBD may struggle with self in terms of continuing a life which they perceive as 'normal' as their body changes and is different to their expectations of what they consider to be 'normal'. Charmaz (2008: 168) relates to the concept of self and argues:

> Physical pain, psychological distress and the deleterious effects of medical procedures all cause the chronically ill to suffer as they experience their illnesses. However, a narrow medicalized (*sic*) view of suffering, solely defined as physical discomfort, ignores or minimizes (*sic*) the broader significance of the suffering experienced by debilitated chronically ill adults. A fundamental form of that suffering is the loss of self in chronically ill persons who observe their former self-images crumbling away without the simultaneous development of equally valued new ones. As a result of their illnesses, these individuals suffer from (1) leading restricted lives, (2) experiencing social isolation, (3) being discredited and (4) burdening others.

This account again highlights the ways in which the person who existed before the chronic condition may be a different person from the person after diagnosis and extended periods of suffering from symptoms and treatment. Their perceptions and consequently 'self' has changed in response to their changing health circumstances. These perceptions may be voiced as a narrative or a story. In qualitative research involving narratives and auto/biographical reflections this may be particularly important as self emerges through the narratives.

> ... sociological self *is*, rather than merely expresses, the narratives which people use to present their autobiographies. Such autobiographies are elicited, amongst other places, in certain types of data gathering... Our argument is that the structure and meaning of talk is the self and that structure and meaning comes out of the narrative... People's selves are generated by the way that they talk about themselves, to themselves and to others (Kelly and Dickinson,1997: 274-275).

Kelly *et al* (1996) propose that identity is the label about an individual which society places upon them – the way in which an individual is viewed by other people as an active participant in the social world. Williams (1996: 703) argues that Kelly's definition of identity should be taken further to include the concept of 'body-image'. Williams (*ibid*) acknowledges that this is less a 'sociological' concept and perhaps more related to psychoanalytic concepts but proposes that it is also an idea worth consideration. Williams (*ibid*: 703) proposes:

> ... the term body-image signals the impossibility of treating mind and body as separate entities. Moreover, of particular relevance to debates about chronic illness and disability, it also points to the extreme 'pliability' of body-image to immense biological, physical, behavioural and social upheavals and transformations.

In a later piece Williams (1999: 812-13) furthers this argument and says we should:

> ... rethink questions of identity, difference and the ethics of care through a commitment to real bodies and real selves, real lives and real worlds... None of this, it should be pointed out, antithetical to a consideration of the *lived* body, or to previous questions concerning the *meaning* and *experience* of chronic illness and disability.

Leading on from these definitions, it is perhaps easy to understand why there may be conflict in chronic illness, and more specifically IBD, between self and

identity. Fear and stigma are relevant to identity and one's sense of self. Indeed, Kelly (1992b: 411) goes on to say 'identity change is concerned with potential labelling, felt stigma, status passage and of experience of power relations in social institutions'.

2.2.4 Biographical Disruption, Chronic Illness and Self-Identity

Returning to the concept of biographical disruption, Bury (1982: 169) proposes that biographical disruption is related to the idea that chronic illness can be seen as:

> … a major kind of disruptive experience… where the structures of everyday life and the forms of knowledge which underpin them are disrupted… there is the disruption of taken-for-granted assumptions and behaviours; the breaching of common-sense boundaries… Second, there are more profound disruptions in explanatory systems normally used by people, such that a fundamental re-thinking of the person's biography and self-concept is involved.

Biographical disruption then can have a profound effect on everyday life, behaviour and associated identity related to chronic illness for it may include:

> … an examination of the constellation of familial and biographical experiences. In addition, the individual is inevitably drawn into rearranging his or her wider personal and community involvements. (Bury 1982: 175)

Asbring (2001) discusses this and considers the disruption chronic illness brings to the life of an individual. Asbring (*ibid*: 315) argues that chronic illness causes considerable disruption and forces and individual to adapt and readjust to a changed identity:

> For these patients this biographical disruption was often a matter of adjusting from a very active to a more passive life. The more active the life one has lived earlier, the more difficult this readjustment may prove… there was often an expression of grief over the loss of the previous identity and the activities associated with it.

She goes on to discuss the ways in which an individual may adapt to an altered or perceived different identity, the way in which an individual may come to terms with such changes discusses this very much in terms of 'activities' and the change in activity as a result of the chronic illness:

> The process of coming to terms with a new identity comprised the biographical work of identifying activities which could be kept up and those which must be given up or carried out in a different way… All in all these were steps on the pathway to coming to terms with the new identity, which included a life with the illness. Asbring (*ibid*: 316-17)

Bury (1991) further considers the adaptations and changes to identity brought by biographical disruption in terms of 'coping' as opposed to a focus on 'activities'. Bury proposes that individuals cope with biographical disruption through the means of a cognitive process whereby people almost have to tolerate the condition and its symptoms in order to maintain and / or establish an ongoing identity: '… involves maintaining a sense of value and meaning in life, in spite of symptoms and their effects' (Bury *ibid*: 461). These coping mechanisms include acceptance to the point of normalisation of the disease and its symptoms. This may be through trying to continue pre-illness activities as far as possible and through trying to hide the illness and its impact from others. Again, this can be related to the concept of passing discussed by Goffman (1963) and Breakwell (1986) (see below), whereby an individual may try to hide their health status from others meaning that there is a conflict

between private and public identity. This leaves an individual susceptible to having a status of being ‘discreditable’.

2.2.5 Biographical Disruption, Chronic Illness and Work

An area that may be impacted by the presence of a chronic illness such as IBD is working life and the ability to earn a salary. Because of the distressing symptoms experienced by individuals suffering from IBD, the condition affects many different areas of life, and this is likely to include work paid and voluntary work. This is directly to the discussion of biographical disruption. Work and working life is often a key part of an individual’s life and identity, and therefore where work and working life is affected it can be seen as disruptive in this sense.

This argument is supported by Meenan *et al* (2005: 548) who carried out research into the impact of chronic conditions, and the subsequent ability of individuals to carry out what they might consider normal life. It was found that:

> Despite this evidence of ongoing, reasonable medical care and adequate function, subjects experienced numerous socioeconomic impacts from their disease. A majority of the working subjects were fully disabled.... and most of the others had to change occupations or reduce their hours. This effect on work was found across all occupational and sociodemographic classes, indicating the pervasive effect of this chronic disease on employment. As a result of this work impact, many subjects suffered wage losses that produced major decreases in personal and family income.

Clearly working life can be affected by chronic illness and that this leads to an impact upon financial circumstances, which may not just affect the individual, but also the family. This in turn may mean that the individual suffers from further stress, which as previously discussed, in the case of IBD, is likely to exacerbate

and worsen symptoms and increase the likelihood of a flare of the condition. It could be seen as a vicious circle. Importantly, part of this vicious circle is the threat and actual impact of the illness on the identity of the individual and the biographical disruption that is experienced.

The effect of chronic illness and biographical disruption related to work is discussed by Moffatt and Noble (2015: 1194), who comment on the way that a diagnosis of, or ongoing chronic illness (in this case, cancer) impacts work:

> Following their shock and fear on receiving a cancer diagnosis, the participants' immediate concerns centred on treatment and prognosis, closely bound up with their anxieties arising from their family responsibilities and the effect of the illness on their ability to work.

The loss of work or the inability to work may also lead to decreased feelings and perceptions of well-being and health due to the effects that this may have on an individual's independence, identity and feelings of self-worth:

> Employment is a major factor in maintaining income levels and living conditions, especially among persons with long-lasting chronic diseases. Moreover, unemployment has been shown to be an independent predictor of morbidity and mortality from suicide and external causes in the general population, thus contributing to social health inequalities in the general population.... Studies have shown evidence for the existence of an impact on employment status of different chronic conditions including rheumatoid arthritis, diabetes, cancer, impaired cardiac function and limiting longstanding illness. This harmful effect of chronic illness on employment has been shown to be higher among the groups with the lowest position on the labour market, i.e. women, low-educated persons, manual workers and those with the most physically demanding work. (Dray-Spira *et al* 2008: 112-13)

The idea that work, or being unable to carry out work has an effect on identity is one supported by Moffatt and Noble (2015:1198) who propose that it can have a profound effect on identity and cause a high degree of biographical disruption:

> Permanent illness or disability from treatment and the inability to resume pre-illness occupations, particularly in the case of manual workers, coupled with the poor state of the local labour market militated against a return to work for most participants. In such cases, identity reconstruction following cancer treatment appeared to be much more challenging.

However, de Rooy *et al* (2001: 1820) propose that the argument that lack of work may cause lower feelings of control, independence, self-worth and well-being can possibly be turned on its head and considered the other way round:

> Ability to work is associated with greater interpersonal and body image concerns and greater physical impact concerns, controlling for the effects of symptoms severity. Even though symptom severity was rated twice as high for those who could not work because of their IBD, it did not explain these disease concerns. Inability to work may be considered a marker of global functional impact of illness. It is not clear if the fact of not being able to work increases concern about disease or, alternatively, if greater disease concern affects a person's ability to work.

Therefore, it cannot necessarily be taken for granted that lack of work decreases well-being and there is a possibility that those who have more worries and concerns are less likely to work in the first place.

Taking into account the above arguments, problems related to chronic illness and employment may not only have an impact on the well-being of an individual, but it may also have more, potentially serious implications, on factors such as identity, mental health, morbidity and mortality.

Dray-Spira (2008: 117) goes on to discuss the impact of chronic illness on women in particular, arguing:

> Women, more involved in domestic and family responsibilities than men, might have more difficulty to combine job demand additionally to household duties and disease management when they have to face a severe health problem.

With regard to whether an individual decides to disclose their illness to their employer or not and what reaction they may receive if they do decide to be open about it may vary and depend upon the relationship with their seniors at work and their employers knowledge or otherwise of IBD.

This is noted by Wyke *et al* (1988: 1234) who state:

> The disclosure of a medical condition to an employer can have a varied response. Some patients reported changes in the attitude of employers or potential employers once they learnt of their condition. This was particularly the case for patients working in the food industry.

Similarly, Vooijs *et al* (2017: 599) found that there was a mixed response to disclosure of a chronic condition in the workplace, which in some cases led to reluctance to disclose such a condition:

> With regard to disclosing their disease to others, some of our participants opted for disclosure while other preferred non-disclosure. In a positive sense, disclosure can certainly facilitate the implementation of other solutions, such as obtaining support and adaptations to the workplace, being able to communicate a patient's capacity for work and setting realistic expectations. On the other hand, negative experiences regarding disclosing the disease led some participants to decide not to disclose their disease to their employer or colleagues.

This would correspond with the idea of stigma and a threat to identity, which is discussed further below, and is an example of sufferers of IBD being seen as unclean or incapable in some way. This may often be due to lack of education

on the behalf of the employers who treat IBD patients differently. Indeed, Wyke *et al* (1998: 1234) go on to suggest:

> ...inconsistencies do exist especially with respect to food handling and further education of occupational physicians may be valuable in helping them to advise employers.... Occupational physicians and employers must be encouraged to take a more optimistic outlook of the longterm (*sic*) prospects and good work record of these patients.

This misunderstanding and lack of education of employers is probably not limited to a single career path. As suggested, education, understanding and looking at the good work that is carried out by people with chronic illness is an important step towards recognising that these individuals are capable of being a worthwhile presence in the workplace.

It has been suggested that employment and income has an effect not only on the individual suffering from long term chronic illness but also on other people within the family, which leads to a discussion of relationships.

2.2.6 Chronic Illness, Identity and Fear

Nijkamp *et al* (2002: 265) discuss the concept of fear and how it may be defined in a medical setting saying:

> Fear is defined as an unpleasant emotional state that is triggered by the perception of threatening stimuli. Psychologists distinguish fear from anxiety because they differ in one important respect. Fear has an obvious cause, and once the cause is eliminated, the fear will subside. In contrast, anxiety is less clearly linked to specific events or stimuli, leading to a more pervasive condition.

This is a helpful definition of fear and it can be applied to chronic illness and more specifically IBD. Fear may occur in diagnosis as it may be triggered, as according to the above definition, by the unknown and the perception of threat to health and the identity of an individual. This suggests that once diagnosis has taken place, and reassurance and/or treatment takes place, the fear will decrease or diminish. Thereafter anxiety may occur at times of poor health during a flare up of IBD. Alternatively if a new or unexpected symptom arises it might be possible that fear may occur again.

However, it is important to consider whether fear is a contributing factor in the initial approach to health professionals and whether it has an effect on the speed at which or the way in which help is initially sought. Smith *et al* (2005: 828) discuss the ways in which fear may play a role in diagnosis:

> After patients had recognised symptoms, fear was noted as a major barrier to seek help... Fear predominately manifested as fear of embarrassment and fear of cancer. Fear of embarrassment was a strong theme; men and women who delayed, especially those with diverse symptoms, worried about being labelled as neurotic, a hypochondriac, or a time-waster.... Fear of embarrassment was also related to the discussion of sensitive or sexual areas of the body and the invasiveness of physical examinations. Symptoms related to the penis and testicles were embarrassing for men to discuss and symptoms related to the rectum were embarrassing for both men and women.

This reinforces the argument that fear may play a role in how quickly help is found for symptoms prior to the official diagnosis of a chronic disease such as IBD. It can therefore be suggested that fear is linked to avoidance (Philips and Smith, 2004). It is likely that the symptoms of IBD such as rectal bleeding and diarrhoea could be feared by some as being a result of cancer. It is also likely

that there may be fear associated with embarrassment in potential cases of IBD as it is closely linked to sensitive areas of the body (e.g., rectum, bowels).

As has already been discussed, chronic illness is long lasting, and has many implications for the everyday life of the sufferer. Charmaz (2008: 174) argues:

> The unpredictable course of many chronic illnesses fosters uncertainty and fear, and as a result, some patients voluntarily restrict their lives more than need be. The unpredictability sometimes consists of lengthy episodes of illness followed by periods of relative remission. Or, unpredictability can have a much narrower time frame and consist of 'good days and bad days' or even intermittent 'bad spells' during the day. But due to their unpredictable conditions, these patients suffer disruptions of their lives and selves that go far beyond the physical discomfort they experience. Such disruptions include the felt necessity of quitting work, limiting social engagements, and avoiding activity.

This shows the way in which fear may be linked to uncertainty. The uncertainty of what is going to happen, the uncertainty of whether life is going to change, the uncertainty of how the disease will be treated. There seems to be an endless list of uncertainties individuals may face when diagnosed or suffering from a chronic condition such as IBD. Calnan (1984) discusses the uncertainties that a patient must face, including the clinical diagnosis process, the prognosis and what will happen next, the treatment and the trust and competence of the health professionals treating the individual.

Adamson (1997: 134) writes of the diagnosis process and the uncertainty involved in IBD:

> ... the individual's awareness that his or her future is open and undetermined. In the medical encounter, existential uncertainty is that form of uncertainty which is experienced privately by the individual

> patient upon the realisation that the future life of his or her mind, body, and self is in jeopardy.

The way in which fears and uncertainties are handled and dealt with during the diagnostic process may influence future coping strategies, and therefore during the medical encounter, health professionals must demonstrate and awareness of the fears of individuals to enable better future outcomes. This concept is acknowledged by Gerend and Maner (2011: 5) who propose that there are:

> ...important practical implications for patient care situations that evoke emotions such as fear and anger. Being diagnosed with a health problem, for instance, could elicit powerful emotions, which, in turn, could affect the way people respond to forthcoming health recommendations.

Additionally, it is again important to remember the concepts of self and identity. The diagnostic experience and the associated fear and acceptance of the diagnosis are likely to play a role in understanding the likely shift in the sense of identity. Purc-Stephenson *et al* (2015: 1203) discuss this specifically in the context of IBD and argue:

> Identifying both positive and negative changes may signal an ongoing struggle to maintain a positive identity in the context of chronic disease – a perpetual struggle between the positive aspects of the individual's present capabilities and coping strategies and the negative aspects of illness-related symptoms and perceived stigma. Understanding how people experience shifts in self-identity may provide insights into the adaptation process and thus put healthcare providers in a better position to help patients navigate through emotional, cognitive, and behavioral (*sic*) illness-related issues.

This not only acknowledges that there is likely to be a shift in self-identity but also that trying to understand this shift is key to helping individuals still adapting and coming to terms with the diagnosis and label of IBD.

This shift in identity is also linked with biographical disruption. As a fluctuating disease IBD has varying levels of disruptions on individuals at different times, leading to a possible difficulty in grounding self-identity. This is recognised by Saunders (2017) who explored biographical disruption in the lives of two individuals with IBD. Saunders (*ibid:* 735) found that the individuals coped with their changing life circumstances quite differently and that the biographical disruption experienced was experienced quite differently:

> Normality therefore appears not only to fluctuate for Samuel, or be contingent on circumstance, but undergoes wholesale changes. With this in mind, a cycle of recurrent biographical disruption and subsequent biographical reinstatement seems a more cogent interpretation of his illness trajectory. Edith, on the other hand, attaches quite different meanings to her experiences. Whilst Samuel represents illness relapse as very much removed from normality and as significantly impacting upon self, Edith's representations appear to show her having assimilated her condition within her self-concept.

2.2.7 Chronic Illness, Identity and Stigma

Within society, people are expected to live within certain social rules and norms. Becker (1963: 1) proposes:

> ... social rules define situations and the kinds of behavior (*sic*) appropriate to them, specifying some actions as "right" and forbidding others as "wrong". When a rule is enforced, the person who is supposed to have broken it may be seen as a special kind of person, one who cannot be trusted to live by the rules agreed on by the group. He (*sic*) is regarded as an outsider.

Therefore, people who are not seen as 'normal' within society may be singled out and seen as different – stigmatised.

More recently, Corrigan (2000: 49) extends this theory, arguing that it is not the label that leads to stigmatisation and people treating a person differently, but that it is the different behaviours demonstrated by someone who has a labelled disease.

Stigma is a term that is frequently used when discussing health issues. Goffman (1963: 3) gives a definition of stigma as an 'attribute that is deeply discrediting' and that reduces the owner 'from a whole and usual person to a tainted, discounted one'. According to Goffman (*ibid*) stigma is, at a basic and fundamental level, a social label which is both discrediting and tainting, and significantly changes how the stigmatized view themselves. Page (1984:1) says 'references to stigma are now commonplace in the media and in general discourse. The term is readily applied to any 'disreputable' person, group, activity, occupation or location'. This description of the term indicates that health problems are often seen as disreputable. More recently, Thornicroft *et al* (2007: 192) further this argument in their study of stigma and mental health problems, saying:

> At a time where there is unprecedented volume of information in the public domain, the level of accurate knowledge.... is meagre. There is evidence that deliberate interventions to improve public knowledge about depression can be successful, and can reduce the effects of stigmatisation.

Goffman (1963: 11) describes the way in which the term 'stigma' was first introduced by the Greeks who 'originated the term *stigma* to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier'. Goffman (1963: 12) goes on to say:

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

Goffman (1963: 3) makes the argument that stigmas may be 'discrediting' whereby they are immediately obvious to observers such as blindness or physical deformities or they may be 'discreditable' whereby the stigmatised condition is not readily observed by other people, such as an ex-mental patient or an ex-prisoner. IBD may be seen as 'discreditable', because the condition is not immediately noticeable to the casual observer. It is understandable therefore why Goffman's book is called 'Stigma: Notes on the Management of Spoiled Identity'. Stigma may be seen as a spoiled social identity because it represents deviation away from what society considers normal and acceptable, and the stigmatised person is then treated as different or unacceptable in some way. As previously mentioned, this may be because of a range of reasons including a physical characteristic, mental health problems or having been convicted of a crime.

Taft *et al* (2009) carried out research into the perceived stigma effects on IBD, and the patient outcomes related to this. This research (*ibid*: 1224) acknowledges that IBD, by its very nature and symptoms, leaves sufferers open to stigma and the effects of stigma:

> The inflammatory bowel diseases (IBDs), including ulcerative colitis (UC) and Crohn's disease (CD) are lifelong, concealable illnesses that usually begin at a young age and are associated with significant burden from

> symptoms and/or treatments. These disease characteristics make IBD susceptible to stigma. Stigma is defined as the societal labeling (*sic*) of an individual as abnormal, and has been identified as an important construct in outcomes for chronic illnesses. In addition to its concealability, symptom burden, and limited treatment options, IBD is at risk for stigmatization because of the nature of symptoms focused around the bowel and rectum, its relatively unalterable course, and its historical background as a psychosomatic illness among lay people.

The research by Taft *et al* (2009) is interesting in that their research found that 84% of participants suffering from IBD felt that they experienced perceived stigma. The results of the study confirmed the effects of stigma (*ibid*: 1231):

> In this study the majority of IBD patients reported perceived stigmatization *sic*), which in turn was a significant predictor of poorer outcome, even after controlling for illness and demographic variables. We provided preliminary yet compelling evidence that the presence of IBD-related stigma is associated with poorer quality of life, psychological adjustment, self-concept, and treatment adherence. Individuals with more complex symptoms ore frequent disease exacerbations may be at the greatest risk for experiencing perceived stigma. Finally, perceived stigma appears to be consistent regardless of remission status and may be a relatively stable illness construct.

Thus, the presence or the perception of stigma by the sufferer of IBD is likely to have far reaching effects. These effects range from whether the individual is compliant in terms of taking medication through to general quality of life. Each one of these factors may also have an impact upon the others. For example, through non-compliance with treatment it is likely that physiologically, disease activity may increase, thus increasing the severity of symptoms and the associated perceived stigma along with the quality of life and psychological issues / boundaries experienced.

Research exploring the link between stigma and IBD is relatively difficult to come by, but Saunders (2014) has recently published an article exploring the

area, and acknowledges that perceived stigma is an important issue, not to be ignored. Saunders (*ibid*: 1021) recognises that IBD is a disease which is prevalent in a younger population whereby self-identity is occurring and that IBD and the perceived effects of stigma may play a negative role in this.

The view of a stigmatised person being bad, dangerous or weak is highlighted by Wahl (1995: 103) who comments that

> ...stigma also leads to discrimination and reduced opportunities. It is clear from both research and observation that people with mental illnesses experience significant discrimination because of their disabilities – or, more accurately, because of what is incorrectly believed about their disabilities.

This is also noted by Markowitz (1998: 335) who says 'persons with mental illness are more likely to be unemployed, have less income, experience a diminished sense of self, and have fewer social support'. Stigma then leads to inaccurate and discriminating beliefs about certain groups of people and these beliefs may lead to reduced life opportunities.

More recent research also recognises the argument that those who are discriminated against or stigmatised are less likely to benefit from what most people in society may take for granted. Stuber *et al* (2008: 354) says:

> Discriminatory interactions also have negative implications for health and well being as they can lead to mistreatment in educational settings, in finding jobs, housing and health care.... stigma and prejudice such as segregation lead to poor health outcomes for marginalized individuals because they are denied access to basic health and life resources.

Goffman (1963: 14-15) argues that there are three different types of stigma that may be encountered. These are ‘abominations of the body’ (i.e., physical deformities), ‘blemishes of individual character’ (e.g. mental illness, addiction, suicide attempts) and ‘tribal stigma’ (i.e., race, nation and religion). Katz (1981: 3-5) furthers the idea of the categorisation of stigma and proposes that threat, responsibility, visibility and sympathy are important elements in the categorisation of stigma. Relating to threat Katz (1981: 3) says ‘within the realm of mental or emotional illness, there should be variations in the threat value of conditions, relating to differences in behavioural [sic] manifestations and potential reversibility’. It can therefore be said that a schizophrenic actively experiencing hallucinations and mood changes would amount to more of a threat to people than a schizophrenic in remission. Katz (1981: 5) argues that people who may be held responsible for their deviance may suffer more from stigmatisation and discrimination. Katz (*ibid*: 4) proposes that sympathy and visibility are linked and says ‘there is a strong social norm in this country that the physically and mentally disabled should be treated well’ and that the amount of sympathy elicited may depend upon the visibility of the stigmatised condition.

Therefore, stigma may exist in different forms and may be experienced to different extents depending upon the categories that the stigmatised individual may or may not fall into. It can also be noted that stigma amounts to a threat to the stigmatised individual – that they become regarded as threatening and abnormal. The sympathy reaction discussed by Katz (1981: 4) may be positive in some respects, in that the stigmatised individual may feel that they are achieving some kind of understanding from society. Katz (*ibid*: 3) stresses ‘all of these factors determine people’s levels of awareness of a particular stigma in

various interaction situations, hence the extent to which they will treat the possessor as deviant'. In turn this will affect the extent to which a discreditable individual will recognise and react to their stigmatised status.

People who are viewed as 'ill' are often labelled with an illness label such as schizophrenic, epileptic, asthmatic etc. Becker (1963: 9) points out 'the person with deviant behaviour is a person to whom this label has been successfully applied; deviant behaviour is behaviour that has been labelled as such by others'. Schulze and Angermeyer (2003: 300) further this by saying 'in line with prevailing cultural beliefs about a condition, labelled persons are then linked to undesirable characteristics'. Rosenberg and Lemert (2010: 551) argue:

> ...violators of norms are given labels such as troublemaker, criminal, delinquent, or other stereotypes that carry negative connotations. The individual, then "labeled," (*sic*) is consistently viewed and treated differently from "normal" members of the social group. The labeled (*sic*) individual is placed in groups, by social definition if not by physical location, with other individuals who have the same label. This new grouping both erects barriers for the individual's future reintegration into the larger social group and provides a behavioral (*sic*) model for further violations of norms. In short, a person actually becomes the label placed on him or her by the social group and exhibits behaviors (*sic*) along those lines. A person labelled (*sic*) as "criminal" because of past actions will be more likely to commit crimes in the future.

It can therefore be seen that, according to this view, the label of a deviant is may also actually cause deviance. Labelling theory appears to be a contested issue. Rosenfield (1997: 660) says:

> … labeling (*sic*) theory proponents and the theory's critics have different views of stigma and thus differ on the consequences of labelling for people with mental illness. The labelling perspective posits that because of stigma, official labelling through treatment contact has negative consequences for mental patients. In contrast, critics of labelling theory claim that stigma is relatively inconsequential. Instead, they argue that

> because labelling results in receiving needed services, it provides significant benefits for mental patients.

Advocates of labelling theory argue that the label itself rather than the displayed behaviour changes the lives of those with mental illness and can create long-term, chronic illness and reduce life chances and opportunities (Scheff, 1966; Link, 1982; Link *et al*., 1989; Rosenfield, 1997). Indeed, Markowitz (1998: 335) argues:

> ...persons who are labelled are rejected and discriminated against when attempting to resume normative roles, and they are relegated to playing the role of patient (Scheff 1966). As a result, a person's identity is altered, leading to behavior (*sic*) consistent with the expectations for the role of "mentally ill". In this version of the theory, labelling and the reactions of others are causes of sustained residual deviance.

This demonstrates that a person may become a deviant through the application of a label. Another example of this possibility is demonstrated by Gove (1970: 294) who says '...in recent years many sociologists concerned with deviance have adopted the viewpoint, commonly known as the societal reaction perspective, that deviants are created primarily by the responses of others' and 'when the societal reaction perspective is applied to mental illness, the mental patient is portrayed as someone who initially did not have a serious psychiatric disturbance, but who was forced by others into the mentally-ill role and who, over time, comes to adopt that role.

Clearly this strict view of the perspective cannot be taken as entirely true, because it implies that mental health problems are a myth and do not exist in the first place. However, it does highlight the potential problems related to

labelling and the way in which labelling can have a negative impact, causing conflict and an increase in symptoms (Huibers and Wessely: 2006).

Labelling is often seen as a method of force, power or control. Rogers and Buffalo (1974: 102) propose:

> …to negatively label a person or collectivity is an act of retaliation for alleged deviance and is under certain circumstances an unprovoked act of aggression. To label oneself or one's reference group negatively is tantamount to self assault.

More recently, Holmes *et al* (2006: 181) discuss the concepts of truth and power in medicine and comment that the health sciences control the way in which individuals are diagnosed and treated with no input allowed from other sources:

> The health sciences take their lead from institutional medicine, whose authority is rarely challenged or tested probably because it alone controls the terms by which any challenge or test would proceed.

Piven (1981: 489) views stigma and the resultant label as a form of control and power, and says:

> …stigma usually accompanies the exercise of force. More than that, it precedes force. The public defamation of rule breakers is a crucial process by which dominant groups reassert the legitimacy of their social ideas and try to discredit the ideas of their challengers.

The attachment of a label can be interpreted as a method of discrediting the labelled person. However, it can also provide someone in need of help with appropriate interventions.

2.3 Becoming and Being a Patient

2.3.1 Biographical Disruption, Chronic Illness and Relationships

Relationships are significant, whether they be in the home, socially or with health professionals. As noted above, there are different factors that have an effect on health and well-being, and because of the number of interplaying factors that have a role, it is likely that opinions and attitudes about health and well-being are unique to the individual and different to that of other people, and crucially the opinions of those close to them and also those of the medical professionals who are treating them. This area is discussed by Stewart (2001: 445) who proposes that individuals require patient-centred care whereby it is recognised that each individual is unique in terms of their requirements and beliefs. Each individual has a unique identity and the ways in which identity is affected will vary from person to person, as will the ways in which each individual attempts to maintain, reform or change their identity as a result of a change in their health and well-being.

Haug and Lavin (1981: 212) argue that the relationship between doctor and patient '... has been redefined by some from a consumerist perspective, in which physician and patient bargain over the terms of the relationship'. This bargaining better allows the patient to have a voice and enables people suffering from chronic illness to not only state their views but also to integrate them into their treatment.

More recently, Kizer (2001: 1213-14) has considered the concept of consumerism in health care and further to the earlier work of Haug and Levin, writes:

> Consumer attitudes and expectations about health care have changed in recent years with consumers increasingly being interested in clinical performance and public accountability. As patients, family members of patients, research subjects, and purchasers of health care, consumers are increasingly becoming activists, demanding and using information about medical treatments, health care products, and health care standards. Contributing to this trend has been the growing recognition of health care quality problems.

This gives us a better idea of why the doctor-patient relationship may have become increasingly demanding. However, this consumerist approach is likely to be balanced by the need to still be treated and advised. Lupton (1997: 373-81) acknowledges this, saying:

> … in their interactions with doctors and other health care workers, lay people may pursue both the ideal type 'consumerist' and 'passive patient' subject position simultaneously or variously, depending on the context.

Relationships with significant others may also play a large role, as the people that patients are close to could either act as an advocate for the sufferer of chronic condition or may offer support in both physical terms and with regard to decision making processes. This is likely to lead to questions of whether the individual's perceived needs are met by doctors and other health professionals or whether their needs to achieve well-being stretch beyond medical definitions and treatment. They may require an element of control over their circumstances and treatment.

Seeman and Seeman (1983: 144-160) argue that lay knowledge and a sense of patient 'control' in chronic illness as a result of this knowledge is important for health outcomes and of course it affect relationships with both health professionals and those close to the patient. The acknowledgement of the

importance of lay knowledge in the 1980's has progressed to programmes being set up in the UK more recently to officially encourage and enable lay knowledge and patient involvement. Similarly, Karlsson (2007: 2) notes:

> Changes in the general health knowledge of patients and their self-efficacy in obtaining and using this knowledge, have given rise to a great deal of optimism concerning what patient education can do for public health. One example is the Expert Patient Programme in the UK, where patients with chronic conditions participate in lay-lead courses which help them manage their own condition.

Thus, there may a focus on the triadic relationship between the individual with an illness, their significant others and medical professionals, which is significant to well-being. Thus:

> ...much of clinical communication takes place in the context of the family and lay referral system... it often involves the family as well as the patient ... the target of treatment, then, will be seen as involving considerably more than the patient's body. The doctor will be viewed as only one, and perhaps not the most important, agent of treatment. And the family-patient relationship or family-doctor relationship will be regarded as the 'real' therapeutic relationship. (Kleinman 1986: 37)

Which highlights the importance of the negotiation, discussion with, dependence on and relationship with family members and those close to the individual suffering from chronic illness. It can be argued that there is a complex web of relationships going on in the background at all times with regard to the treatment of a patient suffering from chronic disease such as IBD. Indeed, Lynn-McHale and Deatrick (2000) propose that relationships between family, health professionals and patient are both complex and important in terms of trust and treatment.

Some previous research indicates that the relationship between doctor, patient and family may not always be satisfactory. Locker (2000: 87) says '… the medical gaze is frequently a narrow one, concerned predominately with disease to the exclusion of its social and emotional consequences for patients and families.'

Because of the powerful and potentially problematic drugs used to treat IBD, individual sufferers may over time develop their own knowledge, views and experiences of not only the disease and the effects that it causes, but also the therapy used to treat it. For example, many will be aware of what side effects in drug treatment they are able to tolerate and what they would prefer to simply accept (Coulter *et al*, 2008). These views and opinions may on occasion conflict with the views of health professionals treating them, and may perhaps be exacerbated by the pharmaceutical industry itself who target the public in advertising of new treatments and medications. This is known as 'pharmeceuticalisation' (Williams *et al*, 2011). However, the individual view is important, because they 'live' with the illness, perhaps even 'own' the illness, and the consequences, and hence become accustomed to what they may regard as 'normal' and what they are able and not able to cope with. Indeed, Kassirer (1994: 1895) argues:

> Many decisions need to be individualized, especially when they involve choices between different outcomes that may be viewed differently by different patients. In such cases we should identify a patient's preferences scrupulously.

Therefore, it can be suggested that it is important that health professionals respect and listen to patients' views, and work in combination with them to

provide the most useful and satisfactory health care for them. Indeed, it is likely that unless the needs and requirements of the individual are met in terms of what they believe has an effect on whether they are suffering from a lack of well-being or not, the person may struggle to find a sense and feeling of well-being. This is discussed by Coulter (2002) who writes about patient satisfaction and how this is achieved. Coulter argues that participation and a sense of being listened to is important to achieve satisfaction from the point of view of the patient.

Suchman (1965: 15) recognises the need to be adaptable in the doctor-patient relationship and argues:

> On the one hand, medical care must become more rather than less personalized with a greater accent on the patient and his family as whole units, as currently advocated by the practice of comprehensive medicine, and public health programs must "reach out" into the community adapting their services to local customs and bringing them to the people rather than waiting for the people to show up at public clinics…On the other side, the public must become more sophisticated and knowledgeable about health and medical care.

A reciprocal relationship is required with input both from health professionals and patients suggesting that health professionals need to become more 'in touch' with the individual as a 'whole person' whilst the must further their knowledge about their own care and health. Street *et al* (2003: 614) discuss the need for a reciprocal relationship where both health professionals and their patients contribute to each other's communication and subsequent treatment:

> ...our findings of mutual influence between partnership building and patient participation indicate that both patients and physicians can use their own communication to help the other be a more effective communicator.

Within chronic illness it is likely that patients develop an active role as they learn to live with their illness and learn what treatment helps them the most. Winkelman (2003: 352-353) argues:

> Patients with long-term chronic disease become experts in the experiential aspects of living with disease. They acquire tacit knowledge over extensive periods of time, not only about the symptoms and sequela of disease and the effects of medications, but also pragmatic insights into the realities of adaptation to chronic disease and problems in care delivery processes.

Also, as the Internet and resources have become more available, it is likely that patients may increase the uses of the resources available to them in order to increase their knowledge base regarding health and medical care. This is supported by Korp (2006: 80) who proposes 'frequent users of health sites on the Internet are patients (especially those who have long-term illnesses) who are searching for reliable information about their specific diseases'.

As argued above, both health professionals and individual sufferers need to take responsibility and be flexible and willing to compromise in order to achieve the best possible outcomes. Therefore the onus is not simply on the health professionals, but also on the person with IBD leading to the issue of 'expert patients' and the ways in which those with long-term chronic illness may become experts in their own health and the treatment of their condition.

Shaw and Baker (2004: 723) comment upon the antipathy sometimes seen in health professionals regarding expert patients:

> …the notion of the expert patient seems to have been criticised by doctors at least as much as it has been welcomed. If one asks lawyers, architects, social workers, or management consultants whether they prefer clients who take an interest in the issues they face and are motivated to work in partnership to achieve successful results, the answer seems obvious. So why does the idea of expert patients provoke such antipathy within the medical professions?

Health professionals may sometimes regard such patients with caution for various reasons including loss of professional autonomy in treatment and having to spend more time talking to individuals about different treatments that the patient may request and the doctor be unwilling to give, sometimes for very good reasons such as possible unacceptable side effects, undesirable effects or a treatment that simply isn't warranted. There must also be financial implications regarding what treatments are prescribed. Certainly anti-TNF therapies are renowned to be exceedingly expensive and treatment with these therapies run into thousands of pounds a year for one individual. Indeed, Shaw and Baker (2004: 723) say:

> The suspicion is that for many doctors, the expert patient of the imagination is the one clutching a sheaf of printouts from the Internet, demanding a particular treatment that is unproved, manifestly unsuitable, astronomically expensive, or all three. Or, possibly worst of all, a treatment the doctor has never heard of, let alone personally prescribed… For these anxious and overworked medics, the expert patient is the demanding patient, the unreasonable patient, the time consuming patient, or the patient who knows it all.

However, an individual suffering from a long term chronic illness such as IBD is likely to know much more about their illness and learn about both the illness and treatments over a long period of time. Many of these people may actively search for new treatments to help them and be desperate for a cure or something to ease the symptoms of their condition. However, health professionals also hold a responsibility for what they prescribe and treat the

person with and if they are unsure of the necessity of a treatment or hold concerns about unwanted side effects from taking certain drugs, then ultimately they have to be accountable for what they have given the person.

Sometimes individuals may be expected to become submissive and drop their everyday authority and mind set. This is voiced by Harris (1989: 3-4) who says:

> …the social arenas in which medical treatment is given – hospitals, clinics, and so on – have their own distinctive rules, roles, customs, and organizational forms. When people enter these arenas to receive care, they are expected to shed the roles and symbols appropriate to other contexts and to become patients willing to accept the scientific explanations offered by medical personnel.

This is an example of the way in which 'patients' may sometimes be treated almost as scientific entities rather than as a 'whole' person. 'Patients' must adapt and accept new roles and rules even though they may believe that their own needs and views are not heard or regarded as important.

This method of treating individuals can be neither beneficial nor effective. Indeed, Young *et al* (2003: 305) propose that communication is vital and that not allowing opinions and a voice may lead to damage in the relationship between individuals and health professionals. Therefore it does not build relationships constructively with a resultant positive health outcome. An individual with a long term chronic illness is likely to become involved in their own care and become increasingly educated about their health and illness as time progresses.

As discussed therefore, the increased sense of autonomy and knowledge in those with chronic illness may have an effect on relationships with health professionals and their subsequent treatment. Dr Rob Lamberts (2010) wrote an open letter online, to all patients who have a chronic condition, discussing the relationship between those with chronic illness and the doctors treating them. It is an interesting recognition of some of the potential problems from a practicing medical practitioner:

> Dear Patients: You have it very hard, much harder than most people understand. Having sat for 16 years listening to the stories, seeing the tiredness in your eyes, hearing you try to describe the indescribable, I have come to understand that I too can't understand what your lives are like. How do you answer the question, "how do you feel?" when you've forgotten what "normal" feels like? How do you deal with all of the people who think you are exaggerating your pain, your emotions, your fatigue? How do you decide when to believe them or when to trust your own body? How do you cope with living a life that won't let you forget about your frailty, your limits, your mortality?
>
> I can't imagine.
>
> But I do bring something to the table that you may not know. I do have information that you can't really understand because of your unique perspective, your battered world. There is something that you need to understand that, while it won't undo your pain, make your fatigue go away, or lift your emotions, it will help you. It's information without which you bring yourself more pain than you need suffer; it's a truth that is a key to getting the help you need much easier than you have in the past. It may not seem important, but trust me, it is.
>
> You scare doctors.
>
> No, I am not talking about the fear of disease, pain, or death. I am not talking about doctors being afraid of the limits of their knowledge. I am talking about your understanding of a fact that everyone else seems to miss, a fact that many doctors hide from: we are normal, fallible people who happen to doctor for a job. We are not special. In fact, many of us are very insecure, wanting to feel the affirmation of people who get better, hearing the praise of those we help. We want to cure disease, to save lives, to be the helping hand, the right person in the right place at the right time.

But chronic unsolvable disease stands square in our way. You don't get better, and it makes many of us frustrated, and it makes some of us mad at you. We don't want to face things we can't fix because it shows our limits. We want the miraculous, and you deny us that chance.

And since this is the perspective you have when you see doctors, your view of them is quite different. You see us getting frustrated. You see us when we feel like giving up. When we take care of you, we have to leave behind the illusion of control, of power over disease. We get angry, feel insecure, and want to move on to a patient who we can fix, save, or impress. You are the rock that proves how easily the ship can be sunk. So your view of doctors is quite different.

Then there is the fact that you also possess something that is usually our domain: knowledge. You know more about your disease than many of us do – most of us do. Your MS, rheumatoid arthritis, end-stage kidney disease, Cushing's disease, bipolar disorder, chronic pain disorder, brittle diabetes, or disabling psychiatric disorder – your defining pain – is something most of us don't regularly encounter. It's something most of us try to avoid. So you possess deep understanding of something that many doctors don't possess. Even doctors who specialize in your disorder don't share the kind of knowledge you can only get through living with a disease. It's like a parent's knowledge of their child versus that of a paediatrician. They may have breadth of knowledge, but you have depth of knowledge that no doctor can possess.
So when you approach a doctor – especially one you've never met before – you come with a knowledge of your disease that they don't have, and a knowledge of the doctor's limitations that few other patients have. You see why you scare doctors? It's not your fault that you do, but ignoring this fact will limit the help you can only get from them. I know this because, just like you know your disease better than any doctor, I know what being a doctor feels like more than any patient could ever understand. You encounter doctors intermittently (more than you wish, perhaps); I live as a doctor continuously.

So let me be so bold as to give you advice on dealing with doctors. There are some things you can do to make things easier, and others that can sabotage any hope of a good relationship:

Don't come on too strong – yes, you have to advocate for yourself, but remember that doctors are used to being in control. All of the other patients come into the room with immediate respect, but your understanding has torn down the doctor-god illusion. That's a good thing in the long-run, but few doctors want to be greeted with that reality from the start. Your goal with any doctor is to build a partnership of trust that goes both ways, and coming on too strong at the start can hurt your chances of ever having that.

Show respect – I say this one carefully, because there are certainly some doctors who don't treat patients with respect – especially ones like you with chronic disease. These doctors should be avoided. But most of us are not like that; we really want to help people and try to treat them well.

But we have worked very hard to earn our position; it was not bestowed by fiat or family tree. Just as you want to be listened to, so do we.

Keep your eggs in only a few baskets – find a good primary care doctor and a couple of specialists you trust. Don't expect a new doctor to figure things out quickly. It takes me years of repeated visits to really understand many of my chronic disease patients. The best care happens when a doctor understands the patient and the patient understands the doctor. This can only happen over time. Heck, I struggle even seeing the chronically sick patients for other doctors in my practice. There is something very powerful in having understanding built over time.

Use the ER only when absolutely needed – Emergency room physicians will always struggle with you. Just expect that. Their job is to decide if you need to be hospitalized, if you need emergency treatment, or if you can go home. They might not fix your pain, and certainly won't try to fully understand you. That's not their job. They went into their specialty to fix problems quickly and move on, not manage chronic disease. The same goes for any doctor you see for a short time: they will try to get done with you as quickly as possible.

Don't avoid doctors – one of the most frustrating things for me is when a complicated patient comes in after a long absence with a huge list of problems they want me to address. I can't work that way, and I don't think many doctors can. Each visit should address only a few problems at a time, otherwise things get confused and more mistakes are made. It's OK to keep a list of your own problems so things don't get left out – I actually like getting those lists, as long as people don't expect me to handle all of the problems. It helps me to prioritize with them.

Don't put up with the jerks – unless you have no choice (in the ER, for example), you should keep looking until you find the right doctor(s) for you. Some docs are not cut out for chronic disease, while some of us like the long-term relationship. Don't feel you have to put up with docs who don't listen or minimize your problems. At the minimum, you should be able to find a doctor who doesn't totally suck.

Forgive us – Sometimes I forget about important things in my patients' lives. Sometimes I don't know you've had surgery or that your sister comes to see me as well. Sometimes I avoid people because I don't want to admit my limitations. Be patient with me – I usually know when I've messed up, and if you know me well I don't mind being reminded. Well, maybe I mind it a little.

You know better than anyone that we docs are just people – with all the stupidity, inconsistency, and fallibility that goes with that – who happen to doctor for a living. I hope this helps, and I really hope you get the help you need. It does suck that you have your problem; I just hope this perhaps decreases that suckishness a little bit.

Sincerely,

Dr. Rob

This letter is interesting because it presents doctors and health professionals as individual people with their own concerns and problems. It demonstrates that health professionals may sometimes not always appear to react in the way a patient may want but that this is not because of a wish to be unhelpful or unkind. As individuals, health professionals also have to deal with their own emotions alongside those of their patients. This is demonstrated by Fallowfield and Jenkins (2004) who discuss the stress doctors may experience when having to approach certain subjects with patients and the way in which health professionals are also emotionally vulnerable.

A patient who is involved in their own healthcare management must surely be a patient who is more likely to 'help them self' in as many ways as possible resulting in an increased sense, feeling and physiological well-being. Indeed, Michie *et al* (2002: 197) proposes:

> It is now widely recognised that the successful management of chronic illness depends on the active behavioural involvement of the patient. Self management of chronic illness involves both the adoption of new behaviours (e.g. blood glucose monitoring in diabetes; adherence to medication, etc.) as well as changes in existing behaviours (e.g. dietary modification). Cumulative evidence shows that achieving behaviour change depends on a range of factors, including perceptions of health and illness, as well as effective communication with health care professionals...a patient-centered (*sic*) approach has beneficial effects on patient outcomes, particularly in engaging patients more actively in their treatment.

This proposes that 'patient involvement' in their own care not only creates a more knowledgeable patient, but also one that is more likely to take the diagnosed tests and treatments prescribed by health professionals. An

individual who is willing and able to take the prescribed medication is a patient who ultimately will take less time and resources from the health system as opposed to a patient who is non-compliant with their treatment regime.

Wilson *et al* (2007: 431) discuss the concept of the expert patient and argue that a knowledgeable patient can develop trust with health professionals and that it is beneficial:

> Mutual respect was often indicative of the nature of the relationship between expert patient and doctor and had generally been built up over time. This relationship was highly valued by expert patients who would make an effort to maintain it.

Hahn (1985) writes about the experiences of doctors when they themselves swap roles and become patients themselves. Hahn (*ibid*: 87) describes the way in which one doctor experiences the rapid transition from respected and highly regarded professional to a patient with uncertain prospects, saying:

> Within minutes, he has been transformed from a highly competent physician, in the prime of life, productive, and seemingly very healthy, to a fearful patient, threatened by a possibly deadly disease with uncertain course.

This demonstrates the way in which all patients, whether medical practitioners or people with rather less knowledge in a biomedical sense, may feel a sense of uncertainty and vulnerability when facing an illness with an uncertain future. Hahn (1985) cites the experience of a physician (Sacks, 1984) who is transformed from physician to patient and says:

> [I experienced] the systematic depersonalization which goes with becoming a patient. One's own clothes are replaced by an anonymous

> white nightgown, one's wrist is clasped by an identification bracelet with a number. One becomes subject to institutional rules and regulations. One is no longer a free agent; one no longer has rights; one is no longer in the world-at-large. It [is] strictly analogous to becoming a prisoner, and humiliatingly reminiscent of one's first day at school. One is no longer a person – one is now an inmate. One understands that this is protective, but it is quite dreadful too (Sacks, 1984:46, cited in Hahn, 1985: 89).

Hahn (1985: 89) goes on to describe Sacks' (1984: 46) experience saying:

> This is the first of three times Sacks waits eagerly for the surgeon's visit. He is severely disappointed. Deaf to Sacks desperate pleas, the surgeon pronounces with utter clarity, terse and cold: "Nothing to worry about. You've torn a tendon. We reconnect. Restore continuity. That's all there is to it".

This appears to be a valuable example of the way in which regardless of what or how much an individual may know, what their wishes may be in the context of their treatment, or the inevitable fears that they may be facing, it is possible that some individuals they may still sometimes be treated purely as 'bodies' that need fixing. The patient perspective itself seems to be quite the reverse of this, with the patient requiring support and somebody to listen to and seriously consider their views on the subject. Shaw and Baker (2004: 724) recognise that patient perspectives are not always heard or listened to, arguing:

> …research has shown that patients' perspectives (including their desire and ability to take medicines) are seldom discussed when medicines are prescribed. As highly educated professionals in well paid employment, doctors are not necessarily best placed to understand the realities of life for many of their patients, particularly those living with debilitating medical conditions.

However, increasingly, there does seem to be a more whole person approach in hospitals and medical schools and the importance of the 'patient' as an individual within medical settings has become more of a feature in recent years.

Fong Ha and Longnecker (2010: 38-39) support the importance of the doctor-patient relationship and propose:

> Good doctor-patient communication has the potential to help regulate patients' emotions, facilitate comprehension of medical information, and allow for better identification of patients' needs, perceptions, and expectations. Patients reporting good communication with their doctor are more likely to be satisfied with their care, and especially to share pertinent information for accurate diagnosis of their problems, follow advice and adhere to prescribed treatment.

The above examples highlight and demonstrate how important the relationship between health professional and patient is. Understanding, and a reciprocal relationship can increase patient well-being and ability to accept treatment. Additionally, an increase in well-being and acceptance contributes to a sense of self and identity which is challenged in chronic illness.

In terms of relationships with people on a day-to-day level, it is possible that individuals with chronic illness may not always be completely open about their problems and symptoms due to worry and concern about bothering people or through fear that they will not be understood. This is supported by Öhman *et al* (2003: 534) who argue:

> Feelings of being left out were especially caused by occasions when participants in the study, without any forewarning, were struck by a sudden deterioration of their condition or when something unexpected happened in everyday life that they could not manage without help... Participants described that relatives had their own lives and could not reduce the feeling of emptiness and sadness that the illness brought... The illness also seemed to cause feelings of being different. The neighbors (*sic*) stopped visiting them as they used to, and the fear of not being taken for the same person they used to be when they were healthy prevented them from getting in contact with other people. Isolation and the fact that they avoided meeting their friends and other people increased the feeling of being outside the mainstream of life.

This very well demonstrates the dramatic and large changes that relationships with other people may take place when an individual suffers from a long term and debilitating illness.

When support from those close to a patient is offered, it may not always be helpful and have a reverse effect. For example, Gallant (2004:172) suggests:

> Social interactions may have unintentional negative influences on self-management behavior (sic). For example, because of misconceptions or a lack of understanding, friends and family members may behave in unsupportive or inappropriate ways, offer well-intentioned advice that conflicts with self-management recommendations, or directly or indirectly promote unhealthy behaviors (*sic*).

Or perhaps others may be unintentionally unsupportive through their actions or behaviour and therefore cause damage either psychologically or physically to the individual.

This concept is proposed by Gallant (2003: 186) who argues:

> Negative influences stemming from the social environment included difficulties presented by social events or special occasions, family responsibilities and obligations that took precedence over disease management, unrelated stress experienced by other family members, and specific behaviors (*sic*) of friends and family members that were perceived as unsupportive. Examples of these unsupportive behaviors (*sic*) are overreactions to asthma attacks, nagging, others' denial of the seriousness of the illness or of the illness itself, unhelpful advice, tendency to treat the ill person as an invalid, dietary advice that conflicts with diabetes management, and unwillingness of family members to adjust their own diet.

The above can be extended to the problems that may occur in relationships with family or friends in the everyday life of the individual who suffers from IBD. Certainly overreacting, nagging, denial of illness of the seriousness of it,

unhelpful advice and poor diet are all factors that could have a detrimental effect on the symptoms and management of IBD. Many of the problems listed could be as a result of inadequate education and hence understanding about the condition on behalf of family and friends.

However, it has been found that relationships and more specifically family relationships are important in illness management and have a major influence on the health and well-being of individuals (Lyons *et al*, 1995). Martire *et al* (2004: 599) has carried out research suggesting that there should be intervention and education carried out for the family members closest to an individual suffering from a chronic illness and argues that:

> An extensive correlational research literature provides strong justification for targeting the patient's closest family member through psychosocial or behavioral (*sic*) interventions. Family factors such as emotional support, intimacy, conflict, criticism, and over-protective or solicitous behaviors (*sic*) have been linked with change in a variety of patient physical and mental health outcomes, including psychological well-being, health behaviors (*sic*), pain severity, and physical disability.

This demonstrates the ways in which relationships with those close to a person suffering from chronic illness may have a profound effect on the health of the sufferer, and it is important to provide the support or 'intervention' to enable the relationships to improve an individual's health rather than hinder it through poor education or lack of understanding.

2.4 Coping and Control

2.4.1 Biographical Disruption, Coping and Control

When a threatened identity becomes labelled, stigmatisation becomes a risk. A labelled person may use mechanisms to cope with their threatened status. Breakwell (1986: 109-121) identifies four interpersonal coping strategies that may be employed in these circumstances; isolation, negativism, passing and compliance. These concepts can be related to other sociological research and work, including commentaries on self identity.

Isolation is the way in which the individual may isolate themselves from other people. Breakwell (1986: 109) argues 'this is more of an inaction strategy than an action strategy' and 'where the threat constitutes an attack on self-esteem via the social stigmatisation of the position occupied, the rationale behind self-isolation is easy to fathom'. An individual who is isolated does not have to face the reactions from others that are appended to the stigma of their condition. This coping mechanism is similar to the idea of hidden deviance mentioned by Lorber (1967: 303) who argues '…to avoid the consequences he (*sic*) feels will occur if his (*sic*) deviance comes out into the open (is socially labeled (*sic*)), he (*sic*) pretends to be conforming to the standards of the group in a position to condemn him (*sic*) for what he (*sic*) is doing secretly'. Isolating deviant or stigmatising behaviour from society is a coping mechanism to avoid condemnation.

Molero *et al* (2011:612) discuss the concept of isolating illness or behaviour from society through isolation or 'hiding', and say:

> When it is possible, the hiding of stigma is perhaps one of the most common strategies of coping with discrimination. People who decide to conceal their stigma may, at least in the short term, avoid prejudice and discrimination; and this allows for positive social interactions with others who are not stigmatized.

Negativism may be regarded as a direct opposite to isolation as it 'involves outright conflict with anyone who would challenge the identity structure' (Breakwell, 1986: 113).

Passing is the way in which a person may attempt to remove themselves from a threatened position. However, Breakwell (1986: 115) argues that 'in reality, actual exit may be impossible. In that case, one alternative at the intra-psychic level is self-misidentification'. Page (1984: 22) suggests that 'the extent to which individuals engage in passing is likely to depend upon whether they accept or reject that a particular attribute is evidence of inferiority. It seems probable that those who accept such an association will pass more frequently than rejectors'. Therefore, it can be inferred that those who use passing as a coping mechanism consider themselves to be inferior or an outsider according to social norms and regulations. Breakwell (1986: 118) says 'passing does not expunge the stigma, it merely gets hidden but hangs around fraught with the ability to discredit. For this reason, passing may only serve to heighten the threat to identity. The person lives with the possibility of exposure and not simply the repercussions of the stigma itself but also the loss of everything which has been built upon the lie'. The possibility of being discredited is present and this can be linked to the work of Goffman (1963). Goffman (*ibid*: 14) says:

> ... the term stigma and its synonyms conceal a double perspective: does the stigmatized individual assume his (*sic*) differentness is known about already or is it evident on the spot, or does he (*sic*) assume it is neither

> known about by those present nor immediately perceivable by them. In the first case one deals with the plight of the *discredited*, in the second with that of the *discreditabl*e.

If an individual is discredited, their path has already strayed away from the social norms or health norms. The circumstances of the individual are already known about by the people surrounding them. In many cases, their disease may be obvious and noticeable to people and therefore the avoidance of telling people or keeping an identity secret is not a possibility. The individual who may be termed as discreditable is the individual who has a condition, such as IBD, that may become obvious or known about by people in the social environment, but is not yet known about and acknowledged by others. Other people have not seen what they perceive may be a problem nor have they been given information about one.

It may be proposed that the person who engages in passing is at risk of being exposed and moving from being in the position of being discreditable to being discredited.

Breakwell (1986: 121) proposes that compliance as an interpersonal coping strategy involves ‘accepting the behavioural prescriptions associated with the threatening position; living up to expectations. It can mean that the threatened person gains social approval as a consequence. If social stereotypes are fulfilled, the threatened person is more easily accepted because conformity to expectations arouses no disruption of status and power hierarchies’. This perspective may be linked to the previously mentioned labelling theory and power hierarchies.

Page (1984) suggests another coping mechanism; covering. This occurs when a person has a stigmatised condition that is either visible or already known about, and therefore passing as a strategy is inappropriate. Page (1984: 23) says 'the discredited may attempt to manage their stigmas by means of covering. By engaging in covering an individual hopes to reduce tension during social interaction. Although such individuals recognize that passing is inappropriate due to the visibility or fame of their stigma, they may nevertheless attempt to ensure that their stigma is as unobtrusive as possible during social interaction'.

Saunders (2014: 1033) discusses IBD and the coping mechanisms individuals may employ to combat stigma and argues:

> It can therefore be argued that, when IBD becomes outwardly perceptible, individuals are faced with decisions over disclosure that involve weighing up their degree of felt stigma against their felt deviance; that is, feelings of shame and fears of being stigmatised if others knew about their illness versus fears of being regarded deviant as a result of unexplained behaviour that others may perceive to be strange or unpleasant.

An article by Link and Phelan (2001: 363) called 'Conceptualizing Stigma' describes stigma as the 'co-occurrence of its components – labelling, stereotyping, separation, status loss, and discrimination' and '…that for stigmatization to occur, power must be exercised'. Labelling may play a major role in the experience of stigma. The label enables stereotyping, status loss and discrimination to take place and stigmatisation ensues. The order of the above list seems interesting in terms of the way in which stigma and ultimately discrimination may occur. Labelling comes first: the individual is given a name for their symptoms which previously to this were just a list of symptoms.

Following this, people with a diagnosed label may in the eyes of others, fit a certain type of person. Social and personal relationships may start to suffer including at work, which in turn may lead to a loss of status both in a personal and professional context. In the end this may be serious enough to lead to discrimination as other people start to include the initial label in their assessment and judgement of a person. The person thus becomes stigmatised. Link and Phelan (*ibid*: 363) go on to say:

> ... because there are so many stigmatized circumstances and because stigmatizing processes can affect multiple domains of people's lives, stigmatization probably has a dramatic bearing on the distribution of life chances in such areas as earnings, housing, criminal involvement, health, and life itself.

Gove (1982) offers a differing explanation concerning stigmatisation, labelling and mental illness. He argues that labels are not attached to people randomly and that the effects of labelling are minimal. He suggests that it is the behaviours originating from the mental illness, not the label that produces stigmatisation. An example of this might be an individual suffering from IBD who may be stigmatized because of his or her 'unusual' behaviour in terms of needing to be near public toilets for example, and not because of the knowledge of the label or the diagnosis of the illness itself.

Identity, as discussed, may be changed or threatened through chronic illness and stigma is another threat to identity. Stigma can perhaps be seen as an important part of identity, as it can be argued that individuals are often attempting to maintain their identity as they know it and use some of the actions and mechanisms discussed above to avoid situations in which they may be stigmatised. Adams *et al* (1997: 190) argue that the diagnosis of a chronic

illness leads to disruption in many areas of life including future plans, relationships and work and that this is likely to lead to a diminished sense of identity, going on to say:

> An important modifying factor here is the significance of the illness to the individual, particularly the negative connotations and stigma associated with the condition.

Therefore it can be argued that the effect of stigma on identity, and how much identity may be challenged is directly linked to the beliefs and attitudes an individual holds towards the illness, its diagnosis and its symptoms. Adams *et al* (1997: 199) go on to argue:

> … when the components which make up an individual's social identity are in contradiction or conflict, he / she will attempt to reconcile attributed social statuses both with each other, and with his / her personal identity. Failure to achieve such a reconciliation is seen as resulting in an unsatisfactory or "diminished" sense of self.

So, it can be summarised that stigma is likely to be a threat to identity. This idea is also supported by Petriglieri (2011: 644) who proposes that identity threats are those which are 'appraised as indicating potential harm to the value, meaning, or enactment of an identity'.

The way in which individuals cope with change to identity and changed narratives is discussed in a very relevant way by Arthur Frank (1995) in his book 'The Wounded Storyteller'. Frank describes three different types of illness narratives. The restitution narrative is maybe the narrative that will sit most easily with most people, as it is a relatively straightforward approach to ill health. The restitution narrative works along the lines that an individual suffers

from an illness, they are able to give a narrative / story about what the illness is and how it is treated, and also what will happen next. It appears to be a fairly medicalised concept and it could be argued that it could be a difficult narrative for those suffering from chronic illness such as IBD which can be unpredictable and difficult to treat.

2.4.2 Challenging Biographical Disruption

A different type of narrative is what Frank (1995) calls the chaos narrative. Frank (*ibid*: 98) describes this as 'the anti-narrative of time without sequence, telling without mediation and speaking about oneself without being fully able to reflect on oneself'. This narrative raises the question that life might not actually get better and that there are no definite answers or resolutions. It is, as its name suggests, chaotic in nature and not easy to hear or listen to as a narrative. It can be argued that this is a very relevant narrative for an individual suffering from a long term chronic illness which is unpredictable in nature.

The third type of narrative Frank defines is the quest narrative. Frank (1995: xi) describes this in terms of 'the ill person who turns illness into story transforms fate into experience; the disease that sets the body apart from other becomes, in the story, the common bond of suffering that joins bodies in their shared vulnerability'. These narratives face illness with the belief that there is something (e.g. experience) to be gained through the suffering of the illness and look for ways to get better or to live differently whilst with the illness. Again, it can be argued that this is relevant to chronic illness as frequently those with chronic illness as searching (on a quest) for new information and new ways of moving forward in life.

The quest for information and the chaotic nature of IBD and chronic illness is recognised by Adamson (1997: 154) who comments:

> The clinician confronts the chaotic flux of disease seeking to discover an order within that chaos which will lead toward a cure, while the patient's project involves learning to live with the chaos of lost control.

I will return to these concepts later, but it is worth bearing in them in mind throughout, as they clearly relate to the experience of chronic disease and the subsequent challenges to identity and sense of self. They also appear to be relevant throughout the other themes raised in this chapter, such as stigma, fear, diagnosis and relationships.

2.5 Conclusion

In this chapter I have discussed key concepts which are relevant to the research. These included chronic disease, health and well-being, work, relationships, fear, and stigma. Throughout this chapter is an ongoing and ever present theme of self and identity, which may be considered a chief sociological observation throughout the thesis. Biographical disruption is also an ongoing theme throughout. A particular focus has been the impact of IBD upon self and identity, examined through the concept of biographical disruption (Bury, 1982).

Chronic disease has been discussed and different definitions have been put forward. What chronic illness means and what it means to live with chronic illness have been described (Gerson, 1976; Blanchflower and Oswald, 2002; Kralik, 2002; Charmaz, 2008). This led to a discussion of the concept of

identity and self along with health and well-being. There are different definitions of health and well-being and some of these definitions have been discussed in relation to IBD. Following this chronic illness and work were examined. It was shown that working life is likely to be affected through having a chronic illness (Meenan *et al*, 2005; Dray-Spira *et al*, 2008) and that this plays a role in other areas of life such as socio-economic status.

A discussion of relationships followed, both between individuals and health professionals and relationships with significant others. This is in the context of becoming and being a patient. Lay knowledge was shown to be important and a significant factor in well-being in chronic illness (Seeman and Seeman, 1983; Karlsson, 2007). Another important factor was support from family, forming a triadic relationship between the individual with chronic illness, the health professionals and the family members / significant others (Kleinman 1986). It was found that a reciprocal relationship is needed with health professionals and that the voice of the individual is important in medical treatment. This is linked with the concept of the expert patient (Michie *et al*, 2002; Winkelman, 2003).

Fear was shown to be an important emotion in the presence of chronic illness. Not only is fear linked to slower uptake of medical help (Smith *et al,* 2005), it is also linked to the uncertainty which many people with chronic illness may face in their lives and their identity (Calnan, 1984; Adamson, 1997; Charmaz, 2008).

The perceptions of both the individual suffering from chronic illness such as IBD and the perceptions and actions of others, mainly through misunderstanding or lack of knowledge, may play a negative role and may indeed be a result of

stigma (Rogers and Buffalo, 1974; Link *et al,* 1989; Rosenfield, 1997). There are different methods of coping with stigma (Breakwell, 1986), but its overall effects have shown to be negative. Labelling has been shown to have an effect on both the individuals with chronic illness and those around them in terms of judgement and possible stigmatisation and its associated problems.

Again, it is important to stress that throughout the thesis, the concept of identity is important and that the factors such as relationships, stigma, chronic illness and relationships may all play an important role in identity of the individual. Identity was demonstrated to be of particular importance when considering coping and control in chronic illness. How individuals with IBD respond to its impact upon their sense of self and identity forms a key focus for the empirical research.

CHAPTER THREE: Methods and Methodology

3.1 Introduction

My research approach is auto/biographical. I suffer from IBD, and I am aware of the significance of this to my research and I have attempted to be reflexive with regard to my experiences and the significance of these for the research process and product.

In this chapter, I outline my auto/biographical approach and the reflexivity which is required when working in this way. I then go on to discuss the ethics of the research reported here and the steps taken to ensure that an ethical approach has been maintained. Access and recruitment are detailed, as are the qualitative methods I used. A short summary about each research participant is included. Finally, I provide a summary of the process of data collection and analysis.

3.2 Auto/Biography and Reflexivity

Through data collection and analysis of the data I seek to generate and formulate theory from empirical data using a grounded theory 'style' (Glaser and Strauss, 1967; Strauss and Corbin, 1990):

> ... inductively derived from the study of the phenomenon it represents. That is, discovered, developed, and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon. Therefore, data collection, analysis, and theory should stand in reciprocal relationship with each other. One does not begin with a theory, then prove it. Rather, one begins with an area of study and what is relevant to that area is allowed to emerge. (Strauss and Corbin, 1990: 23)

Yet, I acknowledge that researchers do not enter the field with 'empty heads' (Stanley and Wise, 1993: 22) and as such all research is in some ways auto/biographical (Letherby 2000b). Mills *et al* (2006: 31) propose in their discussion of grounded theory that '... researchers need to go beyond the surface in seeking meaning in the data, searching for and questioning tacit meanings about values, beliefs, and ideologies'. Therefore, the generation of theory and ideas involves exploring the data at all levels and finding the human meaning within it.

As Denzin (1989: 27) suggests the auto/biographical approach to research includes:

> ...life, self, experience, epiphany, case, autobiography, ethnography, auto-ethnography, biography, ethnography story, discourse, narrative, narrator, fiction, history, personal history, oral history, case history, case study, writing presence, difference, life history, life story, and personal experience story.

Sikes (2007: online article) adds:

> Personal accounts or narratives are essential for auto/biographical researchers for, stories are the closest we can come to experience as we and others tell our experience. A story has a sense of being full, a sense of coming out of a personal and social history….

For Sikes (2007) then experience 'is the stories people live'.

I myself suffer from IBD and in this thesis I write reflexively of my experiences of IBD and include my own feelings and thoughts of and about issues that are important both to me and to my participants. I draw on my own 'story'/experiences as well as those of my participants and attempt critical

scrutiny of the relationship between the self and the *other* in the research process and reflect on the significance of my 'insider' perspective (Okely, 1992; Stanley, 1998; Letherby, 2000a).

Denzin (1989:13) discusses the meaning of the terms biography, autobiography and narrative, saying 'the subject matter of the biographical method is the life experiences of a person. When written in the first person, by the person her/himself, this is an autobiography, life story, or life history'. Denzin (1989:17) goes on to argue that 'autobiographies and biographies are conventionalized, narrative expressions of life experiences'. As Morgan (1998: 655) notes *auto/biography* is not:

> …simply a shorthand representation of autobiography and/or biography but also [a] recognition of the inter-dependence of the two enterprises…. In writing another's life we also write or rewrite our own lives; in writing about ourselves we also construct ourselves as some body different from the person who routinely and unproblematically inhabits and moves through social space and time.

Arguing for the uniqueness of every narrative and that the data produced as varying and broad, Jovchelovitch and Bauer (2002: 110) propose:

- The narrative shows the reality of what is experienced by the storytellers: the reality of a narrative refers to what is real for the teller of the story.
- The narratives do not copy the reality of the world before them. They propose private representations / interpretations of the world.
- Narratives are not open to corroboration and may not be simply judged as true or false: they express a truth from a point of view, of a specific situation in time and space.
- Narratives are always inserted in a social-cultural context. A specific voice in a narrative may only be understood in relation to a context that is wider.

In her discussion of auto/biographical research, Abrahão (2012: 36) develops this arguing that the ‘the past, present and future are intertwined in the moment of telling the story’. For Abrahao narratives carry strong personal meanings through the telling of a life not as it really happened but as remembered.

Chronic illness is an emotive area and a unique experience for each individual. The use of an auto/biographical approach helps to facilitate the gathering of information. Thus, ‘autobiography. . . is very useful in difficult contexts, because of its flexible, adaptable and effective characteristics’ (Aleandri and Russo, 2015: 516). Similarly, Bochner (1994: 30) says that narratives and story–telling are ‘stories people tell about their lives’. I agree, for how are we supposed to understand people’s lives, the events within them and the social interactions that occur within them if we do not listen to the actual stories that people tell us?

Reflexivity is a vital part of this type of qualitative, auto/biographical research (Cook and Fonow, 1990; Letherby, 2002b). This means that consideration is needed of the relationship between the researcher and the researched. Using my own ‘story’ / experiences as a reflexive account was a way of making sense of what the participants in my research were telling me. This method of story-telling or self-reflexivity is what Adams (2008: 175) calls ‘...tools to understand, negotiate, and make sense of situations we encounter’. I endeavoured to ensure that my own experiences were used to understand and make sense of the knowledge and information that the participants passed on to me. To do this I draw on my own story within the data chapters and reflect on this in the conclusion of the thesis.

Hopkinson and Hallett (2001: 118) propose that 'if the individual is assumed to have a unique understanding and experience of the world, which is dependent on social and contextual factors, then a qualitative methodology in an interpretivist philosophical framework is appropriate'. This demonstrates the way in which qualitative research is able to identify in-depth understandings and experiences through the eyes of the people being researched. The use of a self-reflexive account is an expression of values, emotions and biases that attempts to create context and form within the delicate environment of disease and healing. This form of reflexive story-telling has ancient roots but has been widely adopted and utilised by social scientists and researchers to tease out aspects of human experience (Rodriguez, 2001; Richardson, 2003). Although the intention is of course to identify the in-depth understandings and experiences of the research participants, it must be recognised that the researcher themselves has the ultimate power of representation. This is an argument proposed by Letherby (2002c: 4.4) who says:

> My research can be compared to qualitative interpretations in general, where the goal is to consider as many interpretations as possible and to give respondents the authority to define themselves and their position. Even if this happens within the fieldwork, the thesis or report represents the researchers' and not the respondents' definitions… At many places in my writing I have presented several sides of an argument but accept that I evaluated these in terms of MY feminist and sociological standpoints. So I have the final say.

No account is totally detached and objective:

> Writing is personal. There is a narrator, an author, a voice. We have been encouraged to absent ourselves from our writing in sociology: to write in the passive voice, to avoid inserting ourselves. But the author is present, present in the very absences that the passive voice opens, made all the more authoritative in that authorial void. I think it's time to reclaim the I in sociology. (Rothman, 2007: 11)

In this sense I propose that I am a narrator / voice in the research – a voice with experience providing a level of empathy and understanding with experience of the subject matter. Moen (2006: 57) recognises this approach saying 'the narrative approach is a frame of reference, a way of reflecting during the entire inquiry process, a research method, and a mode for representing the research study'. The subject matter itself is an emotive one. IBD is a condition that causes not only physical problems but also emotional responses based upon and around the physical symptoms and treatments.

To expand upon this idea, it is important to recognise that **I** go further than simply having an interest in a subject as a researcher. Letherby (2014) discusses the way in which researchers write from a standpoint of experience and argues that whilst researchers do not need to explicitly draw on their own autobiographies in order to do **good** research but they must reflect on the inevitable presence of their own experiences in order for their work to be accountable. This has a long history:

> . . . from the start, sociologists studied their own societies and brought their own values: clearly Marx had ideas and values about inequality, Weber about bureaucracy. They studied the worlds in which they lived, worlds about which they cared. Increasingly, though, we've come closer and closer, turning our sociological eyes on our own lives. (Rothman, 2007: 12)

This is not just significant for qualitative researchers because:

> ... why would the qualitative researcher's effects on the research process be greater, or less, then (sic) the effects of the quantitative researcher? Doesn't the quantitative researcher have an effect on the collection,

> analysis and interpretation of evidence, including deciding what is evidence?! (Denzin, 2009: 150)

Everything is chosen, written, discussed, analysed at some level by people. People by their very nature live in a social world, with cultural values and norms by which their actions are dictated. Thus, it can be argued that research involves working within the boundaries and rules that are socially accepted, and to take an active part in the culture within which the research is based (Gergen 2001). Importantly, participants are also narrators with 'voices', individuals who have knowledge and opinion. Both my participants and myself as researcher (and participant) are situated within cultural and social frameworks and that rather than this being negative it allows deeper and more thorough understanding of the subject. Thus:

> The process of theorizing, analyzing (*sic*), and categorising personal narratives is shot through and through with the imagination and ways of seeing of the interpreter. When I'm the one interpreting the story, I'm no more free from the cultural frames of reference in which I am embedded than is the storyteller. In this sense, I'm inside what I'm analyzing (sic) and part of it. If the storyteller is a cultural production, well, then, so is the analyst. (Bochner, 2001: 136)

This shows the way in which both the researcher and the participants in research of this nature (and arguably any research) are embedded in their own subjective experiences. This is not a bad thing; for it enables rich, meaningful and deep information to be extracted (Sergi, 2011; Geertz, 1973; Wallace, 1979; Bowker and Tuffin, 2004). Coles (1989: 7) says:

> The people who come to us bring us their stories. They hope they tell them well enough so that we understand the truth of their lives. They hope we know how to interpret their stories correctly. We have to remember that what we hear is their story.

Without lived experiences we would only have abstract theories, and the interpretation of stories and events are vital to understanding the way in which people think and perceive events. This is supported by Lindseth and Norberg (2004:147) who proposes 'essential meaning is something with which humans are familiar in the practices of life, and this familiarity has to be expressed through the way of living, through actions, through narratives and through reflection'. Using a biographical / narrative approach within my research, I believe, enriches the information gained and enables participants to feel satisfied that I am able to 'understand' and allow them to be open and honest with me about their experiences.

Bochner (2001: 134) speaks of the multitude of researchers and articles that denounce auto/biographical and narrative methodology, saying:

> ...the voices in these articles stand in for all the others that have been suppressed, the ones that insisted I conform to the rules of social "science" – rigor over imagination, intellect over feeling, theories over stories, lectures over conversations, abstract ideas over concrete events.

And:

> ...the process of theorizing, analyzing (*sic*), and categorizing personal narratives is shot through and through with the imagination and ways of seeing of the interpreter. When I'm the one interpreting the story, I'm no more free from the cultural frames of reference in which I am embedded than is the storyteller. In this sense, I'm inside what I'm analyzing (*sic*) and part of it. If the storyteller is a cultural production, well, then so is the analyst.

This demonstrates the way in which the researcher(s) may aim to use imagination as well as rigor, feeling as well as intellect, stories alongside theories. This approach openly admits the significance of the researcher's own

imagination and influences. This can include the researchers' own experiences and how their own life influences the conclusions made.

Within feminist research, it is common practice to discuss one's own feelings and influences within the research. '[T]he second wave of the women's movement played a major role in the renaissance of life history methods and the study of personal narratives such as journals and autobiographies' (Chase 2005: 654). Furthermore, many feminists have argued that acknowledging and drawing on personal experience is key to feminist research. Some go further and argue that the shared experience between the researcher and the researched is good feminist practice which leads to good feminist theory (Bola, 1995).

This need not be limited to 'feminist' research, as sharing experiences and being highly reflexive is important within any (qualitative) project. Indeed, the use of shared experiences and narratives in research uncovers information and experiences that would be difficult to obtain in a less empathetic and open research environment. Denzin (1989: 81) supports this, saying 'lives and their experiences are represented in stories. They are like pictures that have been painted over, and, when paint is scraped off an old picture, something new becomes visible. What is new is what was previously covered up'. And:

> ...narrative researchers treat narrative – whether oral or written – as a distinct form of discourse. Narrative is retrospective meaning making – the shaping or ordering of past experiences. Narrative is a way of understanding one's own and others' actions, of organizing events and objects into a meaningful whole, and of connecting and seeing the consequences of actions and events over time. (Chase, 2005: 656)

Meaning and depth seem to be a continuing theme within most commentaries about narratives and auto/biographical methods and within my own research this is what I aim to achieve.

Research may be affected by both the similarities and the differences between the researcher and the participants and therefore researchers often disclose these details, with the expectations that shared experience is a method of building rapport and understanding Bola (1995). This shows the way in which not only similarities must be recognised but also the differences between the researcher and the participants in the research. The methods used in my research utilises accounts both from myself and from the research participants, and shared experiences are stated and considered reflexively within the thesis. It also shows the way in which my shared experiences with the participants enabled me to build a higher level of rapport and understanding with the participants and therefore allowed me to gain more detailed and insightful results from the research. This ensures that the data I have produced is rich and meaningful, and my own reflexivity, biography and shared experiences further enabled these goals and aims.

Letherby (2002c: 5.1) discusses reflexivity in this type of research and proposes that it is important to distinguish between ‘descriptive reflexivity’ (describing reflection on a subject) and ‘analytical reflexivity’ (analysing, comparing and evaluating reflection) when considering the accounts and the narratives of participants. This is an important distinction. Certainly the participants in my research reflected upon their experiences with IBD and the events of the past. They also began the process of analytical reflexivity in so far as they discussed

and reflected upon matters such as the impact of their disease on others and the ways in which their lives were different before and after diagnosis. Letherby goes on to describe how her experience of the research process of research led to '...increased analytical reflexivity in relation to my own experience... I began to consider in greater detail my own experience, emotions and choices just as many of my respondents did'. (Letherby, 2002c: 5.1)

Such an approach enables the research to produce 'results' or 'theory' as it emerges in the writing of the respondents. I did not aim for a particular result, I hoped that trends and experiences would emerge as the data was collected with the overall aim of gaining a better understanding of those with IBD.

As the data was broken down with themes and concepts emerging through this method it took me back to the idea that my own experiences of IBD were very relevant. I felt that it allowed me to feel more 'in tune' with and perhaps more understanding of the people taking part in the research. It also highlighted to me the differences between people with the same chronic disease. Similarities and differences were demonstrated in the data which gives rise again to the theme of reflexivity. So it is possible to be 'an insider, outsider, both and neither.... feel a part of and apart from' (Sultana, 2007: 377). I felt that I was both an insider and an outsider. I could see that I had many similarities in some areas, but in others I still felt unique. I was also aware of my position as researcher.

I believe that my understanding and empathy toward the issues raised through the interviews, due to my own experiences is helpful. Indeed, a level of empathy

is considered by many feminist researchers to be absolutely fundamental toward producing good research (DeVault, 1990). I believe then that 'our understanding of others can *only* proceed from within our own experience, and this experience involves our personalities and histories as much as our field research' (Jackson (1989: 17). But, even though my own perspective may be a useful tool in interpretation and analysis it does not make the task any easier and it has taken its own toll in terms of emotion. Therefore the researcher his/herself may be affected in terms of emotion and emotional labour. Each researcher, due to personal experience may face different difficulties in the research process and the different belief systems regarding privacy and emotions mean that researchers will cope with this in different ways from denial through to support from other people (Lankshear, 2000).

This observation demonstrates that the identity and previous experience of the individual researcher not only affects the research process but also affects the researcher on an emotional level themselves. The research may raise difficult emotional areas for the researcher to deal with as an individual. Gilbert (2000: 4) recognises the need for the emotions of the researcher to be taken account of and comments that until recently this has not been the case and has left a lot of unanswered questions amongst researchers themselves. She gives examples of questions that have been raised and comments on the surprise of researchers about the emotions that their work may raise:

> They are surprised and even startled by the emotions generated by their research efforts. They ask: how do we manage these emotions? Should we even think in terms of managing emotions? What is the proper balance of allowing and controlling emotions? Are emotions appropriate? Should they be used as part of the research process? Should they be hidden and kept from others? What does it mean if the researcher is

> profoundly affected by the experience, even to the extent of going through a spiritual epiphany?

Therefore, there is a certain amount of uncertainty amongst researchers about what is acceptable and what is not, and also about how to deal with the emotions that are inevitably raised during the research process. Self-reflexivity and support structures for researchers are important and raise the validity of the research in question. It is important to protect the interests and well-being of the researcher as well as the traditional protection of the participants in research. Letherby (2000a) argues that it is not until recently that emotions within research have been take account of and their importance recognised. She suggests that traditionally researcher emotions were excluded and not seen as essential to understanding of the research area, whereas now it is common to utilise reflexivity to produce deeper and more personal accounts.

This concept strengthens social research and produces research that has meaning not only to the researcher but also to the reader and the participants of the research itself. It can be said that the qualitative researcher is not as protected in the research process as the participants, and that the role of the researcher's emotions and the self protection and care that is employed by the researcher has not always received due care and attention (Rager, 2005). This highlights the fact that although the protection of participants has been given detailed attention in research ethics discussion the similar needs of researchers have been largely ignored. Strategies need to be employed to help deal with stress encountered by researchers such as debriefing and counselling (Rager, *ibid*).

This observation emphasises a responsibility for both the participant and the researcher and notes the need for the protection of both. This may particularly be the case whereby the research under discussion is of a delicate or upsetting nature. However, everyone has different triggers and what may be of no problem to one person may potentially represent a very emotional threat for another. An example of research that may affect people in a negative way is the research carried out by Griffin *et al* (2003) who discussed trauma research. The research found that participants felt uncomfortable talking about their experiences around traumatic events. On the same level, it could perhaps be argued that researchers themselves could be affected emotionally by such research, not only because of their possible life experiences, but also because of the information that they are given by participants. Strategies such as those suggested above by Rager (2005) may enable a researcher to deal with the emotional response that may be raised such research.

Through discussions of reflexivity, Rosenberg (1990: 3) highlights the way that the research process and outcomes may produce or change emotions. Rosenberg (*ibid*) proposes two different types of reflexivity as important. The first relates to 'the self as the object of its own *cognition*' and explains:

> All cognitive processes of which the individual is capable (e.g. memory, perception, attention, evaluation, abstract reasoning, analysis, synthesis) can be brought to bear upon the self as an object. If people have memory, they can remember the self. If people are capable of logical thought, they can think logically about the self.

She calls this process 'reflexive cognition'. The second type of reflexivity named is 'reflexive agency'. Rosenberg (1990: 3) goes on to explain this: 'Agency refers to the experience of being an active or efficient cause in the production of

some outcome'. These concepts of reflexivity are interesting because they seem to be intrinsically linked to emotions and psychological factors. They may even have the power to not only reflect upon emotions and experiences but also change them. So it can be seen that not only do researchers bring their own thought processes and emotions to the field in their research, but they may also change, adapt and create emotion in research.

I felt different emotions towards respondents depending upon the topic they were discussing. I myself felt emotional upset and distress at some of the topics covered. These included topics with which I was familiar (such as the problems that may be created by health professionals) through to topics that I had no experience of but felt strongly about (such as some of the specific problems experienced in the interpersonal relationships discussed). I also found that I was repeatedly thinking about the subject of IBD. I could not escape it. I found myself perhaps dwelling more on the disease that I suffer from than I would prior to the research. This is not something that was positive for me because I find that the less I think about it, the less I think about the problems associated with it, the less I think of the 'what if', the happier and hence healthier I am. There is recognition of this experience by Sampson *et al* (2008: 930) who argue that 'vicarious hurt' is perhaps an inevitability within qualitative research, especially that influenced by feminist research principles.

This is a point well highlighted by Ellingson (1998: 510) who carried out research on cancer patients having suffered from the disease herself. She says:

> The intimate tangle of my life and my work permits no compartmentalization of research and experience, of pain and analysis. I

> am a wounded storyteller (Frank, 1995) who can neither escape nor completely integrate her different selves, and it hurts. Academic research and life intersect; endeavouring (*sic*) to keep them artificially separated can lead to personal unhappiness as well as eliminating promising areas for research, but exploring the intersections is no easy task (Ellis, 1993; Paget, 1993; Bochner, 1997). Writing my research gives me permission to revise myself, if I dare. As I compare and contrast my illness narratives with those of the patients, I see my pain in theirs, and I can write about the emotions of cancer reflected in this joint construction.

Emotional labour by the researcher is a well discussed issue, and is an issue that has been raised frequently in this chapter. Hochschild (1983: 7) describes emotional labour as 'the management of feeling to create a publicly observable facial and bodily display' and goes on to say that there may be the need to 'induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others'. This is significant to the research process. Researchers cannot approach participants regarding their research in an overly emotional manner and need to create confidence in both themselves and their research. Hochschild (*ibid*) describes this well and the ways in which a researcher may do this both through outwardly suppressing feelings and putting on an outward display – something that might even be thought of as a public performance. Sampson (2008) recognises this as a risk to researchers, in an emotional sense, and discusses ways in which the researcher should acknowledge this, including support from their research organisations.

Ashforth and Humphrey (1993: 90) take the theme of emotional labour and expand on it further in their studies on emotions in the workplace, describing emotional labour as 'the act of displaying the appropriate emotion'. Ashforth and Humphrey acknowledge that they have moved away from Hochschild's theory in that they place an emphasis on behaviour rather than the emotions themselves.

Through a display of appropriate behaviour and emotion, as described above, it can be argued that it is positive in terms of being a 'responsible', productive researcher, and getting the job / work done. However, in terms of the personal it could be seen as a negative situation for the individual psychological well-being of an individual carrying out research. Indeed, Lewig and Dollard (2003: 368) propose that emotional labour may be 'dysfunctional for the worker when dissonance between felt emotions and displayed emotions is experienced'. This relates to Hochschild's (1983) suggestion that an element of cognitive or emotive dissonance may occur if an individual is required to repeatedly demonstrate emotion which is not actually genuinely felt.

Therefore, bearing the concept of emotional labour (emotional challenges) in mind, it is important that reflexivity (as discussed in depth above) is repeatedly revisited and that as a researcher I hold not only my work to account but also reflect on my behaviour and my emotions.

3.3 Qualitative Research

The research on which this thesis is based utilised qualitative research methods through which I gained insight, meaning and understanding of the experience of living with IBD. I chose the research topic and approach for similar reasons: the topic and area was of interest to me and holds meaning to me and it was related to my life experiences. The method I chose offers the opportunity to develop insight and deeper understanding, in real terms, and the everyday effect of living with a chronic illness. There are many situations and

circumstances which a researcher may care enough about in order to study and research (Lofland and Lofland, 1995).

Mills' (1959: 204) view is that: 'The social scientist is not some autonomous being standing outside society, the question is where he (sic) stands within it…' He adds that the sociologist should:

> …learn to use your life experience in your intellectual work: continually to examine it and interpret it. In this sense craftsmanship (sic) is the centre of yourself and you are personally involved in every intellectual product upon which you work (Mills, 1959: 216).

Geertz (1973: 5) argues that qualitative methods should not seek to be 'an experimental science in search of law but an interpretive one in search of meaning'. He adds that 'thick descriptions' (1973: 6) that are rich and detailed in information may only be possible using a qualitative approach to research. These thick and rich descriptions are discussed by Sergi (2011: 192) who suggests that such a research approach also employs 'thick performances' in terms of the research process as a whole. Sergie (*ibid*) suggests that:

> …doing research is a rich, complex and multi-level experience that mobilizes the whole person conducting this inquiry - that is, that doing research takes the form of a thick performance. Research may be processual *per se*, but these processes only come to life through a performance, by performing research… the "soft", "personal", "subjective" or "intersubjective" dimensions, which are at times perceived as "weaknesses" and as "unscientific", are highlighted as inextricable dimensions of doing research, and a number of researchers have indeed underlined that being more open about the nature and influence of the affective dimensions of our research might be a way to produce richer analyses of social and human phenomena.

Thus, it can be seen that the ‘deep’ and ‘rich’ analyses leading to increased meaning in results may be achieved through this approach.

There is a developing literature on the use of e-mail interviews as an effective method for achieving deep and meaningful data, which I drew upon to construct my research design (see 3.3). Using this method I was able to generate a detailed and in-depth understanding of not only the course of IBD experience, but also the emotions and decision making processes of individuals with IBD. This involved asking open questions allowing participants to give detailed answers. Answers tended to be long and detailed, often giving far more detail than the question warranted. This lead to extra information and detail which enhanced the research. The extra information in some cases were a repeated theme between research participants and were therefore important.

Denzin and Lincoln (2000) suggest that quantitative research tends to rely on mathematical based methods and is written in a detached and impersonal way, whereas qualitative research has an emphasis on the individual accounts, biographical, autobiographical and ethnographic prose. It is the impersonal and third-person prose which I have tried hard to avoid. Instead, there is an attempt at a rich and deep auto/biographical understanding gained through the first-hand accounts of both myself and the participants I communicated with. Qualitative research techniques allowed me to develop further understanding of experiences and significance attached to these experiences by the research participants. Therefore through utilising qualitative research I am able to find texture and the intricacies of everyday life, and understand the experiences of the research participants and the significance and meaning that interactions,

social processes and relationships create (Mason, 2002). Through qualitative research I can find higher levels of meaning and depth with a high level of context and complexity (Mason, *ibid*). At a basic level then, it can be argued that qualitative methods produce information and conclusions which are authentic and represent 'real life' – the things that matter to people.

It is important to remember that reliability often goes hand in hand with authenticity and to think about the best ways of achieving this. This is discussed by Seale and Silverman (1997: 379-80) who propose:

> 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.

Thus, Seale recognises that there are different ways of increasing authenticity and reliability, especially through the method of open-ended questions. This is particularly relevant to my work, where I have asked open-ended questions with the intention of gathering 'authentic' understanding of the experiences of the participants. Seale (1999) suggests that an awareness of the issues surrounding qualitative research, such as authenticity and reliability is probably enough to ensure that the research is rigorous and protected against the more obvious mistakes.

Within qualitative research, it is important to also have an awareness of 'self' and to continue, as a researcher, to question one's own input and awareness of the issues. Asking oneself questions about one's own behaviour and about self-strategies plays a part here (Lofland and Lofland, 1995).

This is clearly relevant to my research, and as part of the overall reflexive process it is important to constantly question one's own motivations and behaviours in order to gain an understanding of the issues at hand.

3.4 Online Interviewing

Wallace (1999: 151) proposes 'the tendency to disclose more to a computer… is an important ingredient of what seems to be happening on the internet'. This level of disclosure is supported by numerous researchers, especially in a medical context. For example, Robinson and West (1992) discussed disclosure online related to a sexual health clinic. Patients making online reports were more likely to admit to a higher number of sexual partners, an increased number of clinic visits and a heightened number of symptoms than they would report in person to a doctor. Similarly, Kim *et al* (2003) discuss the concept of disclosure through email interviewing, suggesting that the use of email may safeguard participants and prevent stigma or loss of face when discussing and disclosing sensitive topics. Thus, online research may give participants more control simply through being away from the face-to-face environment where there may be fear of speaking honestly (Hine, 2004). Overall, there does seem to be a consensus that the heightened levels of disclosure that may be achieved through this method of interviewing are beneficial to both the participants and the researcher (e.g. Bowker and Tuffin, 2004).

For my research I utilised online interviewing. There were no face-to-face interviews. Participants were recruited through online means and the subsequent interviews were all carried out through the use of email. This

enabled me to build up a level of trust with participants without the fear of embarrassment. My experience supports the above literature and I found that participants were more willing to disclose potentially stigmatising information without fear of stigma, due to the fact that I am a more distant entity: a person whom they will never meet or know in person.

It is important to remember that there may also be drawbacks to this method of interviewing and that these drawbacks must be considered when analysing and interpreting the data. Meho (2006) discusses this and suggests some of the most important drawbacks and differences compared with conventional interview techniques saying that the biggest difference is the lack of ability to use multiple senses such as body language, tone or the use of eye contact. This could in turn mean that some cues may be missed through the use of online interviewing. However, Meho (*ibid*) goes on to propose that there may be some individuals who express themselves more widely through writing rather than talking, meaning that in some instances the data obtained may be richer through online interviewing.

The participants in my research varied considerably in their written responses. There were a couple of instances where a participant did not understand the question and asked for clarification of what I meant. One of these two individuals simply did not answer the question, and the other asked me to explain. Some participants wrote pages of responses and were very detailed about many areas of their lives. Others were clearly more reserved. However, all of my participants shared a lot of information, with all discussing facts **and** feelings.

3.5 Ethics

When conducting research there is always an ethical consideration to be considered:

> Any qualitative researcher who is not asleep ponders moral questions: Is my project really worth doing? Do people really understand what they are getting into? Am I exploring people with my “innocent” questions? What about their privacy? Do respondents have a right to see my report? What good is anonymity if people and their colleagues can easily recognise themselves in a case study? (Miles and Huberman 1994: 288).

Christians (2000: 139) identifies that most scholarly associations have produced their own codes of ethics with an overlapping emphasis on four guidelines:

1. *Informed consent:* The research subjects need to be informed that they are participating in an experiment or research set and what consequences it has. The participant has to agree voluntarily to participate.
2. *Deception:* The research needs to be designed without deception and with moral principles.
3. *Privacy and confidentiality:* Protection of participants’ identities and research location to safeguard against unwanted exposure.
4. *Accuracy:* The accuracy of the data is a cardinal principle. Fabrication, omissions, fraudulent materials and contrivances are both unethical and non-scientific.

The research on which this thesis is based has endeavoured to keep within all the above parameters suggested above by Christians (2000).

My research outline and framework was submitted to the University Ethics Committee for approval. The application included an outline of the project and my proposed methods. This included my approach to the recruitment of research participants and how I planned to progress once I had recruited the participants.

The information initially given as an introduction to research contained the following description:

> My name is Sarah Ellson, and I am carrying out research considering the perceptions of and factors affecting well-being in people suffering from Inflammatory Bowel Disease (IBD). I am hoping to explore the experience of IBD through key experiences. The research project is a funded PhD through the University of Plymouth.
>
> The research is a qualitative study of people living with inflammatory bowel disease and it will involve email interviews focusing on relationships with health professionals and family and friends and how their support and other factors affect well-being. I would like to hear your story, in your own words, about living with IBD and the experiences that you have had. I anticipate that this will involve an initial email from me with some questions which you may answer as few or as many as you wish. This may lead to further email communication over a space of two months, or if you would prefer to end communication after one email this is not a problem.
>
> There is no pressure or requirement to take part and it is your choice as to whether you would like to contribute to this piece of research. You are free to withdraw from the process at any time without providing a reason and without detriment to your relationship with the support group. You are not compelled to answer any questions that make you feel uncomfortable. The benefits of taking part are furthering knowledge of this area and raising awareness of what people who suffer from inflammatory bowel disease consider to be important in both their health and decision making related to their health.
>
> Any information I collect through email interviews will be made strictly anonymous and at no point will personal names or email addresses be used in the completed research.

> Any help is very gratefully appreciated, and my email address is sarah.ellson@postgrad.plymouth.ac.uk

All the research participants have given informed consent. In all areas I avoided deception, and participants had an awareness of the areas my research is exploring and hence why I am asking particular questions. The identity of participants has been protected at all time. This has involved changing the names of participants within the research and the removal of specific names and places within their interview responses. This includes the use of health professional identities and the real names of family members and hospitals.

In discussing the ethics of qualitative research including the concept of informed consent Mellick and Fleming (2010: 302) suggest:

> The terrain for research ethics in the social sciences includes voluntary informed consent (VIC), risk and harm, anonymity and confidentiality, secrecy and deception, data protection, vulnerable populations, codes of conduct, guilty knowledge, non-human research, and the composition, remit, power and procedures of ethics committees (see McNamee *et al.*, 2006)... good conduct in research ethics invariably places emphasis on the importance of VIC from participants where possible, and for the purpose of this discussion places a responsibility on researchers to avoid (or at least to minimize) harm(s) and to protect the anonymity and privacy when research findings are put into the public domain.

I have attempted to use the data accurately and use as much rich detail and description as possible. I have tried to include what the participants discuss as important to them around the areas of interest and have made an effort to be as clear and honest as possible in the interpretation and discussion of what has been said.

With specific consideration of the ethics carried out using an online medium, Markham (2007: 50) writes:

> Qualitative research concerning the social use and impact of new communication technologies has also raised ethical questions. The Internet provides ready access to textual data for various types of analysis: Who owns this data? The Internet provides easy access to special interest groups and communities: Are these communities' private or public spaces? The Internet provides a global capacity for sending surveys and conducting interviews: How do we gain informed consent? How does one verify the age or vulnerability of participants? Do international boundaries influence the way one collects information? Internet users are in themselves an interesting and readily accessible social group to study: How does one consider issues of authenticity?

Stewart and Williams (2005: 395) discuss research that is carried out via computer and propose 'the survivability of 'traditional' methods within computer-mediated settings is dependent upon their capacity to be utilized and adapted to the technology that mediates human interaction online'. They explore the research carried out by Robson (1999) in inflammatory bowel disease and employment experiences through the use of online focus groups. They conclude that although there are many challenges regarding online research, the information can be collected over lengthy periods of time and narratives may be more considered and in-depth.

3.6 Access and Recruitment

I was not looking to carry out research on 'patients' – I was seeking life-stories and experiences. In the event that any questions were raised that I could not answer or if the participant demonstrated distress I was prepared to provide details of appropriate support. I also had available leaflets from the IBD association to provide information and further points of contact for the individual concerned. However, this situation did not arise at any point.

Having obtained ethical approval from the Faculty of Health, Education, and Society Research Ethics Committee I began data collection in November, 2011. I carried out qualitative in-depth email interviews with adults who suffer from chronic illness (IBD). I have included both those who are in current flare-up and those who are in remission.

Adopting a life-history approach I asked people to tell me their 'stories' about their experiences and therefore posed very open questions, taking a background role and allowing people to write openly about their experiences. This enabled me to gather the 'thick descriptions' described by Geertz (*ibid)* above. This biographical / narrative approach allowed individuals to tell me as much or as little as they were comfortable with, without me pressing for answers to specific questions that they may not feel comfortable answering. Kvale (1996) supports the idea that using interviews in research may give the researcher great insight and understanding of people's experiences and life-stories and suggests that it gives a researcher the opportunity to listen to people, to hear their views and opinions and their dreams. Therefore to understand the world from the point of view from the participant and their lived experience.

This approach applies particularly to email interviews as there are no time restraints or pressure to answer questions. Indeed, Roberts *et al* (1997) propose that shyness and the negative effects that may be a result of this in research is negated through using email interviews and that interpersonal issues are vastly reduced. Using the Internet as part of the research process reaches out to a large prospective audience. Kozinets (2010: 2) says '... there

are at least 100 million, and perhaps as many as a billion people around the world who participate in online communities as a regular, ongoing part of their social experience'. Kozinets goes on to say 'social scientists are increasingly reaching the conclusion that they can no longer adequately understand many of the most important facets of social and cultural life without incorporating the Internet and computer-mediated communications into their studies.... It is a world that includes the use of technology to communicate, to commune, to socialize, to express, and to understand'. My research therefore has used a method that will hopefully have reduced the pressure to answer questions and associated shyness and at the same time achieved understanding.

I accessed participants through a variety of non-medical sources including Internet forums, local IBD support groups and through this, hoped for a snowballing effect. Groups such as local IBD support groups and sometimes Internet forums may involve initiating contact with a gatekeeper prior to accessing any respondents. Examples of this were group leaders or Internet forum owners / administrators. In these situations I initiated contact with these gatekeepers through email, explaining my research interests and goals and asking for access to their list of members. The Internet forums resulted in more participants as the administrators allowed me to post about my research on the forums and people were able to make up their own minds about whether to contact me. The local IBD groups proved more difficult as they have had problems with data protection and would not pass on any email addresses. However, a couple of the groups sent my details and research interests to their members and several participants were sourced in this way.

Stewart and Williams (2005: 398) argue that:

> …taking advantage of existing social groups online is by far the most common and successful method of recruiting participants… Notably, medical sociology and health research have taken advantage of the 'captive populations' online, characterized by health and illness support networks.

The information gained from the participants was rich and detailed. Participants went into great detail about subjects that people perhaps would not normally discuss in everyday interaction. The use of the Internet allowed a sense of anonymity and perhaps allowed participants to reveal more about their situation than might have occurred in face-to-face situations (Stewart and Williams, 2005).

A drawback to this style of research is that participants were limited to people who have the use of the Internet and is probably biased towards those who utilise the Internet as a method of support. I am aware that this may attract different people as research participants than a random sample of people who have IBD taken from the general population. This is discussed by Taft *et al* (2009: 1224) who comment on their own research around IBD:

> The present study also utilized (*sic*) the Internet, including support message boards, for recruitment. The majority of the participants (75%) in this study were recruited online, which may pose significant bias in this sample. Internet access among individuals with IBD has been reported to be as high as 81%, and IBD patients are likely to use the Internet to find information about their disease. While the Internet is increasingly being used as a source of recruitment, recent research has shown that significant differences in psychosocial adjustment are present between clinical and Internet populations among individuals with gastrointestinal illness, including IBD.

It must therefore be recognised that there are likely to be differences between those who seek support on the Internet regarding their IBD and those who have IBD and do not utilise the Internet. Along similar lines, the research method assumes literacy. Only those with a good command of reading and writing were able to take part in the research. It is also possible that those who were more seriously unwell with a flare of IBD may have been unable to take part, and therefore the sample of participants may be biased towards those who are less severely unwell.

I was fortunate enough to have some participants contact me directly through email, having read about the project. Other participants were found through word of mouth. Participants who had already agreed to take part asked other people within their NACC support group if they would also help me with my research.

Once I started receiving responses I generally received one detailed email with answers to my questions from each participant. I did not hear from all the participants again following this. Others responded to my email thanking me and telling me that I should contact them if I required further information. I clarified some further information with three participants. This included partially answered questions and clarifying meaning / prompting participants with regard to meaning.

I did not develop close relationships with the participants. They all acknowledged that they understood the reasons for my research and were very approachable. It was most helpful to be told by several participants that they

were very happy to help me with any further research and I felt that our communications were all carried out on friendly and good terms.

The recruitment method I followed was relatively straightforward and people generally seemed to want to help. Initially the uptake was slow, and I had concerns that nobody would step forward to take part. However, once I managed to get a couple of people interested, they spread the word amongst NACC support groups locally and on related Internet forums online, and it snowballed in this way.

There was one person who communicated their interest in participating on a public forum and then through email. I sent them the email that everyone received after agreeing to take part. Initially they began emailing me asking to meet with me face-to-face. They sent increasingly agitated emails and public messages on the forum, which mainly sounded unrelated to the actual research project and were more about 'meeting women'. This felt rather threatening. The forum 'owner' deemed the man a 'troll' and banned him from the forum. I did not participate any further in email conversation with the person, and neither the forum nor I heard from him again.

Hardaker (2013: 78) defines Internet trolling as:

> Trolling is the deliberate (perceived) use of impoliteness / aggression, deception and / or manipulation in online communication to create a context conductive to triggering or antagonising conflict, typically of amusement's sake.

Conflict quickly arose from this individual, and although he was dealt with courteously and with consideration in all communication by all parties, he seemed to want to cause problems. As a researcher, I felt torn in some respects. Although the individual concerned demonstrated all the characteristics of an Internet troll, and therefore somebody I should not engage with on any level for my own safety, the more empathetic and sensitive side of me worried for in case the person really did have problems and needed intervention in some way.

3.7 Participant Biographies

A portrait of each of the sixteen participants follows. Given names have been changed to protect anonymity.

Graham: has Crohn's disease. Initially he put it down to irritable bowel syndrome (IBS). It took six months for the diagnosis, partly complicated by having been sent to a hospital outside of his local area. He was relieved that the diagnosis was not cancer. He has a sister who is able to offer him support as her daughter (his niece) was diagnosed with the disease aged twelve. He had his own business but he could no longer run it due to the disease and the symptoms associated with it. He is a very recent member of the NACC. He feels that people at work and his friends and family don't really understand what he is going through and that they are not people he will go to for support as a result.

Lauren: was diagnosed with Crohn's disease over twelve years ago. Initially she put the symptoms down to irritable bowel syndrome (IBS). She was pleased to receive a diagnosis but very distressed that she had been diagnosed with an

incurable disease. She has had repeated surgery for her disease and has a good relationship with her health professionals. She uses self-administered anti tumour necrosis factor injections as part of her treatment. In 2009 she had a stoma but still feels that her life is ruled by Crohn's due to the symptoms and looking after the stoma. She has support through the NACC and although it has taken a long time for her to be open with friends and family, she is now finding their support helpful.

Geoff: was diagnosed with Crohn's disease in 1985 when he was fifteen years old. He had missed a lot of schooling due to illness and struggled with achieving qualifications and knowing what he wanted to do with his life in terms of career. When he did start working, he found a full-time job difficult because of his health problems and then in the early nineties suffered from his first episode of depression (which was treated). In his twenties, he furthered his education and then got offered a place at university. Although he struggled to keep up (because of his health) he did go on and graduate. When he started working he found that initially, although his attendance record was not perfect, he enjoyed the work. However, over time his health suffered and he needed a lot of time off work, which he says his employers did not understand. He went from five days a week to four and then eventually three days a week. In 2010 he had ten months off work due to depression. Upon his return to work he was faced with the options of going on a capability procedure or a termination of contract. He left his job. Since leaving his job his health has improved.

Mark: was diagnosed with Crohn's disease in 1993, at the age of twenty-four. He had never previously heard of the disease and was relieved that it was not

cancer. He has pain about 80% of days, and fatigue about 50% of days. He was a bank manager but had to give up full-time work due to stress and fatigue. He took on a part time role as a cashier. He feels that a positive attitude helps and believes that his cycling, walking and golf contribute to his health. He is careful regarding his diet and his opinion on the importance of diet is different to that of his consultant. He has been on many different medications and feels that he has never found one that solves the problems for him. He had surgery in 2009 which he finds has helped him. His general practitioner is good. However his experience with consultants has not always been positive as he has been made to feel like a number rather than an individual. His experiences in hospital have not always been positive either as he feels that the nursing staff have very little tolerance for helping when he requests help. Overall his family and his general practitioner provide him with the support he needs.

Maggie: At the time of interview, Maggie had only been diagnosed for a matter of months. She felt that her treatment and questions were dealt with well by the health professionals, and was relieved that she did not have cancer. She gets her main support from the NACC and the hospital although says that she has had some support from her sister. She reads and educates herself as much as she can about her condition.

Kathy: was diagnosed with Crohn's disease in 1985. She had many visits to the local accident and emergency department prior to diagnosis. When diagnosed, she required surgery on the same day. She had never heard of ulcerative colitis or Crohn's disease and felt that she had not been given enough information by the health professionals. She has now had 3 surgical procedures which she

feels has made her a stronger person. She has a husband, two children and grandchildren. She says that she likes to be positive about life and recognises that the people and surroundings in her life contribute to getting her through the bad times. Her current medication seems to be working well and she maintains good relationships with the health professionals involved in her care. Her family, friends and health professionals all provide her with good support.

Tina: had her first symptoms in 2010 and was given treatment from her general practitioner for piles. In February 2011, she was referred to a gastroenterologist. In April, she was given a colonoscopy and several weeks later had an appointment with the consultant who was not helpful and did not give her a diagnosis, although he did give her medication. It was the general practitioner who gave her a diagnosis in the end having phoned the hospital for the results of the colonoscopy and biopsies. She asked for a different consultant whom she saw and was diagnosed with ulcerative colitis. This diagnosis was then questioned when it was wondered if it was in fact Crohn's disease. Tina has found her life to be severely impacted by her disease. She is unable to leave the house for very long and is constantly tired. She has found the relationship with her children is affected as her relationship with her husband. She now feels in control of her treatment and has a good rapport with the health professionals involved in her care. Her support comes from the NACC and family. She also knows another parent at the school where her children attend, who has Crohn's disease and has found it useful to know someone else who has an understanding of the issues.

Emma: was diagnosed in 2006, at the age of seventeen. She went to the accident and emergency department where she was diagnosed with an appendicitis and taken to have surgery. Her appendix was fine but they discovered the real cause of her problems – Crohn's disease. She had a fairly traumatic diagnosis, not helped by then having to stay in hospital for seven weeks whilst being treated. She got a job working in a nursery with children and remained stable for approximately a year. She then became unwell and was admitted to hospital for surgery. Upon her return to work, she was put into a disciplinary procedure for the time off work which her workplace said was not because of her health. They were forced to reverse this decision and she has been working for two years. She finds her health professionals to be helpful and kind, and has a good relationship with them.

Christine: was diagnosed with proctitis in 2006. The medication prescribed to her cleared things up very quickly. She saw the IBD nurse until 2008 whereby they discharged her as she was still in remission. She takes great care over her diet and avoids food that may trigger her symptoms. She has had two or three flares in the last five years but has simply increased her medication which works for her. Her husband is very understanding as she has continued to have urgency and needs to remain near toilets when she goes out. She seems to have symptoms most days but at a level that she deals with and still continues with everyday activities such as walking the dogs. She believes that her general practitioner doesn't have time to review her but intends on seeing the IBD nurse at some point as it is a long time since there was any health professional input.

Jenny: was diagnosed with Crohn's disease, age eighteen, in December 2002. She had been seeing her general practitioner for nine months before he sent her to a specialist. Because of the ulcers in her mouth her dentist sent her to an oral medicine specialist at around the same time. The oral medicine specialist gave her the diagnosis from looking in her mouth before the gastroenterology department. She was very upset by the idea that she had an incurable disease. She doesn't regard herself as healthy even though she acknowledges that when her blood tests say she is healthy and she is in remission it could partly be state of mind that makes her still believe that she is not healthy. She has great confidence in the health professionals involved in her care. However, she has a big lack of trusts in registrars as they don't know her, she never sees the same one twice, and ask questions that they could see the answers to if they had read her notes. She gets a large amount of support from her mother. She is also a member of the NACC. She does not feel able to talk to her circle of friends about the condition.

Sally: has had the diagnosis of Crohn's disease for approximately fifteen years although has suffered from the symptoms for much longer. Prior to diagnosis she saw many health professionals who gave many different diagnoses including appendicitis, gastroenteritis, and urinary infection, and then finally that it was in her head and that she was seeking attention. It took many years for the actual diagnosis to take place which followed an extensive stay in hospital. She was also diagnosed with Ankylosing Spondylitis. She feels that she 'functions' more than 'lives', and suffers daily symptoms. She finds it hard to discuss with her friends and acknowledges that it is a 'hidden' disease. She has never had surgery and manages to work which she believes gives a degree of self

respect. She has two children who have found her disease and hospital inpatient stay very difficult and her older child prefers to spend time away from her and with her father instead. Since diagnosis her general practitioner has been very helpful and supportive. However she does not feel that her relationship with her consultant is good as it took so long for diagnosis and she feels like the consultant doesn't really believe her. However her consultant is pushing forward with trying to get her onto infliximab. The result of her poor relationship with her consultant is that she doesn't really feel like she has personal control of her disease. Her family is very supportive and her mother has ulcerative colitis. She also has a friend with a chronic condition who offers support, and she is a member of the NACC.

Lucie: was diagnosed by her general practitioner with irritable bowel syndrome initially. Five months later she was still going to the doctor with symptoms so was sent to a specialist who diagnosed Crohn's disease. She finds the condition embarrassing and it has a very large impact on her life. She finds it difficult to easily leave the house and is constantly tired and in pain. She also suffers from Fibromyalgia, Ankylosing Spondylitis, Depression and Secondary Arthritis. She says that the only thing that currently contributes to her well-being is the counselling that she pays for every week. She has been on many different medications and says that her pharmacist is the best person to ask advice from regarding treatment. Lucie does not get support from her family or her friends. Her partner left her after diagnosis as he wanted to have children and she has been told that it would not be advisable to have any.

Abi: was initially diagnosed with piles. The following year a consultant diagnosed her with ulcerative colitis. She felt relief at having a firm diagnosis. Since diagnosis she has only ever had 2 days off work and she considers herself healthy. She gets very tired and works less hours than she used to, but there were other contributing factors alongside the disease towards this decision. She feels in control of her treatment although access to a consultant is more difficult than it used to be. When first diagnosed she had private insurance and now she has to go through the National Health Service. She has support from a couple of friends and the NACC. Her husband is supportive but she doesn't feel that he really understands the extent of the symptoms sometimes.

Rachel: is an intensive care nurse. She became suspicious that she might have either ulcerative colitis or Crohn's disease in 2009. The diagnosis was straight forward and she was put onto mesalazine. Her symptoms deteriorated and she has not been in complete remission since, a fact that she partly puts down to the tablets. She regrets going to the doctor when she did and wishes that she hadn't done so until the symptoms were unbearable. She has problems being admitted to hospital, she says partly because she is a nurse and partly the stress and lack of sleep. She had six months off work but is now working full-time night duty. A combination of tiredness and medication has meant that work is now a lot harder than it used to be. She doesn't see herself as healthy and her marker for health is whether she is taking steroids or not. She is on good terms with her health professionals and retains a lot of the control of the disease herself in terms of what treatments she needs and when she needs them. She says that the weakest area of her treatment is her social support. She does not have family available to offer her support. She is, however, married. She feels

that her husband does try but that he doesn't cope with her illness. There have been periods of time when he will not touch her or go near her because he considers her to not be clean when she is in flare up and suffering from incontinence or needing the loo regularly. Her greatest support has come from an Internet forum whereby she has virtually met other sufferers to gain information and support from.

Michelle: found the diagnosis to take a lengthy period of time and was initially diagnosed with piles. When she was eventually diagnosed with ulcerative colitis she felt relief that it was not cancer. She tries to stay positive and lead a full life. She says that she doesn't believe in 'wallowing'. She attributes many factors toward her well-being. These include socialising, family, friends, sport and church. She sees her consultant on a private basis and access to him is straight forward. She doesn't believe in simply being told or instructed what to do in terms of treatment and wants to be fully involved in the decision making. She has educated herself about her IBD and is up to date with the latest treatments. She is also very aware of her symptoms and knows when she needs treatment and when to seek help. Michelle does not like to talk to people about her condition as she believes that it would put people off seeing her. Her husband understands but she feels that the only person who can really help her is herself.

Frances: found diagnosis very stressful as the health professionals seemed to find it hard to agree on what was wrong. Once she found a consultant she was diagnosed within the week with ulcerative colitis. She felt relieved that it was not cancer. She endeavours to keep good control with medication over her disease

and admits that she has used the diagnosis as a reason to get healthier in terms of diet and exercise. She is knowledgeable about treatment and her needs and says that her own knowledge and experience leads the treatment – something that she has developed over the years. She does not feel able to discuss her disease with other people but her husband offers her support and helps her as needed.

Note: All quotations from participants within this thesis contain the original spellings, sentence construction and short forms in order to allow a better flow and understanding of the participants' original words.

3.8 Analysis

Initially I read all the responses that had been sent to me through email, and then gave each participant a new name to protect their identity. I then used bubble diagrams to pick out relevant themes. I looked at repeating patterns within the interviews and identified common words, issues and observations. Repeating themes appeared to be fear, stigma, relationships with significant others, relationships with health professionals, knowledge, experience and the concept of independence / decision making in the control of the disease. Where I noticed these repeated themes, I made note of them and ensured that they were included within my analysis and discussion as relevant concepts.

The difficulty I found was to correctly interpret the meaning behind what the participants' had written. I did not want to distort what participants were saying in order to fit in with certain themes or set ideas that I might have unconsciously had. I also did not want to take what had been said out of context and thus

create a whole different meaning. I was mindful of this throughout the analysis. Using an approach influenced by grounded theory (Glaser and Strauss, 1967), I took themes from the data using the information and descriptions given to me. I was able to recognise repeated terms and phrases regularly through the participant interviews and not their importance. The areas I chose to explore further were those that seemed to be a running theme in the majority of the interviews and my own story. So, I was able to construct theory through the gathering and analysing the data provided by the participants. Auto/biographical influence leads to epistemological theory emerging from data using 'a grounded use of an auto/biographical epistemology' (Letherby, 2002c: 3.5)

Many of the issues that the participants wrote of affected me in terms of emotions and the empathy that I felt towards them. When initially reading one of the responses I was very upset regarding what I was reading and could not understand how a person could be treated so very badly. Since then, I have not lost the feeling of empathy but I have managed to control it better in order to continue with the research. The way in which the research may affect the researcher is recognised by Bott (2010: 170) who argues 'What I had not anticipated beforehand, nor fully appreciated during data collection, was the sensation of being so divided between my 'personal' and 'professional' 'selves''. This is recognised by Morse and Field (1995: 78) who propose:

> Data collection can be an intense experience, especially if the topic that one has chosen has to do with the illness experience or other stressful human experiences. The stories that the qualitative researcher obtains in interviews will be stories of intense suffering, social injustices, or other things that will shock the researcher.

Certainly some of what I read did shock me, such as one of the responses described the way in which the participant's husband viewed her as unclean during a flare up and how he would not touch her or go near her. Another example of an incident that I found upsetting was where someone wrote that their partner had left them because he wanted children and because of their health they were never going to be able to have children. Unfortunately, I could only focus on the main emerging themes within the data. I had to select the themes that appeared most often and on occasion, make the decision not to take some of the issues raised by just one individual or sometimes two further. The research had to become focussed and the only way I found to do this was to explore the areas that appeared the most often within the interview responses.

The interview responses were analysed simultaneously whilst carrying on with work on the PhD with regard to reading around the literature and starting to write up what I was seeing as emerging subjects. It is easy, now being in possession of the interview responses, to look back and think that there are questions that I missed or should have asked. But it is only with the knowledge of what the respondents have contributed that these questions can be raised. Certainly further questioning along some avenues such as stigma would be likely to give more specific and interesting future results.

Some of the information given to me surprised me in the sense that it was so open and honest. I felt that people were giving me information about their lives that they would not normally be able to or want to necessarily discuss with people, let alone a stranger. In this sense I felt that it was an honour that they

felt able to share their stories with me and to feel comfortable in doing so. This feeling is noted by Dickson-Swift *et al* (2007: 340) who argues 'participants often shared private information about certain aspects of their lives that the researcher would not normally expect to hear due to their status as a stranger'. Dickson-Swift *et al* (2007*:* 340-42) goes on to argue:

> Many of the researchers used the term 'privilege' when describing their experiences. They often felt that they had been afforded a privilege by being allowed to listen to stories that were often private and intimate… Feelings of vulnerability for these researchers often came from the fact that in doing the research they were sometimes learning things about themselves.

As I read some of the respondent replies I felt surprised in some ways, because they had opinions and reactions that, in some cases, were so different from my own in relation to IBD. This in turn did lead me to question my own attitude and opinions. For example, I have never considered that the NACC could help me or even that I would want it to. However, the number of participants that have praised it highly and talked of the different support it can offer has led me to consider joining at some point in the future. Others who talk of not being able to work full-time or even in some cases at all led me to question my own views. I have always believed that I would 'soldier on' regardless and that I would not allow it to affect the important things in life such as work. After reading the interview responses, I realised that perhaps I was full of good intentions and ideological beliefs but that the reality is that my work is sometimes affected, whether I like it or not. I cannot always do or achieve what I would like, even though the aspiration is there.

3.9 Chapter Summary

In this chapter I have discussed my methodological approach and the methods used for data collection and analysis of the thesis. Additionally, the participants were briefly introduced. The research was qualitative and autobiographical using a grounded theory approach. The auto/biographical method was discussed at length and the need for reflexivity (Cook and Fonow, 1990; Letherby, 2002a) within such an approach was also examined. It was seen that through the use of these research methods, in-depth and rich data could be obtained (Geertz, 1973) which includes an understanding of human emotion and behaviour (Rodriguez, 2001; Richardson, 2003).

Ethical considerations were then discussed. This included the considerations of informed consent, deception, privacy and confidentiality and accuracy (Christians, 2000). The steps I took to ensure the research was ethical were stated, including following the above steps and submission of the research proposal to the University Ethics Committee. Following this, I talked about the access and recruitment of participants, along with my approach after initial contact was made. As the research has taken place online, I discussed the advantages of such an approach (Stewart and Williams, 2005; Taft *et al*, 2009; Kozinets, 2010).

Participant biographies were then listed. This section gave a brief introduction to each participant, including some information about each person. Following this, my approach to analysis was discussed, including my feelings about the information.

CHAPTER 4: Sarah's Story

4.1 Introduction

I have Inflammatory Bowel Disease (IBD). My diagnosis has changed over the years from Ulcerative Colitis to Crohn's disease many times, and I have had a lot of intensive treatment, both as an outpatient and as an inpatient. Since my diagnosis of IBD my support systems and attitudes toward the disease have changed, developed and evolved. These changes are a result of my disease patterns and activity and also my knowledge and experience regarding what does and what does not work for me. I think that the biggest thing that I have learned over time is that my voice is important when dealing with health professionals. Without it, or when I am stopped from using it, I become very stressed (which makes my IBD worse). Through learning and educating myself, I have improved my overall health and feel that I am able, to a large extent, to know what I need and when I need it.

IBD has not only had an effect in a physiological sense, it has also played a large role in my everyday life. When I am unwell, depending on the severity of the flare, it stops me from being able to do what I would like to do both as an individual and with my family. The effects of the disease and the treatment mean that when my IBD is in flare I do not have the energy or ability to go out and do the things I would normally take for granted. This is frustrating for me especially as my children (currently aged two and three years) are still too young to understand why I cannot always go out to the park or go swimming with them. The disease is far more than an inconvenience. It fundamentally changes the way I live my life. However, I have learned to adapt and I have

learned how to do things differently in order to make the best of the problems IBD causes me.

In the rest of this chapter I provide an account of parts of my IBD since diagnosis and reflect on and discuss the significance of my journey with specific reference to the research on which this thesis reports.

4.2 Account

'You're going to have to come to terms with this very quickly, I'll leave some bags here for you to look at and here are some pamphlets for you to read' the stoma nurse at the hospital announced in the hot and stuffy hospital room.

I am sitting on a bed in a private room in the hospital. I look at the nurse, hoping for some element of compassion or understanding of what his words mean to me. He simply looks back at me and smiles as another nurse quietly attaches a drip to my right arm. I bite my lip as the nurse tries to get the drip working and realises that the tube in my arm no longer works and that I will need another inserting – the fifth one in two days. Still I wait for them to understand that I am silently screaming for help, that I cannot understand how I was healthy as little as two weeks ago, and now I am lying in a hospital bed, being pumped full of medications and being told that my large intestine is going to need to be removed, involving a series of three major operations resulting in a stoma bag. The stoma nurse has, quite correctly, been told that I want to be told everything, that I have an inquiring mind and that I need to be given all the information before I am able to make any decisions. What he seems to have missed is the fact that this does not preclude me from having feelings that are

running very high at the present time. I feel that I need some support in what I am being told, yet he is showing me pictures of the operation procedure and simply telling me that I will be relieved to have a stoma bag because I will feel better with it. As a 29 year old woman I feel that my well-being involves far more than this: I have a huge feeling of insecurity about having a bag collecting my faeces. Thoughts are running through my head about my future in terms of relationships, family, what people will think, practical issues and also, strangely and unexpectedly, feelings of inadequacy. I need to feel comfortable psychologically as well as physically and I do not feel that a stoma is going to help me in many ways. Yet, it seems I may not have many other options.

I feel so embarrassed and my head is spinning with confusion and worry. I have become frustrated and have started to take out my emotions on those who are close to me. My boyfriend, has been by my side since I was admitted to hospital, I can see that he cares, but I snap at him so easily. Then, through a morphine haze, I feel guilty.

Before this week I had been busy with my work and the usual events of everyday life. Everything seemed 'normal'. Now it seems that I not only have to inwardly digest, but also accept, that I am very ill. I have a flare up of a disease called ulcerative colitis. This means that my large intestine is very inflamed and bleeding, I am no longer digesting the food that I eat, there is high risk of perforation of my large intestine, I am in a lot of pain and my body is essentially rejecting my gut. My treatment involves steroids injected directly into a vein four times a day and a cocktail of other injected pain killers and salicylate drugs. I find it difficult to stay awake due to the morphine and it feels like this is

not a good time to be making life changing decisions. Since the treatment seems not to have worked, the doctors have decided that a surgeon now needs to be involved, and it is the surgeon's view that now is the time to make preparations to operate. The problem is, I do not agree. The decision seems to have been made by the medics involved in my care with little, if any regard whatsoever for what I want, what I believe, what my fears and hopes for the future are and what is or is not acceptable to me.

After another afternoon of extreme stress, worry and talking every possible scenario through with my boyfriend, I come to the conclusion that I have to try every other avenue before I take the surgical route. Waiting for the consultant to come and visit seems to take so long, but as he enters my room I feel myself looking at him with a new determination; a determination to at last take this situation into my control and have an attempt at creating a mutually agreeable treatment plan. Almost immediately my hopes are shattered. The consultant is explaining that all my options have run out. There is an outside chance that an infusion of a drug that has not been licensed to be used as a treatment for ulcerative colitis may have an effect. This drug has been used with some success for Crohn's disease but there is little known about its effect in colitis. The drug depletes the immune system and is associated with a large number of unpleasant and potentially dangerous side effects. I instinctively believe that at this point anything is worth trying rather than losing my gut. I am agreeing with the consultant that an outside chance, however small it may be, is better than no chance at all. We agree that the infusion should take place tomorrow.

It still feels strange, even though in some kind of ironic way I have become more 'used' to the hospital environment, that I feel increasingly embarrassed and belittled by my disease. I am finding that people openly discussing my bowels and toilet habits makes me feel small and degraded. I am also finding that I intensely dislike being referred to by the nurses and doctors as 'the 29 year old with colitis'. I find myself reacting internally to this with thoughts that I AM a person, I DO have a name and more importantly I have feelings and thought processes. I cannot complain about the treatment that I am being given in a biomedical sense. I have been given the textbook treatment as far as a colitis patient goes. What is bothering me is that I need some recognition as a person. Any questions, comments and suggestions that I make seem to me, to be treated with some caution and on some occasions even contempt. I do not know whether it is me becoming more stressed and worried and therefore imagining things, but it seems my life is easier as far as my care goes, if I keep my opinions to myself. Strangely, my boyfriend can understand my point of view on this which reassures me that this phenomenon at least is not simply a figment of my imagination. The hospital environment seems so far removed from what I am accustomed to and I feel that I am only viewed as an 'illness'. The rest of my personality is no longer important. I do not know how much my 'well-being' in terms of emotional and social factors affects my physical well-being, but I have a feeling that if I were to be more comfortable as a complete person it may have a positive impact upon my overall health.

Having talked at length to my boyfriend and my parents, I feel more positive about the upcoming infusion. After all, something has to work at some point and it is certainly worth trying this drug in preference to leaping straight into

surgery. I feel slightly nervous about the possible side effects, but I have hope that it may start working very quickly. The drip is attached to my arm, and now I must sit on my bed having my blood pressure, pulse and oxygen levels monitored closely in case of any adverse reaction. The infusion takes two hours and goes well. I have had no side effects. My consultant explains to me that the other treatment I have been receiving intravenously may as well be stopped now as it has had no effect. To this end, the consultant tells me that I should leave hospital tomorrow, discuss the situation with my family and prepare myself psychologically for surgery. In the meantime it is possible to wait for up to ten days to see if the infusion has had any effect.

Back at my parents' house it seems easiest to try and relax, to spend time with my family and try my best to ignore the fact that there is anything seriously wrong. Certainly, time away from any stressful situations and the opportunity to do absolutely nothing is appealing, and I can feel myself becoming more laid back about the whole situation. I have begun to feel better in myself, although the physical symptoms continue. As a whole I feel that my 'well-being' has improved. The time with my family seems to have flown past far too quickly and it feels that before I know what is happening the time has come to return to see the consultant. My parents have sat down with me and read through all the literature and information that I have been given about the likely operation. We have some concerns about the procedure that I need to raise with the consultant. The operation is likely to affect my future fertility and we are concerned about the impact of my having to wear a stoma bag for the next year until it is possible to remove the bag in a third operation. Although the operation will cure this chronic disease it seems that it leaves infinite problems in terms of

my overall well-being in terms of the psychological and emotional upheavals involved with self-image and the possibility of removing my ability to be able to have children in the future. My mum and dad have also voiced concerns about how radical the surgery seems, removing my entire large intestine when only a part of it is diseased. We just cannot understand why the surgeon cannot remove the diseased parts and leave the healthy parts. My mind is bubbling over with questions and concerns that I must face the consultant with and try to seek some clear answers to what seems an unclear problem.

I walk into my appointment already knowing what the consultant is going to say: that the only real solution is surgery. I am correct. I am told without emotion, and it seems without any thought for the way that I may feel, that my pre-surgery appointment with the surgeon will be booked for me and that I can expect to have the surgery within two to three weeks. I am told that if only the diseased parts of my large intestine are removed then it would only be a matter of time before the healthy parts developed the disease and I would then have to have them removed too. It is therefore regarded as a better plan to have the whole large intestine surgically removed. As far as affecting my fertility, I am told that this is a very real possibility, which usually occurs when the final operation takes place. It is suggested that if I would like children in the future I might like to keep the stoma bag until I have had them, and have the final operation after this. Although I was expecting much of this information I feel slightly shocked and that the operation will entail me losing more than an intestine; but also my fertility, my pride, my dignity. As I walk out of the appointment and into the car park outside a feel tears streaming down my face whilst my boyfriend looks helplessly on, unable to offer any helpful advice or

reassurance that everything will be okay; we both know that everything is far from okay.

Five days later and it is evening. I have noticed this evening that my stomach is not as sore and that I have been running to the bathroom a few times less today than usual. I am hesitant to say anything to my family just in case I am imagining things and that I just want to be better so much that I am noticing something that is not actually there. I decide to sleep on it.

After a night's sleep today I still feel slightly better. Not well, but definitely something has changed. I have an appetite today and I have not needed my painkillers. The pain is there still, but I don't take morphine unless I absolutely have to as it tends to make me sleep through much of the day. As evening draws in I comment to my boyfriend that something has changed. I am surprised when he tells me that he knows: that he has noticed that I have not needed the bathroom as much and that he can see in my eyes that I am not suffering as severely from pain. My eyes always seem to be a giveaway; when I am tired it shows, when I am in pain it shows and when I am relaxed it shows. For the first evening in quite a few weeks I can bear to cuddle up on the sofa and watch a film without squirming in pain. Just this simple luxury of doing something 'normal' feels good and teaches me how much I took for granted before I became so ill.

Another night's sleep and today I wake up with some energy and feel more comfortable. I call my parents and tell them that at last things seem to be improving. The only answer any of us can come up with is that the infusion has

worked, albeit slowly, but nevertheless on the maximum time it is said it is possible to work by the manufacturers of the drug. I see the consultant this afternoon. He seems surprised by my news and even makes me start to doubt that I am witnessing a recovery. He puts more doubts into my mind and I feel my stress and worry level rising. He agrees that the infusion may have at last had an effect but questions whether I can be classed as going into remission again and is still speaking about surgery. It is agreed that I will return to have a colonoscopy (whereby I am sedated and a tube is inserted with a camera along the length of my large intestine) as soon as possible in the next few days. My heart sinks. I intensely dislike having a colonoscopy. It involves a series on enemas to empty the gut which causes severe cramping and pain, followed by having a needle inserted into my hand to give me sedation by which time the procedure can be carried out. I always feel that it is not a very dignified procedure, and lying on my side and bearing my bottom to the world, as a twenty-nine year old woman, is not top on my list of things to do before I am thirty!

The colonoscopy complete, I am telephoned and asked to drive up to the hospital to see my consultant. My boyfriend comes home from work and drives up to the hospital with me. I now know that nobody can argue with the fact that I am feeling better: things have improved remarkably in the last couple of weeks. The question is whether the biopsies and pictures of my insides confirm this observation. Whatever the case, I am now unwilling to even contemplate having surgery, however much I am told that it will ‘cure’ me so that I can never be struck down with another flare up. I would rather take the chance and enjoy this new healthy feeling for as long as it lasts. The consultant greets me with a

smile today, and almost before I manage to sit down he is telling me that it is ‘amazing’ and that he ‘can’t believe it’. My results have shown that the inflammation and bleeding seen on my last colonoscopy has gone. Even the biopsies that have been examined under a microscope show minimal signs of inflammation. It would seem that I am ‘better’. I still have to take a cocktail of very powerful medications including immuno-suppressants and steroids in order to keep me this way. These treatments leave me feeling exhausted and drained much of the time and in that sense I suppose I will not feel ‘well’ as most people would term it. But to me, in comparison with what I have been feeling I feel brilliant.

4.3 Further Reflections

The above events occurred just over ten years after my initial diagnosis. I was diagnosed with piles at first. My general practitioner simply seemed unable or did not want to diagnose me with anything else. I returned to the doctor multiple times, losing blood, suffering from terrible diarrhoea and extreme tummy pains. I felt frustrated that I was told repeatedly that I had a condition which I knew I did not have. I became more and more unwell until my parents insisted to the general practitioner that I should be seen by a specialist. This was initially greeted with a comment that ‘nobody needs to see a consultant with minor piles’. I felt degraded and embarrassed. However, my parents pushed the issue, and the general practitioner reluctantly referred me to a gastroenterologist.

Within fifteen minutes of seeing the gastroenterologist, I had been diagnosed with ulcerative colitis. I was put onto high dose steroids, and shortly after I commenced immuno-suppressant treatment. I was admitted, over the following

years, on several occasions to hospital when disease flares became unmanageable. When this happened, I would be going to the bathroom continuously all day and throughout the night, I suffered from severe bleeding, tiredness, aching joints, stomach pains and such severe mouth ulcers that sometimes I felt unable to even eat.

My problems with the initial diagnosis were mainly that of uncertainty. I knew that my GP was wrong in what he was saying; even at that point, when I had very little, if any, knowledge of IBD. My condition was allowed to deteriorate so much over a lengthy period of time before the diagnosis was made and by the time I saw the consultant and was given a proper diagnosis, I was malnourished and unable to live the life that I had always lived. It had completely changed my life and nobody in the health profession had listened to what I had been describing. This led to an overall distrust of health professionals. I felt that whatever I said I was constantly being challenged or questioned. I felt that perhaps they thought I was making it all up when I went into flare. Certainly I never felt very human and was not, in the early years after diagnosis, treated as an individual. In those earlier years I was never given choices around my treatment or asked for opinions. I sometimes tried to give opinions, but was very quickly silenced. I had no support around the health issues other than the consultant. There was no multi-disciplinary team and even though at that time I was severely underweight, I was not referred to a dietician or a nutritionist. There was no helpline for me to call. If I had a problem with my medication or a flare of my condition, I was required to call my consultants secretary (whom even the consultant admitted was a difficult woman to speak to!) and try and get an appointment at the earliest opportunity.

A lot has changed. I look back and view that time and see it as the very worst time I have suffered with IBD. It has been very problematic since then and I have needed hospital treatment, even recently. But I have gained more power over my own treatment and my understanding has hugely increased. I have massively gained in confidence and my family network around me is even more supportive and stable. However, very recently, my diagnosis has been questioned again. Regularly over the years, my IBD has been renamed from Crohn's disease to ulcerative colitis to proctitis and then back to Crohn's disease. This means that my life has become a little more uncertain again as there is adjustment and education surrounding this. Surrounding these recent changes I have been to see a new consultant. I became weary of the constant changes in diagnosis and the constant changes in the suggested treatment of my disease. The whole thing became very wearing and I became very despondent about it.

My new consultant has lots of ideas and listened to me with regard to my reluctance to take any more steroids due to what I see as unacceptable side effects. I have put on a lot of weight whilst taking steroids and this bothers me, especially as I have taken up cycling and whilst on the steroids and struggle to lose weight even when exercising. The consultant has assured me that I will not be asked to take steroids again in any but the most serious circumstances and that in preference to steroids I will be eligible to receive anti-TNF/biological treatment should there be another bad flare of my IBD. As previously discussed this also comes with risks with regard to the possibility of picking up infections,

but it is a highly effective treatment in many people and one which I am keen to try should I need to.

I have found it hard to find a consultant with whom I will agree with totally regarding my treatment plans. But it does seem to be a matter of compromise and mutual respect and understanding. I am fortunate that I have the knowledge and ability to put my views across to the health professionals and that I do have a say in what treatment I am given. However, it has been harder for me to accept advice and treatment which I am unsure about. I have learned over time that sometimes I have to go through certain procedures and treatments, whether I like it or not, with an overall goal of improving my health.

My family network has changed significantly. I did not remain with the boyfriend mentioned earlier. He became very difficult to be around, according to him partly because of the stress of me being ill a lot of the time. His reactions to me became very upsetting, causing me a lot of stress (which in turn makes disease activity worse) and we went our separate ways. I met someone else. Noel and I met only a matter of weeks after the terrible inpatient stay discussed above and has always known me with IBD. He has always been understanding and supportive and he has never known anything different about me with regard to my physical health. We married a year after meeting, and just five years later, we have two young children, each conceived with no medical assistance.

Because of the chances of my having to have surgery at some point which would affect fertility, we made our decision to have children quite quickly and with little gap between them. In this way my IBD has dictated what we do. But

we are pleased that we have had the time to take the opportunity and that my health has allowed it before what seems like inevitable surgery.

4.4 My Own Experience with Reference to the Research Focus

The following questions are the questions I posed to the research participants by email. I have attempted to answer these questions myself using my experience of having IBD.

Your diagnosis (e.g., the process of diagnosis, the ease of diagnosis, your feelings about the diagnosis):

My diagnosis was not straightforward. I suffered from symptoms for a considerable amount of time before the correct diagnosis was made. I was diagnosed with what seemed like every minor gastrointestinal ailment possible including piles and gastroenteritis. My General Practitioner seemed almost irritated by my continued reappearances at the surgery with continuing symptoms. After a significant amount of pressure from my family I was referred to a specialist who diagnosed IBD. By the time I saw the specialist I was very concerned that I was going to be diagnosed with something dreadful. I knew that my GP was incorrect and it left me with the question of what on earth could be wrong with me if all the more minor ailments had been eliminated. My feelings of the diagnosis were absolute relief. I felt that at last someone was taking me and my symptoms seriously. I could not believe that it took the consultant approximately 10 minutes to make a diagnosis of IBD after all the time I had spent seeing my GP.

To confirm the diagnosis I had to have a colonoscopy and numerous blood tests. These were not a fun experience by any stretch of the imagination, but the thought that I would know with some accuracy what was wrong with me after they were completed meant that they were worth the short term embarrassment and pain. Shortly after the diagnosis and the subsequent colonoscopy, all the biopsies and blood tests confirmed the results. Again, I felt relief. But I also became angry and frustrated shortly after the official diagnosis that it was not diagnosed much sooner and that I had had to suffer needlessly for a prolonged amount of time. The worst bit was knowing that I had told the GP time and time again that it was something else and he made me feel like I was a liar or that I didn't know what I was talking about. It took a relatively long period of time for me to stop caring so much about this. In that time I refused to see my GP unless I was seriously unwell. Perhaps in retrospect this was somewhat unwise as when flares of IBD are caught early they do not have an opportunity to progress into something more serious.

How does IBD impact upon your everyday life?

This depends on the state of my disease at the time. At all times, whether I am in flare or not, I have an awareness that I should be slightly careful in terms of how far I am from a loo. I also get bad days, even when I am not in flare, whereby I suffer from a lot of pain and the symptoms of a flare appear. Sometimes these symptoms have gone again by the next day, and other times it is a warning sign of things to come. This means that I have to be on my guard with relation to symptoms. I do still do normal things. I enjoy going out walking and cycling. Sometimes tiredness stops me from doing this, and tiredness is one of my biggest symptoms both when I am well (not in flare) and when I am

unwell. I enjoy spending time with my young children and the rest of my family and do everything that would be expected of someone my age. Due to the vast amount of steroids I have needed in recent years I have put on a lot of weight, and I am always conscious of this. I am trying to lose weight now and I feel that my confidence will go up as this happens. I like clothes and fashion, but because of my body shape and my awareness of it I feel that I have become very unfashionable in terms of the clothes I wear.

I also find that people do not always understand when I do not want to go out and take part in social activities. I find that I have lost touch with some friendship groups because of this. There are only so many times that people will ask you to join in with them before they stop asking. I am not sure that they always realise that it is not because I do not want to, but it is because I am unable to. When this happens I feel torn. I do not want to make people feel sorry for me by telling them but at the same time I do not want them to think that I am rude or antisocial.

When I am in flare, IBD has an effect on almost everything I do and I have to work my life around the symptoms and the treatments that I am on. The medications make me feel worse quite often, and it is as much as I can do to look after the children and function. The medication I take makes me suffer from frequent sickness. The pain killers which I take make me very drowsy. The steroids make me tired. This is on top of the frequent trips to the bathroom and the symptoms of the disease itself.

Everything else that is important to me is lost at these times. I cannot do the things I enjoy very much and it is therefore a miserable time for me. In turn, it is probably not much fun for my family either, as they lose the wife and mother that they know. However, with new long term treatment recently given to me, it is hoped that I will be able to go into and remain in remission. There is no certainty or guarantees about what will happen from day to day or week to week. But taking a day at a time seems important and not planning around my IBD in advance.

Do you consider yourself healthy? What factors contribute to your feelings of well-being?

I have not considered myself healthy for a while now. I have had quite a few flares, and my treatment has been hard going. In terms of symptoms right now, they are much improved. Once I have more energy and have lost more weight I will certainly consider myself much healthier. I am however much healthier than a few months ago in my mind: because now I am able to go out and do things I enjoy. I can go out walking with the family, play games in the garden with the children and am starting to cycle again. These are all things that make me feel more alive and healthy. My well-being increases hugely with the activities that I take part in and the ability to do things I enjoy. It is not all physical / physiological. It is also a state of mind in my opinion.

***What involvement with your medical treatment do you have? (e.g., with what medications you take and also when you take them, your access to doctors and specialists*)**:

In recent years, I have had a lot of control over my treatment. Quite simply, if I do not want to take a medication, I will not take it. I talk to the doctors about my reasoning and my concerns and although my consultant has not always agreed we have usually reached a compromise. Recently I felt that my consultant was no longer listening to me and was becoming quite difficult for me to deal with. I felt that he had become a little stuck in his ways and was not moving forward with treatment options. I have therefore, in the last couple of months, started seeing a new consultant. She seems to be more forward thinking and is very supportive of my objection to taking any further steroids, because of the weight I put on. So far she seems 'open minded' and is also treating me through dietary adjustments. Nobody has ever done this with me before, and it is like a breath of fresh air. I would much rather alter my diet and reduce harmful medications wherever possible. She is open to the idea of utilising anti-TNF therapy instead of steroids when I next have a flare. Although these drugs do not come without their problems, I am more willing to use these medications that to take more steroids.

My access to consultants has always been relatively straightforward. I have private healthcare, and I simply need to speak with the consultant's secretary when I need to make an appointment. I do not know whether this would be very different through the NHS. However, despite my easy access to a consultant, there are other issues surrounding the private healthcare. Firstly it is expensive, and it is an expense that we find hard to cope with. Secondly, the NHS provides

a whole team of gastroenterology staff. This includes hotlines and IBD specialist nurses who can provide advice and prescribe at any time should you have an urgent problem. Because I have been seeing my consultants privately, I have not had access to this resource. When my consultant is away or on holiday, I have no medical support system in place at all. There is nowhere for me to access help other than to go to the local accident and emergency department. This is clearly not ideal and is something that has occurred a couple of times now. I do wish that the consultants would at least put a NHS lifeline in place, such as the contact details for the helpline and the specialist nurse for when situation like this arise. It would be easier on me and it would be a more appropriate use of healthcare resources compared with my admission through accident and emergency departments.

How would you describe your relationships with health professionals? How significant is our own knowledge and experience in medical decision making? How much do you feel in control of your IBD and the treatment of it?

My relationships with health professionals are usually fairly good, although I think there is a certain amount of frustration both on my behalf and that of my consultant, because I hold fairly strong opinions regarding my treatment. However, I think that my own knowledge and experience is absolutely vital in my treatment and disease management. I am the only person who has to put up with side effects of treatment and the disease itself. I know what is or is what is not acceptable to me in terms of side effects, and how much they will limit or restrict my everyday life. The times that my relationship with health professionals has been poor have, in recent years, generally been when I am

unwell and I feel that I am not being listened to sufficiently. I am not afraid of giving an opinion and taking a role in the decision making process, and it is important to me that I am happy with the decisions that are made. If I am not happy, then it is less likely that I will take the recommended treatment and in turn my IBD will not improve. Therefore, I tend to try and avoid any health professional who is not willing to listen or to take account of the lay perspective.

Are there any people – other than health professionals – who provide considerable support and/or care for you? If so, who are these people and what do they do to help you?

My family are the people who offer support. These are: my parents and my husband. They are the people I can talk to the most about my feelings. My parents do not directly support me in a physical way, but they do help me with the children when I am feeling unwell. This may be in terms of babysitting or picking the older child up from nursery. My parents are very 'down to earth' and grounded, and this is helpful at a time of illness where my emotions can be running high. I rely on them to keep calm and the advice and support they offer me is always in my best interests. Sometimes that is difficult to remember when I do not necessarily agree with what is being said, but my family are the only people whom I know will be giving me the best possible advice which is relevant and appropriate to me, as a person.

I feel able to talk to my husband about how I am feeling and he, around a busy working schedule, supports me in whatever way he can. It is often as simple as getting the children quickly off to bed in the evening, or helping to prepare dinner. He also attends hospital appointments with me when I want him to and

he talks through different treatment options with me. This has been particularly helpful. When new treatments are being discussed and there are potentially serious side effects it is useful to be able to talk about the best way forward. Sometimes I have to make decisions about two different treatments both of which have problematic side effects associated and it is good to work through the pros and cons with someone who has my very best interests at heart.

In terms of the physical aspects, there is very little anyone can do to make me better. To me, it is good enough to know that there are people around me who care and are willing to do anything to make my life a little bit easier when I am in flare. When I have been very unwell in hospital my husband has helped in a physical sense with baths and helping me dress whilst avoiding pulling out any drips for example. He is a very patient person and tends not to judge people. This means that I do not feel awkward talking about my feelings or letting him see me whilst I am vulnerable. In this sense I am very fortunate. We have an extremely close relationship. I think that perhaps the fact he has seen me so unwell and has been able to offer me love and support at these times has made us even closer than we would have been. It has meant our understanding and compassion towards each other has increased.

I do not tend to talk to friends about my IBD. I am not really embarrassed about it, but I do feel that when I have discussed it in the past there have been embarrassed silences whereby people are trying to think about what on earth they are going to say to me! I do not expect support from friends and therefore I do not really discuss it. If I did, I feel that the only outcome would be that they would feel bad that I was feeling bad and they could not help. The downside of

this is that they may say inappropriate things or laugh at me when I keep running to the bathroom when I am feeling unwell. I cannot blame them, as they cannot know if I do not tell them. There have been certain friends who have asked me out to social events so many times when I have not been able to attend because of my symptoms that they have simply stopped asking me and I do not hear very much from them anymore. In a couple of cases they were aware of the reasons why. I do not dwell too much on this, although it is unfortunate that it has happened.

4.5 Discussion

The reflexive account provided above (section 4.2) recounts my time spent in hospital with a flare up of ulcerative colitis. Having been in remission for a lengthy period of time I suddenly became very ill and was admitted to hospital very quickly for a prolonged inpatient stay. During my years of remission I had been mainly off all medication and had been relatively fit and healthy. I sometimes had 'bad' days whereby I would suffer from severe stomach problems and go through several weeks of extreme tiredness, both of which are related to the chronic illness. Since the episode in hospital which I have described, I have again suffered from flares of my IBD which have led to me being hospitalised and/or being put on powerful and toxic medication which have had serious side effects and problems for me.

Here, I attempt to analyse my own experience as part of my auto/biographical approach. As previously argued, self reflexivity in research is vital (Gouldner, 1962) and the personal views, experiences and preferences of the researcher should be discussed openly. More recently, Finlay (2002: 212) argues:

> When it comes to practice, the process of engaging in reflexivity is perilous, full of muddy ambiguity and multiple trails. To what extent should researchers give a methodological account of their experience? How much personal detail can be disclosed and what forms can it take? How are researchers to represent a multiplicity of voices while not hiding themselves? In some ways, embarking on reflexivity is akin to entering uncertain terrain where solid ground can all too easily give way to swamp and mire. The challenge is to negotiate a path through this complicated landscape – one that exposes the traveller to interesting discoveries while ensuring a route out the other side. Researchers have to negotiate the 'swamp' of interminable self analysis and self disclosure. On their journey, they can all too easily fall into the mire of the infinite regress of excessive self analysis and deconstructions at the expense of focusing on the research participants and developing understanding.

Therefore, through this chapter, I have attempt to link my account to accepted views regarding chronic illness, but I also aim to enable the reader to understand the research position from which I come from before reading my analysis of participant interviews. I do not include large amounts of self disclosure whilst discussing the participant responses in the analysis chapters, and my analysis focuses on furthering understanding of the responses and the participants themselves. Therefore it is useful to describe my own interest and involvement separately.

Immediately it can be seen that the flares of ulcerative colitis that I have suffered from have led to many burdens physically, socially and emotionally. This tallies with the work by Bury (1982: 169) who recognises the long-term and disruptive impact of chronic illness upon the sufferer. Certainly, as far as disruption goes, I was hospitalised, handling a medical crisis, acting to control my disease and dealing with the impact of this upon my social and work situation (Gerson, 1976: 802).

I have been given a great deal of medical information, all based around the scientific results of tests and treatments. In some ways I certainly could be called an 'expert patient' because I make sure that I am up-to-date with the latest treatment news and because I always ask the health professionals to tell me every piece of information about my health that is possible. My hope is that through having all the information I will be able to make informed decisions myself about my own treatment and not simply be 'told what to do' by the medics running my care. The idea of an expert patient taking on the above roles is described by Greenhalgh (2009: 629), in her discussion of chronic illness and the expert patient who says:

> Practitioners have been encouraged to eschew paternalistic management and instead to involve people in their own care.... Self management is seen as the foundation for a pyramid of care that has low cost, lay led interventions at the bottom and increasingly specialist care towards the top.... Self management training leads to significantly improved disease outcomes.

However, there seems to have been a negative side to this. Whilst I was given all the medical/scientific information I could wish for, it was given at the expense of not realising I was a human being with emotions that were running high. I had needs other than simply the scientific evidence and treatment being given to me. Weatherall (1994: 1671) reports the way in which individuals suffering from chronic disease may need more than simply treating:

> Above all else, those with distressing chronic or terminal illnesses need continuity of care – that is, the attention and friendship of one doctor whom they can come to trust, and with whom they can share their hopes and fears. Yet this kind of relationship is all too rarely available to them.

I did not want the stoma that was being offered to me and had begun to feel like a 'patient' rather than an individual person with complex needs. This partly coincides with Suchman (1965: 2) who talked about patients having a primary goal or retaining and/or returning to a normal functioning in social terms. I did not see that having a stoma would be acceptable both in terms of embarrassment and what I regarded as 'normal'. As Locker (2000: 87) commented I found the medical gaze to be a '...narrow one, concerned predominately with disease to the exclusion of its social and emotional consequences'.

As a 'patient', clearly it pleases me that the medical profession were doing all they could do to medically treat me and, as I commented in the above account, I could not complain about the actual treatment. However, the way in which I was treated as a 'medical case' simply to be treated raised concerns and I felt that in many ways I lost identity as a person.

As a person with a chronic disease, over time I have adapted and learned to live with the symptoms. I do not consider myself to be suffering from ill health whilst in remission, even though I frequently experience symptoms that probably to the average person with average health would be unacceptable. Somehow, this just seems a part of me and a part of my life. I value all aspects of my life and they all contribute to my sense of well-being. This fits with the views proposed by Beaton *et al* (2001) who believes that people suffering from chronic illness may redefine life values and norms within the context of their illness. It can therefore be argued that I do have an altered perception of what well-being is and that what I consider to be 'well' is most unlikely be what

another individual would consider to be ‘well’. During my admission to hospital these redefined life values and norms were being pulled apart. I was in a position whereby I had to accept and deal with symptoms, treatment and the depersonalisation that seem to go hand-in-hand with an inpatient hospital/medical environment.

I tried my best to become involved in my own care, wanting to know what was happening and why things were happening. In this way I was contributing to what I hoped would be a reciprocal relationship with the medical professionals (Suchman 1965: 15). More recently, Borg and Kristiansen (2004: 503) promote the use of a reciprocal relationship with health professionals proposing ‘a reciprocal relationship between helper and service user will involve a view of the affected person as capable and resourceful’. I hoped that the doctors would place emphasis upon me, as a person and a whole unit, in a more personalised way. However, this did not occur and it seemed at least that the pressure of dealing with anything that was not grounded in science, such as emotional, psychological, spiritual and social had to be taken on by myself and those who were close to me. This led to feelings of decreased well-being and indicated the importance of multiple factors in leading to a sense of well-being. This sense of loss of well-being due to other factors is mentioned by Haslam *et al* (2009: 18) who says:

> ...social identities and the sense of psychological community associated with them – constitute much of what we live for and of what we live by. Indeed, it is for this reason that they are such a fundamental part of our lives and so central to our well-being.

The description given by Hahn (1985: 89) of the experience of Sacks (1984: 46) seems apt whereby Sacks is keen to meet his surgeon and is disappointed by the clear, terse, cold words of the consultant who is deaf to his pleas and comments. He is told of his treatment in a very matter of fact way as a run-of-the-mill treatment by his surgeon. What seems to be similar in both cases is the lack of acknowledgement by the medical professionals that it was a life changing event that was occurring. A combination of fear and loss attributed to the situation by myself existed. I was frightened of what was happening to my body and the seeming lack of control that I was able to exercise over the situation. Surgery appeared to be a big and frightening monster looming around the corner and seemed to be approaching at an alarming pace. To the medical professionals this was all viewed as quite routine and 'normal' and something simply to get on with. As a patient I was not keen to meet this 'monster'. To me, a person who was used to living with a chronic illness, I had been placed into an environment that was both unnatural to me and turned a chronic illness that I was used to into something that I did not have the personal capabilities to deal with.

Harris (1989: 3-4) says:

> ...the social arenas in which medical treatment is given – hospitals, clinics, and so on – have their own distinctive rules, roles, customs, and organizational forms. When people enter these arenas to receive care, they are expected to shed the roles and symbols appropriate to other contexts and to become patients willing to accept the scientific explanations offered by medical personnel.

More recently, Halfmann (2012) has discussed the concept of entering these arenas to obtain health care and linked it with the concept of mediatisation.

This, he observes, is connected to medical imperialism, capitalism, patriarchy and social control. This can be linked to the previous idea of patients having to drop their usual roles in order to enter this system.

This statement proved to hold truth in so many ways. I have some medical knowledge, and as a person with an inquisitive mind I read around my illness and find whatever information is possible. However, I am not a medical professional and the purely scientific explanations offered seemed cold, distant, and worst of all, uncaring. This in turn lowered my feelings of hope, happiness, comfort and relaxation resulting in a high level of stress. This stress, as mentioned in the literature review, could result in making the already existing illness worse.

I can link my perceptions of my experiences with IBD with the five components that Petrie and Weinman (2006: 536-37) articulate:

> **'Identity of illness'**: I saw physical symptoms that I attributed to my illness, ulcerative colitis. This included pain, diarrhoea, sickness, bleeding and frequent trips to the bathroom. In this particular case, I was never told by the medical professionals that my symptoms were not related to the disease. However, there was some confusion at one point regarding my extreme fatigue. Ulcerative colitis causes tiredness but it is also a recognised side effect of the morphine that I was regularly being given. In that sense, both the disease and the treatment were causing an unwanted effect.

‘Causal beliefs’: It is difficult as a patient, to suggest the reason why I developed ulcerative colitis. I do not believe that there was anything that I ‘did’ that caused the disease. Although the reasons are unclear on why any one person should develop the disease, factors such as immune system deficiencies, infection and genetics have been questioned. There has been some question in the past of the MMR vaccine, given in infancy, playing a role in the development of IBD. Certainly, I enjoy dairy products (which are rumoured to have a negative effect on existing disease), but I have never noticed a specific and timely detrimental effect from their consumption. This perception of ‘causal beliefs’, certainly in this case, is one that is very confused and although often thought about, a perception that is unlikely to become very clear until more is known about the disease. Clearly this patient perception is likely to play a different role in different diseases where more is known about the aetiology of the disease.

‘Timeline beliefs’: I regard IBD as a chronic disease, one that lasts through time even though it has periods of remission and periods of flare-up. It was demonstrated that patients under this illness perception with a chronic perception of illness were more likely to adhere to their medical treatment. I always make sure that I take my medication as I look at it with the long-term in mind to avoid situations such as the recounted hospital situation. I do not aim to become seriously ill and put myself in a position whereby I have very little control over the situation. Medication is the answer and enables me to live life more easily with a chronic disease.

‘Control or cure of illness’: The control I normally exercise over IBD is good and I generally only experience symptoms that I am able to deal with myself. Flare of my disease does occur though. My personal account shows what can happen when this control is lost. It is typical of a chronic disease – control can vary and although it is sometimes very good, it can also descend into the uncontrollable, even by the medical profession. My account highlights the way in which even medical treatment can fail, and drastic measures such as surgery are considered. The feeling as a patient that not only you, but also the medical profession, are unable to control the disease is not a comfortable one. The problem encountered by myself and reflected in the above account was that I finally put myself in the hands of the professionals because I was unable to make myself better using the usual medications and techniques. I lost my individuality and rights to being a ‘whole’ person in the hospital environment and was treated as a ‘medical entity’. But this treatment did not work and even though I had submitted to being a ‘patient’, and the sacrifice on my behalf had made no difference.

‘Consequences’: The consequences of the stay in hospital shown in my account were large. It had an impact upon my work, deadlines, social life and position and the lifestyle that I had become accustomed to. When I became ‘better’ or in remission again, I had to make many adaptations in order to be able to live comfortably. My level of activity had to be significantly reduced, and many of the activities that I carried out before I became ill with a flare-up could not continue afterwards. In

turn this meant that socially I did not see and communicate as much with friends and acquaintances. Although this is a subjective view, I argue that there were and still are, many consequences of the flare-up of IBD.

With regard to support and stigma, I tend to depend on my closest family members if I require any additional support. I am not afraid of other people outside of my family knowing about my condition, but I do feel that it might cause them embarrassment or make them feel uncomfortable. This is mainly from experience as opposed to how I fear people will react. I am unsure whether this reaction is because people are embarrassed by the disease itself or whether it is frustration and discomfort because they are unable to really help or change the situation for me.

4.6 Chapter Summary

In this chapter I have discussed my experience with and my subsequence learned knowledge of IBD. I have included an account of part of my journey with IBD at a time when I was very unwell and requiring a lot of medical intervention. Following this personal account is a discussion of what the events meant to me and how things have moved on since that time. I then attempted to answer the questions I have posed to the research participants in my own words, from my own experiences.

I then briefly discussed my personal and I attempted to be self-reflexive in order to allow the reader to better understand my research position (Finlay 2002). I discussed my perceptions of health and well-being and acknowledged that with regard to my own beliefs it is multifaceted and includes the physical, social and

emotional and involves a degree of biographical disruption (Bury 1982). This can be linked with research by Williams (2000: 58) who discusses emotions in chronic disease, arguing:

> ...if emotion management and the 'psy complex' constitute one particular strand of biographical revision, if not disruption, in late modernity, then our current obsessive preoccupation with health promotion, screening and surveillance, constitutes another. Again the upshot of these processes suggests that our bodies, like our emotional selves, can rarely if ever be taken for granted.

Through interrogation of my own history I have attempted to carry out the research with openness about my IBD, including the physical and emotional consequences of the diagnosis and experience.

CHAPTER 5: The Data

5.1 Introduction

In this chapter, in line with my auto/biographical approach, I present, in the main data from participants and on occasion draw on my own story. The chapter is divided into three main sections. These are – *Living with IBD*, *Becoming and Being a Patient* and *Coping and Control*. Living with IBD includes the discussion by participants of their health and well-being, living with chronic illness, and the identity and biographical disruption it may cause. Becoming and being a patient involves discussion around the experience of being a patient such as the concept of the expert patient and relationships. Coping and control includes further discussion of identity / self and the ways in which a sense of control may be maintained through the narratives.

5.2 Living with IBD

5.2.1 Health and Well-being

Danna and Griffin (1999: 361) propose, that the ways in which health and well-being are measured and defined vary, and they argue that there are likely to be two different concepts. The first suggests that health and well-being can be related to the actual physical health of individuals, as defined by the physiological / medical symptoms and by the statistical rates of physical illnesses, symptoms and diseases. The second relates to the idea that the terms health and well-being can refer to any of the mental, psychological, or emotional traits of individuals as shown by emotional states and the rates of mental illnesses and diseases. Throughout, I refer to disease as the anatomical

/ physiological and illness as the term for the individual experience of a chronic condition.

The physical definition of health and well-being is evident in several participant accounts. For example, Tina writes:

> I do not consider myself healthy as I am anemic, due to blood loss, my joints hurt everyday. I suffer from debilitating headaches and am constantly tired no matter how much sleep I get.

And Jenny:

> I regularly regard myself as being 'broken' inside. I will often say that I have a digestive system that 'doesn't work'. I think because I know Crohn's will be with me forever that I think I will never think of myself again as 'healthy'. But saying that, my blood tests show that I am healthy at the moment, so clearly it's a state of mind.

Both Tina and Jenny link their health to biomedical factors; of how their body and its physiological state is or is not functioning. There is no mention of other factors that they may consider contribute toward health and well-being, indeed Jenny is self-critical of her own feelings.

Conversely Frances argues that her diagnosis has made her healthier:

> I have also used it as an excuse to get healthier – almost to compensate I suppose! I do more exercise and eat healthier than I ever did previously.

Mark also writes about physical activity and its relationship to health: 'Apart from crohns I am pretty healthy and cycle, golf and walk whenever I am able'.

Similarly Maggie writes ‘I consider myself to be reasonably healthy and lead a busy and active life’.

On the other hand, Graham writes: ‘Due to tiredness and fatigue I am in bed by 9pm most nights rarely managing to stay up to 10pm this has dramatically affected my social life which is virtually nonexistent’. Geoff, similarly writes:

> I did struggle still with trying to keep up with fellow students and as time went on I began to learn what my body was and wasn’t able to do with regards to endless opportunities for nights out!

Lauren, writes that she tries to do more ‘normal’ things but is held back due to fatigue, which in turn has a bearing on her health and well-being. She says ‘I feel well on the outside but it’s a burden, the Crohn’s is always there, like an unwanted passenger. I try to do normal things but fatigue plays a part. If I lose weight that makes me look unwell and that always bothers me’.

Kathy believes that she is healthy when not having a flare of IBD. Her beliefs regarding health and well-being seem to be based upon a combination of physiological and psychological symptoms. She writes:

> When I am in remission I just get on with life as normal and enjoy my family and my job and living in [place name]. But, when I have a flare up this all changes and I have to temper my life according to how I am feeling. I get very cross sometimes because the disease stops me from progressing through life. I have to stop and wait to feel better.

Abi’s account demonstrates how people may need to adapt or feel they need to adapt / experience pressure to adapt in order to live a full life and consider themselves healthy:

> Yes, consider myself healthy – lots of people out there worse off. I get very tired and now work three days a week instead of full time – my job can be hard but it was not necessarily only the illness that made me reduce my hours.

The need to adapt, for various reasons, is a common theme running through the data:

> Also as its quite a hidden disease people can't see the pain and misery you go through everyday. It leaves you exhausted, irritable, sore, run down, depressed, lack of energy or enthusiasm, drained and mentally and physically wiped (Sally).

> I have become much more protective of myself i.e. being quite militant about taking breaks. Until I can see enough improvement to enable me to get off the steroids without deteriorating symptoms I am not going to feel particularly positive or consider myself to be regaining health…. I do not feel healthy. The very nasty experiences I went through in hospital have made me extremely twitched. (Rachel).

Thus, individuals changed and adapted consciously in order to live a better life and to make their life easier. It is apparent from participants' accounts that these adaptations to life make life more manageable in terms of their disease, but also to make them appear 'well' and as other people might expect a 'healthy' person to look and/or behave. This is something I myself experience. For example, I ensure that I go to bed much earlier than I used to in order to get enough sleep and rest. I try to get more fresh air and to spend time outdoors more than I used to as I find this lifts my mood and my energy levels. These activities also allow me to see friends more and to have a more normal and active social life.

Lucie finds that being able to lead a normal life depends on the biomedical treatment available:

> I know and understand that there is no cure and they can only control it or hold it at bay but nothing has seemed to work as yet and now funding has been cut I don't see that us sufferers are going to receive the treatment that we need and require to be able to function properly and have a "normal" life.

The concept of 'normal' and the adaptations made by respondents mentioned above was described by Weiner (1975) who wrote of normalisation and the ways in which behaviour may be modified to maintain a normal life. This includes covering up the illness and attempting to keep up with the peer group.

The concept of health and well-being as referring to any combination of mental, psychological, or emotional traits of individuals is highlighted by various participants:

> I am healthy much of the time. I have a disease but my life isn't ruled by it. If I can do what I want and be happy then I am healthy. Factors – I don't really know. I suppose having everything I am used to like my family, friends, socialising, church, sport. They all make me feel alive and healthy (Michelle).

> I always describe myself as a well person who is occasionally ill, rather than an ill person who is occasionally well. Being positive about life and appreciating the good things like family, friends and your surroundings helps me get through the bad times (Kathy).

> In February 2010 I was signed off with depression and stayed off until December. The thought of going back to work always made me feel worse. And obviously the worry and anxiety can aggravate illnesses like Crohn's (Geoff).

> My mental health has improved greatly through not being at work because of not struggling to fight the constant fatigue and stress about

> worrying over having to take time off. A recent Crohn's flare up and infection have reminded me how debilitating the illness can be at its worse. At its best, for me, at least I can now make it through each day without feeling as though I no longer have any enjoyment in life (Geoff).

> I have 2 girls aged 10 and 13 (one of whom is severely physically disabled) means that I can't stop and feel sorry for myself about my IBD. I feel that a positive attitude helps in control of the disease (Mark).

Michelle's and Kathy's accounts demonstrate that a broad range of factors impact on their well-being, including family, friends, surroundings, socialising, church and sport. Geoff and Mark comment on the psychological factors which contribute to their health and well-being and mention mental health and a positive attitude.

The participants' accounts and their varying ideas show how complex understandings and experiences of well-being are, and how many factors contribute to what they consider to be their well-being. Many of them discuss their interests and the activities that they need to maintain in order to live a full and 'healthy' life. Participants' accounts contribute to and challenge some widely accepted definitions of health and well-being and demonstrate that individual and identity both in terms of self and in the social, contribute to well-being.

Participants write of ways in which they have changed their life, and redefined themselves and what they do as a result of having IBD. Kathy (see above) attempts to normalise her situation and has turned her illness into something positive rather than something to hold her back. Another example here is Abi, who writes 'Still horse ride. Very involved in horse sport as an organiser / judge. Get used to finding loos / bushes in emergencies'. Clearly to the general

population needing loos / bushes as a regular emergency would probably not be seen as normal. But for Abi such activity is necessary in order for her to carry on in a way that feels normal.

The idea of adapting, adjusting and coping to function in a new way of 'normal' is clearly important to the participants in my study and relevant to the way they self-identify and cope with IBD and its impact upon their lives.

5.2.2 Experiencing Stigma

Many participants write about the sharing of their health-related problems with other people. This includes those in their close and extended social circle. The data appear to raise two distinct strands to this reluctance to talk about their IBD. One of the issues lies with how individuals' perceive that people would react when talking about and discussing the disease, especially with its reference to bowels and what many people would class as personal and private body functions. The other strand lies with the way in which some of participants have been treated by others after sharing their story or after other people have seen them whilst they are acutely unwell and suffering from obvious symptoms.

Individuals who are not seen as 'normal' within society may be singled out and seen as different which is the foundation / basis of being stigmatised (Becker, 1963; Corrigan, 2000). This appears to be what several participants are worried about. They believe that bowels and toilet habits associated with their disease is a subject that they should not be talking about with others, and/or that other people would not, or do not, understand what they are going through. Thus,

participants try to keep within what they perceive to be the 'rules' to avoid 'outsider' status:

> I don't talk to other people about my ulcerative colitis. There aren't very many people who would like to meet for a coffee and talk about bowels! It's not really a pleasant thing to talk about and it would most likely put people off seeing me (Michelle).

> Other people I would not turn to for help or support with this. It isn't something that I would feel comfortable telling our friends about and really there is no need for them to know (Frances).

Additionally, Jenny is concerned to appear brave, stoical:

> Strangely enough I don't really talk to my friends about my Crohn's unless it comes up in conversation. I don't want to seem different to anybody and it's very important to me personally that I appear brave and able to cope with whatever life throws at me, no matter how weak I feel inside (Jenny).

Rachel speaks of her relationship with her husband and the affect her IBD has both on him and their relationship:

> …he tries very hard, but he does find my illness extremely difficult to cope with. He is a very, very squeamish and fastidious person where body fluids are concerned, although I would stop short of describing his attitude as being one of obsessive/compulsive. I am not sure how he would deal with my having major surgery with a stoma - my main reason for being desperate to avoid surgery for as long as possible. The very idea of him having to put up with a wife who has a stoma and one which will inevitably leak at times makes me quail to be honest. When I was in hospital he would not touch me for the first eight days because I spent most of the day on the commode or being incontinent and did not have the facility to wash my hands in accordance to his standards.

Rachel's account highlights not only her husband's reactions, but also how she modifies her behaviour and possible disease treatment options in order to maintain the status quo with him. She is concerned that her husband may judge

her negatively and that this would have an impact on their relationship. As discussed in Chapter 2, Goffman (1963: 3) gives a definition of stigma as an 'attribute that is deeply discrediting' and that reduces the stigmatised individual 'from a whole and usual person to a tainted, discounted one', which seems particularly pertinent here.

Tina writes that people regarded her both differently and wrongly as a sufferer of IBD:

> Unfortunately I have come to realise there are people who still think I am lazy, rude and just can't be bothered to come out and join in on social events.

Tina clearly feels judged by other people and feels that there is no understanding of the real issues she has to deal with. The stigma she, and other participants, felt resulted in a 'spoiled' identity, 'discreditable' and 'discredited' (Goffman 1963).

In order to avoid other people having these types of beliefs some participants simply avoid the topic with people in their social circle. For example, Sally writes:

> You don't so much live with IBD but more function. It is such an unpredictable disease you don't really know what to expect from it. It is antisocial and very hard to discuss with people that don't have it as they find it hard to understand….
>
> Relationships can be difficult because not everyone will understand the disease and be sympathetic.

Graham also writes of his isolation at feeling unable to talk to people because of possible misinterpretation or misunderstanding:

> ...having Crohns and/or UC can be a very lonely place. People at work dont really understand even though I have been open about it. Friends and family also dont really get it as they dont fully understand.

My own situation is very complex even to my health professionals. I often do not discuss it with those in my social circle because they simply would not understand. There are so many different strands and complexities I feel that it is likely that I would be misunderstood if I open up too much. A bit like Graham, my condition isn't a secret, but at the same time in an attempt to avoid confusion or being misunderstood, I often do make an effort to keep my problems to myself.

5.2.3 Feeling Fearful

Fear was expressed by participants in a variety of ways. This varied from fear during the process of diagnosis, to fear of what might follow a diagnosis of an incurable and long-term disease. Also mentioned was the fear of treatment and the beliefs held about different drugs and treatment options (with particular reference to when treatment decisions are not fully explained).

Several participants commented upon their fears prior to and around the time of diagnosis. There often appeared to be a fear of what the diagnosis might be and the word most often used in relation to what participants' feared the diagnosis to be was 'cancer':

> First thoughts were being glad that it wasn't cancer (Graham).

> When I finally was diagnosed I was so releaved that it wasn't cancer (Mark).

> My feelings regarding the diagnosis were at first shock and then relief that I had not got bowel cancer (Maggie).

> It was really due to concern about the potential for bowel cancer having had the bleeding a few months previously which made me pursue the need for diagnosis (Rachel).

> By the time I went to see the consultant, I was convinced that I was about to die from cancer. In some ways it was a relief when the consultant told me that he thought it was ulcerative colitis and at the second appointment when this was confirmed I felt a lot of stress drop away from me. At least this thing was less likely to kill me! (Michelle).

> I was worried (after all the messing about and suggestions thrown around by the other doctors) that it was something more serious. Because a couple of close relatives have had cancer it is always at the front of my mind (Frances).

Without a diagnosis, whilst suffering from painful and potentially frightening symptoms, it would perhaps only seem natural that a person might assume the worst.

Adamson (1997: 136) writes about clinical uncertainty surrounding the diagnosis of IBD, arguing:

> ...the disclosure or reminder of clinical uncertainty can exacerbate existential uncertainty, provoking anxiety, breakdown, or psychological denial which may, in turn, lead to non-compliance with medical instructions.

There were several examples of delayed diagnosis as follows:

> I first started having problems with urgent bowel movements around July 10. These at times were extremely urgent and frequent up to 4/5 times a morning. I went to the doctor in September and was booked for a Colonoscopy in the October. That's when the problem went away and thinking it was just a case of irritable bowel I foolishly cancelled the Colonoscopy. Ten days later the problems returned with a vengeance (Graham).

> I was diagnosed with Crohn's 12 years ago, after a six month period of sudden weight loss, pain and fatigue. I think it began 10 years earlier when i was pregnant, i was 9st pre pregnancy and 7 stone immediately after my daughter was born. I suffered with stomach aches and a change of bowel habits from her birth onwards but i put this down to IBS (Lauren).

> I had a pretty horrendous time before I was diagnosed, I was in and out of hospital with pain in my stomach which I can only describe as being in labour. I think over a period of a year I was in about 6 times. Every time I was allowed home without any diagnosis or any idea as to what was wrong. I was told it was anything from appendicitis to gastroenteritis to urine infections and then my favourite, I was attention seeking and it was all in my head (Sally).

> By 2000 I was suspicious that I might have developed either crohn's or colitis since my bowel function had been subtly changing over a number of years and my bowel function/ symptoms seemed to be increasingly mirroring those of a nursing colleague who had Crohn's and also patients we admitted for gastroenterology investigations. When I noticed small evidence of bleeding in May 2000 I realised that investigations were necessary (we have a strong history of bowel cancer in the family), but since I was getting married in the September and moving... I delayed this process until the October when I had registered with a new GP and had started my new job in intensive care nursing (from acute general/emergency/renal medicine) although at the time my bowel symptoms had settled down. It was really due to concern about the potential for bowel cancer having had the bleeding a few months previously which made me pursue the need for diagnosis (Rachel).

Alongside the feelings of fear of the unknown and delay in seeking medical attention, some participants also express their relief at having a diagnosis and having a tangible reason for feeling the way that they did with regard to their symptoms. Certainly, when I was diagnosed (after an extremely lengthy process

including misdiagnosis) it was almost a relief as it enabled me to seek appropriate treatment and to start the path to feeling better again.

Other participants talk of the fear of their disease and its presence after diagnosis:

> Sometimes I imagine my Crohn's to be like Cancer – something that maybe one day will just consume me completely with me being completely powerless in stopping it. That scares me beyond words can say (Jenny).

> My worst experience was being prescribed methotrexate and not being told it was a chemotherapy drug. I had to go to the chemotherapy ward to be shown how to inject and it was a shock when I arrived for my appointment. It was very upsetting and traumatic at the time (Lauren).

> I have found it hard at times knowing that you have a chronic disease and that there is no cure (Graham).

> I was glad to know what it was but very upset it was incurable (Lauren).

> I didn't know what was going to happen to me, was I going to be this sick for the rest of my life? (Jenny)

Delayed diagnosis leaves many participants experiencing differing emotions and further heightened levels of fear, particularly of the unknown and what 'might' be wrong with them. Examples include:

> ...diagnosed in 1993 with crohns (aged 24). Had never heard of it until then. It took ages to get diagnosed. When I finally was diagnosed I was so releaved that it wasn't cancer (Mark).

> I was diagnosed with Crohns disease in 1985. We were living in Kent and it took months for my diagnosis to be given. After many trips to A & E I was eventually admitted for tests and a local surgeon explained that he thought he knew what was wrong and would operate that same day. I

> was totally shocked and had never heard of Crohns or colitis. A friend told me about NACC but it was months before I would realise that it wasn't cured after my first re-section (Kathy).

Delays in diagnosis and in some cases incorrect diagnoses seem to be fairly common amongst participants. There seems to be a lack of procedure or urgency in the diagnosis of IBD. For example:

> I first went to my GP in December 2010 due to bleeding from my back passage. I was given some cream in case it was piles and told to come back if things didnt improve. I went back again after Christmas and was given some pessaries to try. Things didnt improve and I went back again in February. This time I was given a referral to see a member of the Gastroenterology Unit at [name of hospital].....The consultant I saw was not very helpful and after telling me he didn't know why I was there he went on to say that all that was wrong with me was probably a sensitive bowel and I should change my diet... I was assigned a different consultant who cautiously diagnosed Ulcerative Colitis (Tina).

> I was officially diagnosed with Crohn's disease in the December of 2002. It was a very long process. I had been going to my GP with abdominal problems, acid reflux in particular for about 9 months before hand before he referred me to a gastroenterologist for an endoscopy and biopsies. Luckily at this time I was covered under private health care so the procedures for this were carried out quickly and results came a week later (Jenny).

> I started experiencing painful bowel movements before/during and after, the pain was waking me up everyday at about 4/5 in the morning so in Nov 2008 I went to the G.P and they thought it was IBS so prescribed Buscopan which did nothing. I was still complaining in 2009 and was referred to Gastro April 2009... After further complaining about the pain that I was getting on the left hand side of my body near the abdominal area they decided to perform and endoscopy on October 2009 and I was told that I had inflammation in my stomach and upper bowel... I received a consultation a month or so later and was told that the inflammation was Crohn's (Lucie).

> Initial Drs appointment put the bleeding down to piles, following year was referred and saw a consultant privately (I have insurance via work) was diagnosed then very quickly with Colitis with a colonoscopy very soon afterwards to check the extent of the illness (Abi).

In other cases the delayed and inaccurate diagnoses also include the inference that the individual was making it up and thus was not to be believed:

> I was told it was anything from appendicitis to gastroenteritis to urine infections and then my favourite, I was attention seeking and it was all in my head! I changed GPs as my old one was useless and didn't think anything was wrong. I saw surgeons, and consultants and specialists but nothing was done... The years rolled on but there was always a question mark over my diagnosis... after a particularly nasty spell, I ended up... under a consultant called [name] and, for me, he was a godsend. He... finally gave me a diagnosis of acute crohns and irritable bowel (Sally).

Jenny, Sally, Lucie and Abi are all examples of individuals who were incorrectly diagnosed before eventually being given the correct diagnosis. Sally and Lucie in particular had to return many times to the doctor reporting severe symptoms. Sally appears to be an extreme example whereby she was given many different diagnoses from other physical disorders through to psychological problems.

> Diagnosis wasn't very easy. I had to go and see my GP many times before he eventually sent me to a consultant. He had insisted that it was piles and given me therefore all the wrong treatment. Meanwhile my symptoms got worse. By the time I went to see the consultant, I was convinced that I was about to die from cancer. In some ways it was a relief when the consultant told me that he thought it was ulcerative colitis and at the second appointment when this was confirmed I felt a lot of stress drop away from me (Michelle).

> Diagnosis was silly really... A lot of the doctors were suggesting a lot of things. Nobody seemed sure of anything. This was not easy on me or my relationship with my husband. When I get stressed everybody knows about it! Eventually I got myself (privately) a good consultant, who, within a week had me diagnosed with ulcerative colitis (Frances).

Michelle's and Frances' accounts highlight the stress that can be caused by slow diagnosis. This impacted on them as individuals and also on significant others.

So, delay in diagnosis and incorrect diagnoses given may lead to various problems. Many participants (as noted above) comment on the uncertainty and anxiety they experienced through incorrect and lengthy diagnosis.

All but two participants have suffered from delayed diagnosis and/or misdiagnosis. One of the two who did not is a highly qualified nurse. As noted above, delayed diagnosis may not help the symptoms of IBD, as stress and anxiety make the symptoms worse (Sajadinejad *et al*, 2012: 7). Carter *et al* (2004: v2) recognise that there is frequently a delay in diagnosis of IBD arguing 'delay in diagnosis is common and may be accompanied by dismissal of symptoms as due to stress'.

5.2.4 Working Life (paid) and IBD

Some participants seem to find it difficult to carry on as 'normal' in their working life whilst suffering from IBD. Several comment on their difficulties, and it seems that for some, the physical symptoms become too overwhelming and time consuming to be able to carry out a job or in some cases at least, a full time job. This is also something noted by Bury (1982: 176) who argues that in chronic illness '…one of the most difficult areas of maintaining normal relationships, and mobilising resources, especially among younger sufferers, is at work'.

As Graham writes:

> I had my own plumbing and heating business but due to the Crohns I had to pack it in and now work as a maintenance engineer in a hotel where I have the choice of approx. 140 lavatory's lol. Due to tiredness and

> fatigue I am in bed by 9pm most nights rarely managing to stay up to 10pm.

Geoff writes in detail of the effect that IBD had in both his education and in his subsequent working life:

> When I left school my qualifications were quite limited due to the amount of time I had missed at school due to illness. I also stayed on for a year to re-take some exams, which helped. However, because I had no idea what I wanted to do as a career and more importantly that I felt I was excluded from so many options in work because of my health I ended up taking a clerical job for [name of workplace]. I stayed there for about seven years, doing various roles including some accounts work and finally as a Survey Technician.

He continues:

> Even back then I struggled to cope with a full 37 hour week and would often be away for periods with health problems..... Eventually I decided to go from a 5 day week to a 4 day week, which helped for a while, but did not stop my absences which became more regular and longer. The pressure to not keep taking time off was very strong and obviously added to my stress and mental health. I then tried a 3 day week for a while but once again could not keep up and was just tired all the time. I was referred to Occupational Health several times but although supportive of my condition they could not offer a solution to my managers to improve my attendance.

Geoff's situation demonstrates the very negative ways in which chronic disease can play a major role in the ability to work and earn an income and the way in which chronic disease may dictate what career path is taken. Indeed, working life is one of many characteristics that form a person's identity, and the loss of work or inability to fully participate in working life may therefore affect and / or change an individual's identity. I can relate closely to this. I have a strong work ethic and have always wanted to be in full time employment. This is impossible due to my health situation and I do not have the choices available to me that I

might wish for. However, over time, I have learned to accept this alteration and disruption and to learn, and adapt to, what might be possible rather than focus on what is not possible.

Mark is another whose career path and opportunities have been severely affected by his suffering from IBD:

> IBD affects me every day. I have pain about 80% of days and fatigue about 50% of days. I was a bank manager but had to give up my position and take on a part time job as a cashier as stress and fatigue in full time work was too much.

Similarly, Abi writes: ‘I get very tired and now work three days a week instead of full time - my job can be hard but it was not necessarily only the illness that made me reduce my hours’. Abi does not make it clear what other factors made her reduce her hours at work, but it is clear from her writing that she leads a very busy life and that she also has other priorities, such as fund raising for the NACC.

Emma has suffered negative consequences at work due to her IBD and also because of surgery related to her IBD:

> I was stable for a year my crohn's under control. I soon after went back into hospital for a further seven weeks again with a flare up and another issue a peri-anal fistula which accrued from a rupture in my colon. So under the knife I go and they removed the fistula and stitched up my colon. I went home having my open wound dressed daily by a district nurse from the hospital. That caused me to the time off work to recover and my open wound to heal, so as you could guess the company was not happy. I was called in for a disciplinary which I took my mum to and all my hospital notes. After reading all my notes they protested that it wasn't to do with my health, where in the letter they sent it clearly stated Health, Absence and illness from work. They soon retracted everything they had said and placed me back into my job.

This story is sadly familiar to other participants who have IBD. Geoff suffered a lack of understanding and terrible consequences from his employers at one time:

> In February 2010 I was signed off with depression and stayed off until December. The thought of going back to work always made me feel worse. And obviously the worry and anxiety can aggravate illnesses like Crohn's... In December 2010 after no longer receiving any pay from the [workplace] and starting to claim Employment & Support Allowance I was offered the choice of going back to work where I would be placed under the 'Capability Procedure' or I could have my contract terminated and take a week's pay for every year of service (8 years in total). I knew that if I returned to work it would only be a matter of time before I would have to be off sick and under the Capability rules, this could give my managers the option to terminate my contract anyway. So I decided to leave.

On the other hand Sally writes about her supportive employer, which enables her to work:

> i am lucky that I hold down a job, i spent 5 years on incapacity benefit and started working nearly 3 years ago. That was a very important thing for me as it gave me some normality and self respect. Although I do struggle with lack of energy and it can be difficult when im in and out of the toilet half the day. I have a sympathetic employer and that helps.

Yet, she notes her frustration regarding the lack of support and recognition of IBD generally and how sufferers should be more able to get help, including financial support through benefits, saying:

> It angers me that we don't get recognised as having a disabling illness and life could be made a little bit more bearable for us if we were given a little extra hand so that we didn't have to work and worry and stress over our illness which undeniably makes it worse. The stress of having to take time off and the pressure it puts on us makes us have a flare up and in a lot of cases we have to give up work altogether, yet we don't qualify for the benefits that we should be entitled to so that we can live with just that

> little bit more easily. The disease is hard enough to deal with without that added stress and burden.

Rachel writes of the impact of her severe IBD on her work:

> ...my energy levels, drive and motivation are much more depressed and I take much longer to deal with everyday situations. I have had 6 months off work, but am now back to full time and night-duty. Work is much harder than before, partly due to less energy/drive and also because I am pretty much permanently using my Predfoam enemas twice a day; administering the morning one so that it stays in for long enough (3 hours) to be completely absorbed requires it to be taken once the bowel has been as fully open as possible - not always easy to predict when doing shift work.

It appears that there may be a lack of recognition by employers of the problems and hurdles faced by those suffering from chronic illness. This is recognised by Varekamp *et al* (2005) who in their research of rheumatoid arthritis argue the importance of employers having a recognition and understanding of chronic disease in order to prevent work disability.

Tiredness and fatigue seem to be a very common theme amongst participants and these factors understandably appear to have a negative impact upon the ability to work or to work full time.

5.2.5 Working Life (unpaid) and IBD

Some participants detail their struggles with family life whilst suffering from IBD. Tina writes: 'It affects my children as I have no energy to play with them and we cannot go out for the day due to toilet needs and lack of energy', thus demonstrating the way in which her disease has directly impacted upon her home and family life. Sally also has problems regarding the care of her children and the repercussions of her chronic illness:

> I think they find it difficult when I am in hospital as they don't really understand and I think it scares them a bit all the wires and tubes! they are beginning to accept it more now but I hate how its becoming normal to them. My oldest girl has found it difficult and spends a lot more time with her dad generally spending most of the week at his, thats hard for me but I can appreciate why, she doesn't like seeing me like this and I think she gets angry that I don't have the energy to do stuff with her.

The guilt of being unable to care for children due to illness and the side effects of treatment is discussed by Vallido *et al* (2010: 1441) who says '...guilt related to feeling too tired to mother, being short-tempered when feeling unwell'. For those who have a chronic disease such as IBD, it is common to experience anxiety, depression and have other negative thoughts, but it is how well these emotions and feelings are dealt with which affects how well an individual adjusts to the disease (DeRidder *et al*, 2008: 248) and how the disease may therefore affect relationships with family members.

Michelle writes about her children and how the care of them has to sometimes be passed to her husband:

> My husband knows about the symptoms - he sees me suffering from them - but there is nothing he can do for me to make it better other than to help out with the kids when I am feeling very rough. Only treatment, and myself can make things better.

So, it can be seen that there is a large impact on unpaid work and relationships within the home as a result of IBD and its associated symptoms. Additionally, the role of an individual within the home may be considered part of the individual's identity and therefore, this is another area in which the participants

discuss threats and barriers to their identity.

5.3 Becoming and Being a Patient

5.3.1 Involvement in Decision Making

Some participants comment on their treatment, their ease of access to services and their ability to be involved in the decision making processes, including positive and negative aspects and experiences. Some find that they have easy access and others find it difficult to access specialist advice without undue delay, thus suggesting that conformity to guidelines varies according to place of treatment and the health professionals involved:

> I can contact my consultant easily through his secretary and he always returns my calls which makes a huge difference (Lauren).

> I have had easy access to health professionals (Maggie).

> The team of nurses and doctors in our Gastro dept. are really helpful and discuss fully all the aspects of your medication. The access to the team who administer my infusion is very good I have a direct line phone number for any problems I might have. My consultant's secretary is extremely helpful and will communicate very well what is happening with appointments and test results etc (Kathy).

> ...there is [name], who is an IBD Specialist Nurse and is just beyond amazing. Her knowledge of IBD and her naturally caring personality has made the last 10 years just such a fantastic experience. I have cried on her (a lot!!) and have shared in the good times too. She has always been there for me on the end of the phone if I was unsure about something or just for general reassurance (Jenny).

> Here in [town name] we have access to an IBD helpline which is supposed to ring back within 24hrs but this service has let me down twice since I have been diagnosed (Graham).

> At the first sign of any flare I start taking steroids. If I don't feel better within a couple of days I ring my consultant's secretary and can usually see him the same week. Access to him is easy - probably because I pay vast amounts in health insurance and he makes lots of money out of me! (Michelle).

These statements show the vast differences in access to health care professionals in individuals suffering from IBD. Poor support can have implications in terms of feelings of health and wellbeing. Frances, for example, worries about coping:

> When I do feel that my ulcerative colitis is flaring up or the medication I have is not working it is near on impossible to get any medical help. My GP is very nice but useless as he claims the area is too specialised for him. It has taken up to 5 weeks to get an appointment with the consultant which seems a long time when I'm in flare. This makes me feel really worried and afraid that I am not going to be able to manage until I see him (Frances).

In terms of having a choice between different treatments participants have varied experiences and attitudes. Some place great emphasis upon their ability to choose and make independent decisions. Others either allow health professionals to solely make decisions for them and/or they feel that they are not in control of their disease and its treatment at all. Examples follow:

> I have researched on the web and read several books regarding Chrons with the view of me being in control of it (Graham).

> After suffering for 26 years I have gained lots of knowledge and experience from Consultants and health professionals from four different hospitals in England. I have always tried to control my Crohns disease myself and unless I get a bad relapse have been quite successful (Kathy).

> I do feel, now, that I am very much in control of my treatment and when I see my IBD team, we do discuss what treatment would be beneficial for me take (Tina).

Thus, we can see that Graham, Kathy and Tina have all actively expanded their knowledge and over time gained in experience, resulting in their ability to increasingly make decisions and take some control over their treatment. Thus, they have become 'lay experts':

> I trust the medical specialists I see with their guidance on the medication I take...And as much as I hate them, I trust her opinion and am willing to carry on with the treatment... I'm quite happy to do as I'm told when it comes to IBD and the treatments. However, sometimes I can feel quite uncertain of what I can do in my everyday life to help make me better and to hopefully make my prognosis a bit more positive (Jenny).

> When I was first given the immunosuppresant drugs I don't beleive I was given enough information, I was just handed them and told to take them. I wasn't told about side effects or the dangers of pregnancy, I was just told not to get pregnant. When I was given the mercaptapurine again wasn't told anything about the drug and when I got my prescription filled i panicked. I wasn't told it was a chemotherapy drug and it wasn't explained to me why I was being put on it... In terms of my treatment I don't really feel in control as I don't really have a say. Part of this is because I don't really have a relationship with my consultant but my GP is fantastic and I know I can speak to him if things are getting on top of me. I was recently put on anti deppressants due to a whole mixture of factors including the Crohns (Sally).

In contrast, Jenny and Sally do not feel that they are in control of their treatment. Jenny is happy to do as she is instructed by health professionals and Sally feels that she lacks control as a result of not being able to have a say regarding her treatment.

> I feel like a guinea pig, I know and understand that there is no cure and they can only control it of hold it a bay but nothing has seemed to work as yet and now funding has been cut I don't see that us suffer's are going to receive the treatment that we need and require to be able to function properly and have a "normal" life. I let the Consultants prescribe the

> drugs and then I speak to my pharmacist as he has a better idea as to what these medications do and how they interact, he is my saving grace and my Counsellor (Lucie).

> ... it is undoubtably true that the more clued up a patient is on medical terminology, practices and procedures, the better they are able to communicate with medical professionals and the better care they receive... I can basically turn up for an appointment (I don't go to see them often), and tell them what I think the problem is and sometimes the treatment I think I need, and they invariably agree with me and just dish it out (Rachel).

> I think that although my consultant is very good, many health professionals take the view that patients are helpless beings who require instruction! I'm not into that kind of thing and if someone tries to tell me to do something that I know isn't right for me, then I won't do it. I think that I am the one with the disease - not them - they learn about it in theory but they don't live it. They don't 'live' the medications and side effects either, so I think that my view is very important. I have found a good doctor fortunately who understands the way I work so none of this is an issue within my own control of ulcerative colitis (Michelle).

> I don’t see too much of health professionals (fortunately!). I was, when first diagnosed, happy to do whatever they told me. I have got wiser with experience and take responsibility for my health and my needs. Treatment never really ‘changes’ – you know what you need and when you need it – it’s always the same and doesn’t change. So insofar as I have familiarity with the pattern and process my own knowledge and experience NOW dictates my treatment. That wasn’t the case when I had no knowledge or experience when I was first diagnosed (Frances).

Rachel, Michelle and Frances are all examples of individuals who do not wish to be told what to do by health professionals and require their treatment plans to be led and dictated by themselves.

Many of the above responses indicate that through increasing knowledge and subsequent confidence, the participants take an active role in self-management including the treatment of their IBD. This approach is supported by Kennedy *et al* (2004: 1643) who propose:

> IBD is a condition well suited for guided patient self-management; it is chronic with unpredictable relapses, therapy is required quickly when relapse occurs, and routine follow up visits rarely coincide with relapse. We have now shown that the great majority of IBD patients are both willing and able to self manage their condition, achieve benefit from doing so, and can reduce their use of health services.

Some participants go out of their way to learn more about their illness and how to cope with it. This subsequently includes the ability to take a higher level of control over their disease in terms of treatment and also a reduced level of fear and anxiety due to an increase in knowledge:

> I have researched on the web and read several books regarding Chrons with the view of me being in control of it (Graham).

> As well as learning about the symptoms through suffering from them I have also read large amounts on the interenet and in books so that I know what I'm talking about and this has helped me to feel more relaxed about the whole process. I do think that it's a shame that health professionals don't direct you to sources of information because they see you in an appointment, give you a diagnosis of some previously unknown disease and then expect you to just deal with it. Until I learned more this frightened me. I'd just been told I had an incurable disease (Michelle).

Other participants, such as Sally and Francis, believe that they were not given enough information, which led to fear and upset and a feeling of not being cared about by their health professionals:

> When I was first given the immunosuppresant drugs I don't beleive I was given enough information, I was just handed them and told to take them. I wasn't told about side effects or the dangers of pregnancy, I was just told not to get pregnant. When I was given the mercaptapurine (*sic*) again wasn't told anything about the drug and when I got my prescription filled i panicked. I wasn't told it was a chemotherapy drug and it wasn't explained to me why I was being put on it. As I had previously had a leukemia scare I panicked and got very upset and confused (Sally).

> I don't think I've ever felt particularly enlightened by the health professionals. They're totally rubbish at explaining things which is really

> unhelpful particularly when your first diagnosed. I didn't understand what was going on and they didn't enlighten me even after the firm diagnosis. I taught myself everything I know about the disease. How come people with my asthma (like my husband) get to go to clinics regularly at the GP's and their symptoms get checked and medication changed etc. Not so with this disease. Nobody really cares about it (Frances).

Maggie feels that it would be helpful to be given more paper information, and Tina started her research about IBD from home. This is interesting because it indicates that not all individuals would like to take control of researching their condition and obtaining information for themselves:

> It would be very helpful if more paper information was given at the hospital after diagnosis (Maggie).

> I went home feeling very depressed and very alone as I thought this was all in my head. I started the tablets and also started to research IBD on my own (Tina).

A different way of acquiring information and subsequent support is discussed by Jenny who telephoned the NACC and then became a member:

> I didn't know what was going to happen to me...Then I found what was then called the NACC – I applied for membership with the Charity and I can so clearly remember the day when the information from them came through the door in January 2003. I remember reading the information with tears streaming down my face realising that there were so many other people out there like me and that there were ways of actually living with this disease. It was like the sun breaking through the clouds and I suddenly realised that I could cope; it was a real turning point for me and my Crohn's (Jenny).

The statements above show just how important education of individuals suffering from IBD may be. There are a range of opinions and attitudes above, but there is a common theme that an individual will suffer from fear and uncertainty if they do not know or do not understand what is happening to them. The data also demonstrates why individuals are likely to educate themselves in

order to know what is happening to them and also to take control of and live with IBD. I too have personally taken responsibility in my own health care. I have researched IBD, using many different sources, and keep up to date with new research and treatment options. I feel that this enables me to be active in contributing to my own treatment decisions and to have some kind of control over my own circumstances. For example, when I see a new treatment is being trialled or approved which may be superior to my current treatment in terms of treatment effect or side-effects I will ask my doctor about their experience of it and whether it would be a good idea to alter my treatment plan.

5.3.2 Mutual Support from Other Sufferers

Several participants mention that they get the most, and best, support from people they know in their daily lives (as opposed to through support groups) who also suffer from chronic disease rather than health professionals and / or the closest family members. For example, Graham says:

> I then rang my sister as she understands about living and dealing with Crohns (*sic*) as my niece her daughter was diagnosed with the disease when she was 12 she is 19 now and the UC side of things is extremely bad…. It obviously helped having someone close to talk to them and still now but I have found it hard at times knowing that you have a chronic disease and that there is no cure... I have my sister for support which is great and I think I am lucky to have that as having Crohns and / or UC can be a very lonely place. People at work dont really understand even though I have been open about it. Friends and family also dont really get it as they dont fully understand.

Similarly Tina writes:

> I have since found another Mum, at the school where my youngest son attends, she has Crohns and we are always texting or phoning each other to offer support. That has been a great relief as I can text her and say ‘this is happening, is this normal?’

And Sally:

> I am very lucky that I have a very good family network who are very supportive. My mum has ulcerative colitis, so understands how i am feeling and i can share a lot with her regarding medication and symptoms and side effects. She can also understand the fatigue and is a great support with my children.

Abi:

> I guess I was quite alone at the start but found a couple of friends with family that were also sufferers which helped.

She continues:

> One of my closest friend's son has just been diagnosed with an IBD and she now apologies for not being more supportive – I think there is a definite lack of knowledge and awareness of the illness.

So, positive and good support is found from other people who either have the disease or have other family members who suffer from the IBD. Participants put an emphasis/value upon 'understanding', and how those with knowledge and experience of IBD are therefore able to offer them more understanding than other people without that knowledge and experience.

One source that several participants said has helped them through mutual support and education regarding their disease is the NACC (National

Association for Colitis and Crohn's), which is often simply called Crohn's and Colitis UK. The NACC (http://www.crohnsandcolitis.org.uk/Aboutus/about-us):

> Crohn's and Colitis UK is the working name for the National Association for Colitis and Crohn's Disease (NACC). Founded in 1979, the charity has been providing information and support, funding research and fighting for change by bringing together people of all ages who have been diagnosed with IBD, their families and friends, and the professionals involved in their care.

The NACC not only funds research into IBD but it also provides invaluable information for those who suffer from IBD which can be especially useful for those who have been recently diagnosed or those who are seeking information on treatments. They provide a wealth of information on all aspects of IBD aimed at different sections of society. They also provide a helpline and membership which enables the member to have access to a special key to gain entry to most disabled WC's across the country. Importantly, they also set up support groups locally, all around the country, where people suffering from IBD are able to meet and offer mutual support. There is also often a consultant gastroenterologist linked to each of these local groups who is able to offer advice and information to group members. This is similar to support groups offered by other charities such as Arthritis Care who run groups for individuals with arthritis on a regular basis across the country.

Graham mentions that he has recently joined his local support group, writing: 'I went to my first NACC local meeting last week. Which is quite supportive and they have a Q & A session at the end which was very interesting'. So not only does the group provide the mutual support mentioned above, but it also has an aim of educating people regarding their disease. Maggie also speaks of such support**:** 'I am still getting used to living with Colitis, although it is still quite

difficult. I have had wonderful support from the Colitis Society'. Tina utilises the various avenues of help that the NACC offer: **'**I have joined the NACC. They have been very helpful and have wonderful resources available. They have also sent me a free radar key, so when I am able to go out I know there are toilets available'.

The NACC had a profound effect upon Jenny, and effectively enabled her to start reliving her life again after diagnosis:

> I applied for membership with the Charity and I can so clearly remember the day when the information from them came through the door in January 2003. I remember reading the information with tears streaming down my face realising that there were so many other people out there like me and that there were ways of actually living with this disease. It was like the sun breaking through the clouds and I suddenly realised that I could cope; it was a real turning point for me and my Crohn's.

This demonstrates the importance of accurate information and support to a person who has been diagnosed with a disease that is going to be with them for life. The respondents generally mention disbelief, shock and lack of understanding of their diagnosis when they are first diagnosed with the disease.

Sally was diagnosed fifteen years ago, and she still benefits from the NACC support groups: 'The Crohns support group is also fantastic as you can have a good moan and they are very sympathetic and appreciate where you are coming from and how you feel. Its (*sic*) helpful to be able to speak with other sufferers'. This is another example of mutual support and the way in which a sufferer may feel more comfortable talking about their health problems with other people who also have the same problem, without feeling judged. Rachel has also utilised the support of other sufferers and comments on this: 'By

discussing issues with others who have different levels of disease - looking at their issues from a clinical perspective, I have gained a huge amount of extra knowledge'.

Abi joined the NACC as soon as she was diagnosed to increase her knowledge and to gain support: 'I had never heard of it before (had heard of Crohns but no idea what it was) - so straight home to the Internet to research and join NACC. I think I was dumbfounded but at the same time relieved to have an answer'. She goes on to write 'I think there is a definite lack of knowledge and awareness of the illness. I am a member of the fund raising team at... hospital and now know how supportive they are and I think NACC do a wonderful job in trying to raise awareness'.

Although most participants appear to have contact and a relationship with the NACC, some use online support forums as an additional means of support. This is discussed by Sawyer *et al* (2007: 1487) who propose 'evidence is also growing that Internet-based support and self-management programmes and other technologically-mediated methods can improve outcomes for people with chronic conditions'.

The general consensus amongst participants is that this is helpful and that it is easy to ask questions in an anonymous way. For example, Michelle says:

If I have a quick question to ask, or it is something really embarrassing I ask on the forum. They don't know who I am, and also I find that I can answers really quickly from the forum. Usually within minutes someone has something to say.

It is quicker than waiting to meet with any groups or doctors.

5.3.3 Relationships with Family and Significant Others

Chronic disease may play a role in relationships with others and this section discusses the participants' comments surrounding this area. This includes the physical impact and the impact of the change in identity and disruption to life.

Tina writes: 'It effects the relationship with my husband I am unable to be intimate with him due to bleeding. I also do not feel clean down below as I am going to the toilet up to 20 times a day'.

This idea can be taken further still. In some cases the physical symptoms and repercussions of chronic illness may change irreversibly or even terminate relationships. Lucie writes:

> My partner left me just before I got diagnosed with the Crohn's because he wanted children. I was told by the medical profession that I had made the right decision not to have children given my conditions and that I could pass them on and I can't look after myself.

Rachel writes:

> I was also very psychologically compromised by the effects of the steroids. I retained insight – having nursed so many patients in similar situations, but my husband was completely unable to see this even though I kept trying to explain to him. I discovered that he holds a deep suspicion of psychology in every form (linking it all to psycho-analysis / "quackery"), and this makes it extremely difficult to get him to relate to my experiences; all he could see was that my personality had been altered and he just wanted "his Rachel" back.

Another repeating theme in the data is the way in which IBD has an effect upon the ability to do what may be considered 'normal' things or to carry out a 'normal' life, including maintaining positive relationships with family and particularly with children within that family.

Tina writes of how her IBD has a negative effect on the relationship with her children and the ability to take them out: 'It affects my children as I have no energy to play with them and we cannot go out for the day due to toilet needs and lack of energy'. Similarly, Sally writes:

> My oldest girl has found it difficult and spends a lot more time with her dad generally spending most of the week at his, that's hard for me but I can appreciate why, she doesn't like seeing me like this and I think she gets angry that I don't have the energy to do stuff with her.

Showing how everyday situations, habits and ways of doing things may change, Christine, says '… my husband is a star and very understanding and always plans our routes past public loos': a simple, but effective, way that her husband has enabled her to continue doing normal things through adaptation.

5.3.4 When Things go Wrong in Relationships with Health Professionals

It is important that those who have a chronic disease are treated as individuals in so far as they are individuals with personal circumstances, different emphases upon what enhances their well-being, and different social relationships. Health professionals need to be available and able to support patients suffering from chronic illness to participate in their own health care – to respect the views of both them and those close to them in order to increase perceptions of health and well-being.

The data highlights that sometimes this does not always happen and individuals can be left feeling uncared for, alienated and/or being treated as a statistic rather than an individual. Several examples follow:

> I had to change consultants last year as the old one was rubbish, I just felt like a number when I saw him. He was always looking at the clock as if to say hurry up and get out. New consultant is much younger and shows more interest. I hate going into hospital as in my local one if you ring the buzzer beside your bed the nurses go mad! I would hate to be elderly with the treatment they get (Mark).

> The consultant I saw was not very helpful… I made an appointment to see my GP to talk through what was said at my meeting with the consultant. My GP was very supportive and understanding and was not very happy with the treatment I had got from the consultant (Tina).

She continues:

> After the next appointment I requested a different consultant for my next consultation as I had no faith in the current one. This I did through the specialist IBD nursing team, who I have been able to contact through the helpline.

Interestingly Tina attributes some of the problems she has encountered due to lack of communication between health professionals:

> I get on very well with my IBD team and my GP has been very supportive in my treatment so far. I would like to see better communication between the hospital and GP though, as my GP does not always get a copy of my test results so does'nt know what is going on.

Several participants have problems with their health professionals regarding the care of them and their chronic disease. These problems seem to arise from a

variety of sources. They appear to arise from miscommunication, lack of communication and lack of understanding or time for them.

One example of lack of understanding and not taking symptoms seriously enough on behalf of the health professionals comes from Graham:

> My own doctor has also let me down in responding to my problem. In April I went home early from work because of the pain and rang the IBD helpline and the following day rang my doctor and was told to come in. I explained I have Crohns and they got the doctor to ring me back. He said I was having an attack and to change my diet immediately to a bland one. After two more days of excruciating agony I called out the night doctor who sent for the ambulance and took me into hospital.

It is unclear whether the problem lies in the doctor not taking the symptoms seriously or whether they did not have enough information to adequately diagnose the seriousness of the condition. But either way, it would appear that the doctor-patient relationship broke down due to not working in a partnership between doctor and patient. Jenny writes:

> I absolutely cannot stand going to see registrars. They don't know me. I see someone different every time who spend the first 5 minutes asking me questions that if they had just bothered to read my notes would know the answers about. Then when I ask them questions they can't answer properly. It frustrates me when I've waited 2 hours to supposedly see my consultant and I end up seeing the monkey rather than the organ grinder. I once had a registrar actually go home before even bothering to see me. Don't get me wrong, I have a lot of respect for health professionals, but it would be like a parent waiting ages to see me at a parent evening and then me not seeing them and instead putting a student teacher there instead – they don't know their child, just like a registrar doesn't know me.

The feeling that health professionals may not always listen, understand or take the symptoms seriously enough soon enough is extended even further by Sally

who felt as though she was not believed or that health professionals thought that she was making it up:

> I don't have a particularly good relationship with my consultant, for a long time because I didn't have typical symptoms and my test results were never text book, I always got the impression that he didn't believe me.

Rachel gives a possible answer to the above problems:

> My job as an ITU nurse means that I am pretty articulate medically - even in comparison with many nurses who work on wards. It does make me angry, but it is undoubtably true that the more clued up a patient is on medical terminology, practices and procedures, the better they are able to communicate with medical professionals and the better care they receive. It's partly all about how a history is given - many patients simply don't realise what factors are important and relevant and which ones are not and they also are often unaware of the questions to ask.

As a health professional herself, it is interesting to see Rachel's belief is that the more the patient has educated themselves regarding their disease and treatment the better the care that they receive. This supports the earlier discussion surrounding education and knowledge in chronic disease. From a personal perspective, I have found Rachel's assertion to be correct. The more knowledge that I have gained, the more I seem to be taken seriously and the better the treatment I receive. I am sure that sometimes I may come across as demanding but I am treated with so much more respect and given a lot more time than when I was first diagnosed.

5.3.5 When Things go Right with Health Professionals

Although many individuals within my research flag up difficulties in their relationships with health professionals, others indicate the importance of communication between themselves and their health professionals and also

ease of communication. For example, how easy it is to contact their health professionals and how easy it is to talk to the health professionals, the ease with which questions are answered and anxieties are addressed, and how the health professionals look at the whole person as opposed to just the pathology of a condition.

Lauren writes of her relationship with health professionals:

> I can contact my consultant easily through his secretary and he always returns my calls which makes a huge difference. I have a good relationship with the IBD nurse and the dietican who is particularly good and she has made a significant difference with my disease management.

Lauren continues: ‘I now have a very active role in my disease management, i have built relationships with my healthcare professionals and i am given choices as much as possible’, demonstrating how easy access and good relationships with health professionals may have built independence and confidence in dealing with her own health leading to shared decision making.

Michelle is another participant who takes control of her disease and has easy access to health professionals: ‘I don't take treatment when I am well. At the first sign of any flare I start taking steroids. If I don't feel better within a couple of days I ring my consultant's secretary and can usually see him the same week’.

Kathy discusses the role of communication and states:

> The team of nurses and doctors in our Gastro dept. are really helpful and discuss fully all the aspects of your medication. The access to the team who administer my infusion is very good I have a direct line phone

> number for any problems I might have. My consultant's secretary is extremely helpful and will communicate very well what is happening with appointments and test results etc.

Again, this indicates the importance of communication and ease of access to a diverse team of health professionals.

It also demonstrates the positivity that can be created in disease management through being given information and the sharing of knowledge:

> After suffering for 26 years I have gained lots of knowledge and experience from Consultants and health professionals from four different hospitals in England. I have always tried to control my Crohns disease myself and unless I get a bad relapse have been quite successful (Kathy).

Kathy sounds very positive regarding her treatment and her relationships with health professionals. She appears to have a high degree of independence and confidence in dealing with her IBD and acknowledges that over a lengthy period of time she has learned from her health professionals and accumulated a great deal of information and knowledge through her experiences that enables her to be in control and to make decisions surrounding her health and well-being. She is a positive example of how experience, willingness to learn and good relationships with health professionals enable patients to enrich and expand their own feelings of well-being.

Jenny has easy access to her IBD nurse and depends on her not only for medical advice, but also her IBD nurse proved emotional and psychological support. As previously discussed, these factors contribute to overall health and

well-being and are important to living a full and more ‘healthy’ life. Jenny writes about her IBD specialist nurse:

> …[she] is just beyond amazing. Her knowledge of IBD and her naturally caring personality has made the last 10 years just such a fantastic experience. I have cried on her (a lot!!) and have shared in the good times too. She has always been there for me on the end of the phone if I was unsure about something or just for general reassurance.

Sally also sees continuity of care as important and over time has managed to build up a beneficial relationship with her general practitioner:

> He’s worked with me to enable me to go back to work and has been a bit of a rock during the last few years. He has followed my disease over the last 5 years and knows me and it inside out that has been very helpful, feel like I have real continuity of care.

Sally’s positive relationship with her GP appears to somewhat make up for a lack of a positive relationship with her consultant which has previously been mentioned. Regarding this, she writes ‘In terms of my treatment I don't really feel in control as I don't really have a say. Part of this is because I don't really have a relationship with my consultant but my GP is fantastic and I know I can speak to him if things are getting on top of me’.

Maggie indicates the importance of having support with questions and anxieties addressed appropriately: ‘The treatment I received at the hospital was excellent, anxieties and questions answered’. Sally, also mentions the importance of appropriate support saying ‘…since my diagnosis my GP has been brilliant, very supportive and pushes for treatment for me’.

5.4 Coping and control

5.4.1 Control and Choice

The terms “control” and “choice” appear to be words that are repeated regularly by many of the participants with regard to their treatment and intertwined with their relationships with health professionals and the positivity or negativity associated with their treatment. Many participants put great emphasis upon these two concepts with regard to their treatment and they seem to be linked to positive relationships with their health professionals.

Examples of this include Tina: ‘I do feel, now, that I am very much in control of my treatment and when I see my IBD team, we do discuss what treatment would be beneficial for me take and we also discuss how we might proceed if this treatment does not work’. Abi writes about control: ‘I am very happy with my Consultant (have not seen an IBD nurse as was private and now in control) and have a good relationship with her but I am in control’.

Other examples include:

> ...if someone tries to tell me to do something that I know isn't right for me, then I won't do it. I think that I am the one with the disease - not them - they learn about it in theory but they don't live it. They don't 'live' the medications and side effects either, so I think that my view is very important. I have found a good doctor fortunately who understands the way I work so none of this is an issue within my own control of ulcerative colitis (Michelle).

> I don’t see too much of health professionals (fortunately!). I was, when first diagnosed, happy to do whatever they told me. I have got wiser with experience and take responsibility for my health and my needs (Frances).

Sally links lack of control to a poor relationship with her consultant. She writes ‘In terms of my treatment I don't really feel in control as I don't really have a say. Part of this is because I don't really have a relationship with my consultant but my GP is fantastic and I know I can speak to him if things are getting on top of me’.

Thus, choice within disease management is important and feelings of control are major contributors toward well-being. This can marry back to the concept of the Expert Patient as previously discussed. Because of the powerful and potentially problematic drugs used to treat chronic illnesses and the obstacles that may be faced over a long period of time, patients may develop their own knowledge, views and experiences of not only the disease and the effects that it causes, but also the therapy used to treat it. People will know what is important to them as an individual. For example, what side effects in drug treatment that they are able to tolerate and what they would prefer to simply accept. The patient lives with the disease, perhaps even ‘owns’ the disease, and the consequences, and therefore becomes accustomed to what they may regard as ‘normal’ and what they are able and not able to cope with.

5.4.2 Coping Strategies

If a person suffers from a threatened identity, with the possibility of others finding out about their disease, there is a possibility that at some point they may become stigmatised and discriminated against. Below is a discussion of some of the coping strategies individuals may employ in order to deal with their threatened identity and to avoid stigma which are directly relevant to the participants.

Isolation

Isolation occurs when an individual isolates themselves from society and other people when they have a threatened identity. This is as a means of a personal coping strategy and is intended to protect them from the observation and/or judgement of other people.

Lucie tends to isolate herself from others to the point that she does not believe that she will ever regain her former life back again:

> I find it difficult to stay at friend's houses or family as I find this condition so embarrassing. I am single and think it will probably stay that way because of this condition.....

And Frances:

> I do everything I can to make sure that my situation regarding colitis is never a topic of conversation. I also never discuss my symptoms or any treatment related problems with them. I don't want people to see me any differently or treat me any differently because I have this disease.

Frances admits that she is afraid of the reaction of other people and that her tactic is therefore to keep her symptoms, disease and treatment secret. It is almost as though she isolates a part of her life from the rest of her life and the people in it, in order to avoid possible stigmatisation and unfavourable reactions. Frances seems to be trying to project a chosen identity which is perhaps more akin to a pre-diagnosis identity. She seems to be aware that her 'identity' has changed but is working with these changes to accommodate her position and psychological comfort and ease with life.

Overall, for all participants, there seems to be an overall attitude of not wishing to tell people around them about their disease and regarding as a subject which would not benefit them to discuss with other people. There is an emphasis on disclosure. That is, who people do or not tell about their IBD and their approach towards this. It appears to be a method utilised to avoid embarrassment, embarrassing symptoms or a way of avoiding judgement by other people.

Challenging others

As opposed to isolation, some individuals may directly challenge any person who questions them or makes them feel uncomfortable about their status. Frances talks of an incident that would fit within this category very well:

> I don't want people to see me any differently or treat me any differently because I have this disease. In fact, when I was asked by one family friend if I was 'ok' I am ashamed to say that I overreacted. They didn't (and still don't) know about my disease. But they saw me looking uncomfortable and rushing off to the bathroom quite a bit when they were having dinner at our house. I was quite aggressive in my assertion that I was fine – even accused her of trying to make out I was ill so that she didn't have to eat the food that I had prepared. It wasn't my proudest moment. But nevertheless my justification is that I'm still me. Not the disease.

Clearly Frances wants the identity to remain hidden and to allow other people to see her simply as a 'normal' individual and not an individual who is different or blighted in any way. She does not see her IBD as a part of her identity that is represented to the outside world. However, it is likely from what she says that she is very aware that her IBD is a part of her personal identity. Perhaps a part which she would like to reject and therefore feels that she needs to alter what may now be natural behaviour in order to preserve the social identity she would like to maintain.

Exiting or distancing

This appears to occur when an individual makes an attempt to get themselves out of or distance themselves from a perceived threatening position. If this is not possible, the individual may prefer to pretend to the outside world that they are somebody or something different than their reality – which is, in this case, an individual suffering from a chronic disease. An example of this is Emma who says:

> I don't want to seem different to anybody and it's very important to me personally that I appear brave and able to cope with whatever life throws at me, no matter how weak I feel inside.

It can be seen that Emma just wishes to fit in with other people and not be perceived as the odd one out or the one that is different or needs help in some way. So, even if Emma feels unwell or weak, she makes her outward appearance, demeanour or behaviour consciously different to compensate and to appear the same as everyone else.

Another example is Frances, whose reaction discussed above could also be seen as distancing herself from the situation. She is perhaps trying to be somebody she isn't, or she feels that she will only represent herself to the world as she wishes the world to see her.

Therefore, individuals such as Emma and Francis, who maintain a pretence to the outside world of being fine with no problems in their life may be at particular risk of moving from *discreditable* to *discredited* (Goffman, 1963). Arguably

though they may be in a precarious position in terms of people finding out about their chronic illness.

Sally talks of IBD as a ‘hidden’ disease:

> It is antisocial and very hard to discuss with people that don't have it as they find it hard to understand. Also as its quite a hidden disease people can't see the pain and misery you go through everyday.

It is important to note the point that an individual does not necessarily intentionally ‘hide’ the disease. IBD is a disease that people will not necessarily notice or know a person has unless they are told. This in itself may contribute to the lack of understanding from others. People who do not know that an individual suffers from the disease and subsequently find out may assume that it is nothing serious or else they would have known before. Also because it is an unseen disease, particularly when an individual is not in flare, people do not have the opportunity to learn and to educate themselves about the disease. If it is not normally encountered there is no reason or mechanism by which people have a raised awareness of its seriousness and associated problems.

Frances has not disclosed the details of her IBD to people other than her husband:

> The only person who really has any awareness of what is going on is my husband. He is, as in all things, supportive and will always help out if and when I need it. Other people I would not turn to for help or support with this. It isn’t something that I would feel comfortable telling our friends about and really there is no need for them to know.

Clearly for many participants the transfer between two states of discreditable and discredited (Goffman, 1963) is what they are actively trying to avoid through not telling people of their disease and taking measures to prevent people finding out.

Knowledgeable avoidance

This might occur if a person has a condition, such as IBD, whereby stigma may be experienced by an individual suffering from the condition, but the condition is visible to other people **or** is already known about by others. In the case of IBD it is less likely that the condition is visible but the individual may have disclosed to others that they have the condition.

This is something that Abi acknowledges. Her group of friends / social circle may know of her illness, but she does not make it a subject of conversation with them:

> I keep it low key among my circle of friends so maybe missed out on their support.

It could be Abi's sense of perceived stigma rather than actual stigma that has led to this situation.

Frances also describes a similar scenario, saying:

> Two friends do know, not because I wanted to tell them, but because my husband told them when I was in hospital. However, I do everything I can to make sure that my situation regarding colitis is never a topic of conversation. I also never discuss my symptoms or any treatment related problems with them. I don't want people to see me any differently or treat me any differently because I have this disease. I will in fact often act

> when I am around people. I will pretend to have huge levels of energy and enthusiasm – almost like superwoman! I cover up and smooth over the creases. I guess it is a bit like a duck. Everything is normal and calm on the surface and I am paddling frantically underneath... I'm still me. I'm not the disease.

This account shows how much some sufferers of chronic disease, and specifically IBD, may fear being stigmatised, being treated differently or being treated unfavourably due to their disease diagnosis and symptoms. Frances points out that she does not believe that the disease makes her who she is, more that she prefers to think of herself as being in control of the disease and that the disease itself may be what she makes of it. She does not want other people to see her as a person with a disease: she wants to be an individual with a unique identity.

Francis's statement summarises everything said so far about coping mechanisms and stigma and the unwanted effects the label of a disease may have on a person. But it also evidences how hard individuals suffering from chronic disease, in this case IBD, may have to work at maintaining the status quo. Relevant here is Exley and Letherby's (2001) discussion of the emotion work that can take place in terms of having to manage disruption to life and having to manage the reaction of others to one's 'damaged identity'. In this case, Frances is openly acknowledging that she cannot be herself, even around people she knows. She actively pretends to be something she is not in order to hide her IBD and avoid feeling different. It appears to be one of her biggest fears – that people will treat her differently or not understand if they were to have an awareness of her IBD. This element of fear of stigma, being labelled, being 'exposed' or being treated differently can be linked to the previously discussed concept of fear. Frances is constantly living in fear of other people

knowing about her chronic disease. In this sense, fear is her constant companion.

5.4.3 Participation in Health Care

The participant narratives show some variation in the roles that patients take in the control of their disease. A large majority of participants seem to be very active, independent and knowledgeable about their health and the treatments required. Rachel, writes: 'I can basically turn up for an appointment (I don't go to see them often), and tell them what I think the problem is and sometimes the treatment I think I need, and they invariably agree with me and just dish it out'. And Frances writes:

> I am now knowledgeable about treatments and what I need / when etc. I take medication if / when I need to without seeing the doctor – the medication is on repeat prescription. I just make an appointment to see my consultant if the medication doesn't seem to be working or if the flare up seems different or worse than normal in any way.

This demonstrates the ways in which experience may enable some individuals with IBD to gain in confidence and to take an active and decisive role in the decision making around their disease.

Other examples of this amongst the participants are:

> ...my prescriptions are reviewed annually with my Dr but I am in total control of when I take them as long as I take the min of 4 per day. I know I can increase them if I have a relapse (Abi).

> After suffering for 26 years I have gained lots of knowledge and experience from Consultants and health professionals from four different hospitals in England. I have always tried to control my Crohns disease

> myself and unless I get a bad relapse have been quite successful (Kathy).

An individual with a long term chronic illness may become involved in their own care and become increasingly educated about their health and disease as time progresses. A patient who is involved in their own management may be said to be a patient who is more likely to 'help themselves' in as many ways as possible resulting in an increased sense of wellbeing.

This idea recognises that patient involvement in their own care not only creates a more knowledgeable patient, but also one that is more likely to take the diagnosed tests and treatments prescribed by the health professional alongside lifestyle modifications. The data demonstrates that some people suffering from IBD may take their own involvement and adoption of new behaviours further than even advised or suggested by the health professionals. For example, Mark says:

> I do the cooking n our house so this give me more control over my diet. My consultant says that diet is nothing to do with crohns but this is nonsense! I reckon that anything to do with your bowel must be food related.

Other participants recognise, as mentioned above, that modifying existing behaviours and self-education is a form of self-help and control of their disease. Graham writes: 'I have researched on the web and read several books regarding Chrons with the view of me being in control of it'. Whereas Mark writes: 'Apart from crohns I am pretty healthy and cycle, golf and walk whenever I am able. I read somewhere once that physical activity is good for crohns . I watch my diet and don't eat chocolate, real fatty food or too much bread.

Bodenheimer *et al* (2002: 2470) argue that 'traditional views regard physicians and other health professionals as experts, with patients bringing little to the table besides their illness'. This is not seen very much amongst the participants of my research study, but there are a couple who feel that they lack control and that health professionals either would not allow them to take control of their disease or they feel unable to. Jenny writes:

> I trust the medical specialists I see with their guidance on the medication I take.... And as much as I hate them, I trust her opinion and am willing to carry on with the treatment... I'm quite happy to do as I'm told when it comes to IBD and the treatments.

Sally felt that she was not given choices in the care of her IBD: 'In terms of my treatment I don't really feel in control as I don't really have a say'. These two participants are the only ones in my study group who do not take an active role in the management of their disease and allow a more traditional or patriarchal medical model to take precedence. Although this might be more common in the general population than my self-selecting group of participants. Arora and McHorney (2000) found that in their research sample, 69% of individuals have a preference for health professionals to lead decision making.

5.4.4 Expert Patients

In chronic disease, a new paradigm is emerging where people with chronic conditions are their own principal caregivers; and health professionals – both in primary and specialty care – should be consultants supporting them in this role (Bodenheimer *et al*, 2002: 2470)

A reciprocal relationship is required with input both from health professionals and patients suggesting that health professionals need to be in touch with the individual patient as a 'whole person' whilst the patient must further their knowledge about their own care and health.

The amount of control that a patient has in relation to decision making has been shown to be related to the amount of information that they have about their condition and the treatment (Annandale, 1987: 1247). Information and knowledge, as well as increasing patient control, may also increase the confidence that an individual has in their health professionals. An example is Jenny who writes:

> I have a lot of respect for my consultant, even if her time keeping leaves much to be desired. I think I've seen about 3 consultants over the last 10 years and she is a million times better than the last consultant I had under the NHS. She seems incredibly knowledgeable about Crohn's and IBD. When I go to see her she will often refer to course and conferences she's been to about Crohn's and different therapies available. This helps my confidence in her.

Sally writes of how she was given a new drug without enough information:

> When I was first given the immunosuppresant drugs I don't believe I was given enough information, I was just handed them and told to take them. I wasn't told about side effects or the dangers of pregnancy, I was just told not to get pregnant. When I was given the mercaptapurine again wasn't told anything about the drug and when I got my prescription filled I panicked. I wasn't told it was a chemotherapy drug and it wasn't explained to me why I was being put on it. As I had previously had a leukemia scare I panicked and got very upset and confused. My GP again was brilliant as he explained why they were using that drug and assured me that my bloods were fine, he was angry with my consultant for not explaining the drug to me and for just handing it out.

Sally goes on: ‘In terms of my treatment I don’t really feel in control as I don’t really have a say. Part of this is because I don’t really have a relationship with my consultant’.

This demonstrates the harm that a lack of knowledge can do. It also shows how information, knowledge and an involvement in care increases the feeling of control. Unfortunately in this case it shows a lack of explanation to and involvement of the patient. This is mentioned by another participant, Lucie, who says ‘I let the consultants prescribe the drugs and then I speak to my pharmacist as he has a better idea as to what these medications do and how they interact, he is my saving grace and my counsellor’. These two participants therefore show that some doctors may have a lack of willingness to provide patients with enough information to allow independent decision making and/or confidence in their treatment and indeed the ability to become ‘Expert Patients’ in their own disease.

Rachel shows a high level of control in the management of her disease overall, but she comments that this level of autonomy does not always sit easily with health professionals: ‘I generally have a pretty good rapport with the team although there have been two atrociously rude registrars who clearly were not of the opinion that it was beneficial for patients to have so much control’.

This is furthered by Michelle, who writes:

> I think that although my consultant is very good, many health professionals take the view that patients are helpless beings who require instruction! I’m not into that kind of thing and if someone tries to tell me to do something that I know isn’t right for me, then I won’t do it. I think that I

> am the one with the disease – not them – they learn about it in theory but they don't live it. They don't 'live' the medications and side effects either, so I think that my view is very important.

Again this demonstrates how important it is to inform patients, to educate them and let them take an active part in the decision making surrounding their disease and treatment of it. The possible consequences of not doing this are highlighted by Michelle who says that she won't follow the instructions given to her unless she knows that they are right for her in her opinion.

5.5 Conclusion

In this chapter I have presented the raw data from participants, related to the main themes and sociological discussion upon which the research is based. The data has been presented in line with the themes of the literature review. In the following chapter I discuss the sociological significance of the data in more detail.

Chapter 6: Discussion

6.1 Introduction

In this chapter I explore the link between the participant narratives, my own experience and the literature. The chapter develops themes identified in the data chapter (identity, stigma, diagnosis, relationships with families and professionals, and choice and control) to explore stages in the development of personal narratives as responses to the biographical disruption caused by IBD. The purpose is to show how these narratives can be understood within the contexts of specific and differing circumstances.

The discussion is structured around the main data themes of 'Biographical Disruption and Illness Narratives', 'Living with IBD', 'Becoming a Patient', and 'Coping and Control'. Running through these the theme of health and well-being in relation to IBD and how the disruption to health and well-being is ever present.

Danna and Griffin (1999: 361) propose that the ways in which health and well-being are measured and defined vary and that there is a tendency to lean toward two different concepts. The first suggests that health and well-being relates to the actual physical health of individuals, as defined by the physiological / medical symptoms and by the statistical rates of physical illnesses, symptoms and diseases. The second suggests that the terms health and well-being can refer to any of the mental, psychological, or emotional traits of individuals as shown by emotional states and the rates of mental illnesses and diseases.

The physical definition of health and well-being is evident in several participant accounts. For example Tina says that she is not healthy because of blood loss, pain and headaches. Jenny says that she can never consider themselves as healthy again as she knows that her body is 'broken'. Conversely, others, for example Frances and Mark, comment that their diagnosis has been a factor in changing lifestyle and becoming healthier. The idea of being given a diagnosis and subsequently modifying behaviour is noted by Newson *et al* (2012: 51) who say:

> For people with a chronic illness, adopting a healthier lifestyle, such as smoking cessation, increased physical activity, eliminating heavy alcohol consumption and improving diet, can extend longevity, reduce the recurrence of an event and enhance quality of life.

Participants drawing on Danna and Griffin's second concept frequently highlight factors such as their friends, their social circle, church and sport as part of what contributes to their health and well-being.

Thus, there is a whole array of factors contributing towards well-being and these factors may be viewed as part of being / feeling 'healthy' or 'unhealthy'. For Dolan *et al* (2008: 94-122) factors which relate to the concept of well-being include income, age, gender, ethnicity, education, physical and psychological health, work, community involvement, exercise, religious activity, having children, having relationships, family and friends. This demonstrates how far-reaching the idea of well-being may be. It is not a concept that is based purely upon physical or mental health or ill-health. Rather well-being may be positively or negatively influenced by many factors within the life of an individual.

Drummond (2000: 235) relates health and well-being to happiness and social relationships, and goes on to also propose that well-being depends upon the setting / context of individual circumstances, suggesting that the most important issue and area of importance to people was how happiness may be experienced and found within the context of emotionally-significant relationships in the social arena. Drummond goes on to propose that there is great variation between different individuals and that this also varies through time, therefore implying that the idea of quality of life should be considered as an existential concept. In some ways my research supports Drummond. There is evidence amongst participant accounts that their health and well-being is related to multiple factors. This may be the physical symptoms of IBD, but also factors such as exercise, social interactions and relationships with others (e.g. Frances, Mark, Abi). However, there are challenges to Drummond. Some participants within my research do focus primarily upon the physical symptoms and treatment of their IBD as a measure of health and well-being (e.g. Tina, Jenny, Lauren).

6.2 Biographical Disruption and Illness Narratives

6.2.1 Reflections on Biographical Disruption

The disruptive impact of IBD on lifestyle, and sense of self and identity, was a recurring theme. Bury (1982: 169) proposes that biographical disruption is related to the idea that chronic illness can be seen as:

> … a major kind of disruptive experience… where the structures of everyday life and the forms of knowledge which underpin them are disrupted… there is the disruption of taken-for-granted assumptions and behaviours; the breaching of common-sense boundaries… Second, there are more profound disruptions in explanatory systems normally

> used by people, such that a fundamental re-thinking of the person's biography and self-concept is involved.

This definition of biographical disruption is applicable in many areas of participants' lives. For example, several discuss the effect of their IBD on their paid / employed working life (e.g. Graham, Geoff, Abi, Mark, Emma and Rachel). Some seem to find it difficult to carry on as 'normal' in their working life whilst suffering from IBD. Several comment on their difficulties, and it seems that for some, the physical symptoms become too overwhelming and time consuming to be able to carry out a job or in some cases at least, a full time job (e.g. Mark and Abi). This is also something noted by Bury (1982: 176) who argues '…one of the most difficult areas of maintaining normal relationships, and mobilising resources, especially among younger sufferers, is at work'.

The impact varies significantly between different participants, but IBD appears to have a general negative impact in the ability to remain in paid employment. There are examples of hours being reduced (Mark, Geoff and Abi), time off sick (Geoff, Emma, Sally and Rachel) and individuals being taken through disciplinary procedures due to time off work through illness (Geoff, Emma).

Working life is one of many characteristics that form a person's identity, and the loss of work or inability to fully participate in working life is therefore affecting and / or changing an individual's identity. Asbring (2001: 312) supports this and argues 'people with chronic illnesses often suffer from identity-loss'. Asbring (*ibid*: 315-316) goes on to say:

> Becoming chronically ill can lead to extensive social consequences which are often significant for identity, such as not being able to carry out one's work, having financial difficulties because of unemployment or a low level of sickness benefit, or a limited social life and family problems.

This is something that rings true with some participants. For example, Graham describes the way in which work leaves him so fatigued that he is unable to do anything in the evenings other than go to bed early. Michelle writes about the way in which her symptoms mean that she is unable to fully care for her children and that she has to get help to do this. Sally writes about how having been on incapacity benefit she started working again and that this allowed her some self-respect back.

Meenan *et al* (2005: 548) carried out research into the impact of chronic conditions, and the subsequent ability of individuals to fully continue with or carry out paid employment. They found:

> Despite this evidence of ongoing, reasonable medical care and adequate function, subjects experienced numerous socioeconomic impacts from their disease. A majority of the working subjects were fully disabled.... and most of the others had to change occupations or reduce their hours. This effect on work was found across all occupational and sociodemographic classes, indicating the pervasive effect of this chronic disease on employment. As a result of this work impact, many subjects suffered wage losses that produced major decreases in personal and family income.

Again this is very relevant to the participants in my research. Many of them (Graham, Geoff, Mark, Emma, Abi, Sally, Rachel, Michelle) report that they have problems with work, from changing occupation through to reducing hours or stopping working completely.

This is a good example therefore of the way in which the structures of everyday life are affected. The taken-for-granted assumption that an individual is able to work and earn an income is challenged and there is disruption, potentially permanent, to the life which an individual may have previously taken for granted. So many participants in my research have had their working lives severely disrupted and numerous examples are shown. Within my group of participants it is clear that IBD has a major impact on the ability to work and earn an income. But this lack of ability has a wide-reaching impact.

Tiredness and fatigue seem to be a very common theme amongst participants and these factors understandably appear to have a negative impact upon the ability to work or to work full time. Tiredness and fatigue are not symptoms that can be openly 'seen' or 'observed' and may therefore make it more difficult for employers to understand. It is recognised that hidden symptoms may be a problem with regard to people being taken seriously (Garro, 1994; Lipson, 2004) or in extreme cases being disciplined. Hay (2010: 268) comments '…people who cannot be productive while chronically ill are at best pitied and at worst condemned, their suffering delegitimized and their worth devalued', and indeed this seems to be the case above with some participants in their workplace. I have already noted that two participants (Emma and Geoff) have been through disciplinary procedures due to time off work because of their IBD symptoms. But this condemnation and de-legitimisation is another disruption. I argue that it is a disruption to life, identity, self and has a deep impact on the individual's narrative. There are legal avenues to protect people against this situation but as with all legal solutions they can be costly, take time and are certainly stressful (Hurstfield *et al*, 2004).

Biographical disruption and a change in self and identity does not just happen with paid work. It can also happen in unpaid working life. Another area worthy of consideration is the effect of chronic illness on the ability to continue work within the home. 'Domestic tasks and activities continue to be seen as 'non-work' not just because they are not paid, but also because they are seen as born out of love and affection and are contained within duty and obligation' (Gregory, 2005: 374). Gregory (*ibid*) goes on to say: '[m]uch of the *social* interaction which takes place in families also ensures the well-being – emotionally, physically, psychologically – of family members. The intrusion of the unexpected and the unwelcome, such as illness or disability, can mean considerable disruption to family life'.

Some participants write about their struggles with family life whilst suffering from IBD. For example, difficulties with playing with children, going out for the day and being able to care for children. For example, Tina writes of the way in which her daughter finds the situation so difficult to deal with that she would prefer to spend time with other family members at weekends and is angry that Tina does not have the energy to do things with her. Michelle describes the way in which her IBD symptoms means that she is unable to carry out the childcare which she believes she should be carrying out and that she needs to ask her husband for help.

The guilt of being unable to care for children due to illness and the side effects of treatment is discussed by Vallido *et al* (2010: 1441) who says '...guilt related to feeling too tired to mother, being short-tempered when feeling unwell'. For

those who have a chronic disease such as IBD, it is normal to experience a range of emotions such as anxiety, depression and other negative thoughts, but it is how well these emotions are dealt with which affects how well an individual adjusts to the disease (DeRidder *et al*, 2008: 248) and how the disease may therefore affect relationships with family.

Motherhood, fatherhood and caring for the children in the home is part of many people's identity. Wilson (2007: 616) discusses identity, chronic illness and motherhood in chronic illness (her research is based on HIV positive individuals). She argues that many of her participants were aware of the stigma of not doing a 'good enough' job and that they were keen to promote their identity as a 'good' mother. I see no obvious evidence of this within the participant narratives. I see disruption within the home as a result of IBD symptoms and there is evidence of regret at not being able to carry out tasks in the home. However, no participants comment that they outwardly try to project or create an image of something that they are in reality unable to achieve.

Mothering (and fathering) may be threatened by chronic illness, where the symptoms and the effects of illness may be debilitating (Karnilowicz, 2011). The impact on mothering through lack of energy and exhaustion is also highlighted by Savvidou *et al* (2003) who found that the medications associated with treatment, produced symptoms of tiredness and lack of ability to effectively cope with children and therefore have a positive relationship with them. Many of the drugs used in IBD such as steroids, create extreme tiredness. The disease itself also causes tiredness. This therefore may have an effect on the ability to

carry out work in the home and also to maintain positive relationships with children. It is interesting that there is little research on the impact of chronic illness on fathering and also that the male participants in my study did not highlight this as a problem for them. Evidence perhaps that parental expectations are still differentiated by gender (Letherby, 1994; Dermott, 2008).

Another area where biographical disruption occurs, as defined by the above definition, is within relationships with friends and significant other people. The participants regularly discuss their changed ability to fully participate in social activities and friendships. Many say that they cannot be fully open about their condition with their social circles. Other participants openly discuss the effect that their diagnosis and symptoms have upon those close to them. Sally notes the way in which it has drawn her closer to her mother who also has IBD and that she receives a lot of support from her mother, including childcare help. However, Sally has also found that her daughter has withdrawn from her since diagnosis, preferring to spend time with other family members. Rachel writes of the way in which her relationship with her husband has deteriorated as a direct consequence of her IBD. He finds her unclean and the disease too much to deal with. This effect varies amongst participants and ranges from support through to almost ending relationships as a result. Certainly, it does not seem that there is a clear predictive impact on individuals with regard to their relationships with others. Each participant seems very unique in their assessment of the situation. However, what is consistent is that there is an element of disruption (either positive or negative) and a rearrangement of what is acceptable or normal within the life of each individual.

Bury (1982: 169) talks of the changes that a diagnosis of a chronic condition may cause. He describes it as 'the kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted'. He goes on to argue that a serious illness will prompt the movement of resources from other people within a social network 'bringing individuals, their families, and wider social networks face to face with the character of their relationships in stark form, disrupting normal rules of reciprocity and mutual support'. This is certainly relevant to my participants' responses. Additionally, my own experience is that on occasions I do have to ask for more help than I would like to and am sometimes unable to return the favour. I limit the number of people I am likely to turn to, and these are generally the people I am very close to who I know fully understand my predicament. They are the people who are emotionally involved with my life and who will not question. However, the disruption of normal rules appears to work both in a positive and negative way. This is demonstrated by the fact that some participants receive higher levels of support and understanding. Others feel that their relationships are threatened and that their diagnosis and symptoms are driving significant others away.

Certainly some research suggests that support from social networks may decrease over time with a chronic condition. As an individual becomes more dependent on others, the relationships may become unbalanced, leading to this breakup (Grant and Wenger, 1993; Williams, 1995). The involvement of significant other people therefore may well fluctuate according to their own needs, whether these be emotional or their perceived sense of level of responsibility (Muhlbauer, 2002; Carpentier and Ducharme, 2003). It has also

been documented that caregivers (including those close to the individual) may sometimes experience a high level of frustration which may lead to them minimising contact and involvement. This is something that is certainly seen within the participant responses (for example Rachel and her husband). But conversely there are many examples of individuals who experience a great deal of support from those around them. Again, this demonstrates that there is a high degree of variability and that there is not a one size fits all.

6.2.2 Illness Narratives

Illness narratives are an essential part of this thesis. The accounts given by the research participants are the core of the research and their voices / narratives give great insight into how individuals respond to the biographical disruption associated with IBD.

In his later work, Bury (2001) has a very relevant discussion about chronic illness narratives which acknowledges differences between narratives. Firstly Bury (2001: 268-274) discusses what he calls the 'contingent narratives'. This is described as the aspect of an individual's story which is involved with beliefs and knowledge about factors involved with the onset of a chronic disorder, its symptoms and the effects that it has upon the body, the self and other people. According to Bury (*ibid*), within this narrative, it can be said that there are two different views of illness, these being 'categorical' and 'spectral'. Categorical views may be considered as having a bio-medical slant and involve the recognition of the difference between normal and pathological, where symptoms are seen as abnormal from the normal state. Examples of this within the participants are numerous. For example, Tina sees herself as unhealthy

because of her anaemia, headaches, joints and blood loss. Jenny sees herself as unhealthy because her body is ‘broken’.

The spectral view relates to the personal and social and relates more to social status and the reaction of others. It is clear that although these views are seen as separate, individuals are likely to move fluidly between these views within the contingent narrative. Certainly, my own experience is that of a deepening meaning and understanding of disease pathology and treatment and the difference these treatments may have. However, I temper this knowledge with the difference the disease and the treatments have upon me as an individual and how this affects the way I live my life and my interactions in different areas of my life. As seen in the data chapter, participants discuss the symptoms of IBD in quite some detail but within the same narrative also go into depth regarding how these symptoms affect them and their lives – the disruption that IBD causes to their lives.

The next narrative Bury (2001: 274-277) discusses is called the ‘moral narrative’. This narrative relates to the individual evaluating the personal and the social aspects. It is where the person attempts to understand and justify the altered relationship between self, body and society which has been brought about by illness. This is very apparent within all the participant accounts, and has clear links to the concepts of stigma previously discussed and the ways in which an individual may publicly deal with a long term condition. It links with what Frank (1997: 117) calls people trying to be ‘successfully ill’, whereby an

individual attempts to live with, adapt and change in order to keep face and continue to live as others would expect.

The third type of narrative discussed by Bury (2001: 277-280) is called the ‘core narrative’. This type of narrative relates to the ways in which individuals will try to understand events in terms of how they feel they relate to themselves and to others around them. There is a cultural and experience element to this type of narrative and it is related to the core experiences and understanding a person has and how they use this to interpret what is happening to them. Examples of this are scattered throughout the participant accounts with numerous individuals commenting on the ways in which they deal with their IBD and the ways in which they feel they should ‘cope’ with it. For example, Abi feels that she must make the best of it, that there are people worse off than her and that she must therefore just continue as best as possible.

There is a clear link here to the illness narratives suggested by Frank (1995) which are the chaos, quest and restitution narratives. The chaos narrative refers to the experience of a lack of control, struggling to comprehend what is happening and frequent changes in health which may ultimately end in struggles socially. The chaos narrative seems very applicable to the ever-changing nature of a chronic condition such as IBD and is demonstrated regularly throughout the participant accounts. For example, Kathy describes the way in which she lives her life normally and then has to change everything when her condition flares up. She says that she has to live life according to how

she is feeling at that moment in time. Sally speaks of being irritable, exhausted, depressed and lacking enthusiasm as a result of her fluctuating symptoms.

The quest narrative refers to the way in which an individual may see their illness as something to be challenged and fought against, which may lead to change in order to experience as little disruption as possible. The restitution narrative refers to the way in which an individual may believe that whilst treatment and medicine will restore the body to how it should be there is an expectation that the individual also has the duty to make an effort to resolve the illness and move forward. Certainly the participants demonstrate this narrative in various ways from education through to trying to develop a healthier lifestyle through diet and exercise. Within this thesis, the participants show elements of all these narratives, not uniquely, but in combination together. There appears to be elements of each narrative present in each individual at any given point in time. I however focus more on how the narratives play out with reference to the main themes below.

6.3 Living With IBD

6.3.1 Identity and Self

Kelly (1996: 245) argues that self is:

> ... a cognitive construct that is constantly being reconstructed and which is expressed in the various narrative and autobiographical accounts which are offered by the individual in self-presentation. Self is linked to body in so far as common-sensically (*sic*) self and body are experienced as one and the same thing. However, when bodily demands conflict with desired self-presentation the individual becomes acutely aware of the divergence between body and self.

This conflict between the desired self and the body as it is, is apparent in the participant narratives. This is voiced in different ways and ways of coping are demonstrated via the use of different approaches. For example, there is evidence from some participants including Michelle, Kathy and Mark, that they make a distinction between when they are 'well' and when they are 'unwell' (when they are or are not suffering from symptoms and how bad those symptoms are).

A bigger pattern and emphasis across the data involves the need to adapt life as a result of the disruption to 'normal' life caused by IBD. Weinert (2008: 364) discusses chronic disease and the need to be able to adapt life around a chronic disease, saying:

> Because chronic illnesses are the foremost health problem globally; many people are faced with the task of adapting to a chronic health condition. Adapting is the process whereby thinking and feeling individuals use conscious awareness and choice to create human and environmental integration.

This fits in with participant responses whereby they have changed and adapted consciously in order to live a better life and to make their life easier. For example, Abi discusses the way in which she has changed her working hours in order to make her life easier alongside her IBD. Frances argues that her diagnosis of IBD has made her make more of a conscious effort to become healthier and to exercise more and eat more healthily. Rachel writes of becoming more 'militant' in taking care of herself and taking breaks in order to keep functioning 'normally'. My own experience dictates that I do need to be reasonable in my expectations of myself. I find that I need to go to bed earlier and get a lot of rest in order to be able to function better the following day. If I

am unwell or tired I limit my activities to those which are most essential. I try to eat more healthily overall and make sure that I have a freshly prepared meal every day. Perhaps these are all small changes, but I find overall that they make a difference and help me. These are all good examples of Frank's (2000) restitution narrative, whereby participants are demonstrating the behaviour of making conscious changes in order to positively rectify their health in order to move forward and make themselves better.

The concept of 'normal' and the adaptations made by participants supports Weiner (1975) who wrote of normalisation and the ways in which behaviour may be modified to maintain a normal life. This includes covering up the illness and attempting to keep up with the peer group. This links to the coping strategies discussed in the previous data analysis chapter, where one of the coping strategies suggested by Breakwell (1986) and Page (1984) was described as 'covering'.

6.3.2 Fear and Receiving a Diagnosis

Fear is expressed by participants in a variety of ways. This varies from fear during the process of diagnosis (e.g. Graham, Mark, Maggie, Rachel, Michelle and Frances) to what happens to the person now that they have an incurable and long-term disease (e.g. Jenny, Graham and Lauren). Also involved is the fear of treatment and the beliefs held about different drugs and treatment options (with particular reference to when treatment decisions have not been fully explained).

Several participants comment upon their fears prior to and around the time of diagnosis. There often appears to be a fear of what the diagnosis might be and the word that seemed to be used in relation to what the respondents fear the diagnosis to be was ‘cancer’ (e.g. Graham, Maggie, Mark, Michelle, Rachel and Frances). There is a clear link to the chaos narrative described by Frank (1995) during the time prior to and around the time of diagnosis. It is a time of uncertainty and fear. It is a time described by the participants of not knowing what will happen and having an uncertain biography and future.

Many of the participants report lengthy delays in diagnosis (and subsequently treatment) and incorrect diagnoses before eventually reaching the correct diagnosis. In most cases it was a long process to achieve a diagnosis and to get the help required to reduce or eliminate symptoms (e.g. Graham, Lauren and Sally). This is also true to my own eventual diagnosis. It took a lot of time and incorrect diagnoses before I eventually got the correct diagnosis and subsequent treatment.

Some participants also express their relief at having a diagnosis and for having a tangible reason for feeling the way that they did with regard to their symptoms. This demonstrates how fear is caused by uncertainty, the unknown and lack of control over time. Woodward *et al* (1995: 328) acknowledge this, and argue:

> Without a diagnosis and without affirmation that they were ill, they had struggled to make sense of what was happening to them. Without a name for the condition, they had lacked a language for discussing their complaints with others. A compelling part of their lives could not be shared. They had no way to explain their grief at so many changes in the way they lived their lives. In contrast, with a diagnosis, they had a label that others might understand or recognize (*sic*), a label that reassured

> them that others had also shared their form of suffering…. Armed with this framework of understanding their symptoms, many said they felt more in control of the circumstances of their lives, able to work out meaningful ways of managing their problems.

Without a diagnosis, whilst suffering from painful and potentially frightening symptoms, it would perhaps only seem natural that a person may assume the worst and within my participant group, without exception, there was concern and worry regarding what the diagnosis 'might' be. As highlighted above, the main concern is a possible diagnosis of cancer and therefore it is worth adding that there have been big government campaigns with regard to bowel cancer and awareness. NHS online describe the symptoms of bowel cancer as:

> The main symptoms are blood in poo for three weeks or looser poo for three weeks or more. Other symptoms include:
>
> - a pain or lump in your tummy
> - feeling more tired than usual for some time
> - unexplained weight loss
>
> (http://www.nhs.uk/bowelcancer/pages/blood-in-poo.aspx)

The description of the symptoms of bowel cancer is very similar to the symptoms that an individual suffering from IBD might experience. It is therefore understandable that an as yet undiagnosed sufferer of IBD may be concerned by this. Although the UK Government are attempting to raise awareness of bowel cancer (and rightly so as it is a major cause of illness and death), they may also causing alarm and concern amongst other groups of people who suffer from similar symptoms but who do not suffer from bowel cancer.

Nijkamp (2002) argues that fear is experienced when there is clear cause for it: in the case of IBD diagnosis it will be because of the very obvious symptoms that an individual is suffering from without an understanding of what is causing

these symptoms. So although there is a clear cause in terms of concerning symptoms, there is also uncertainty and an element of the unknown which is likely to also compound the feelings of fear that an individual may suffer from.

Kennedy *et al* (2008: 404) describe the way in which patients who have been suffering from undiagnosed symptoms may begin to fear the worst, arguing:

> A host of conditions (such as multiple sclerosis, Lyme disease, systemic lupus erythematosus [SLE], and hyperparathyroidism) present with ill-defined symptoms; these are often difficult diagnoses to make. Moreover, when symptoms persist and defy diagnosis, some patients fear the worst and assume an insidious course from a progressive condition.

The data indicates that the diagnosis of IBD can be a lengthy and frustrating one. Health professionals seem to get it wrong frequently in IBD diagnosis before they make a definitive and correct diagnosis. This is demonstrated time and time again in the responses from the participants and also in my own experience. Participants (for example Frances, Michelle, Lucie, Abi, Jenny and Tina) were routinely diagnosed with less serious problems such as irritable bowel syndrome, haemorrhoids and dietary issues before they, after a lengthy process of misdiagnosis, are diagnosed correctly with IBD. The inability to diagnose correctly from the outset added to the fear and anxiety that the participants suffered, due to the uncertainty experienced. This uncertainty directly links into disruption, identity and the legitimisation needed through being given a medical diagnosis / label. The disruption experienced in the participants' lives whether it be at home, socially or in employed work is linked with everyday identity and until a diagnosis is given it is hard to validate this disruption and make it 'acceptable'. This links in with research by Ballard *et al* (2006: 1299)

who looked at delayed diagnosis in the chronic condition endometriosis, proposing:

> Before diagnosis of endometriosis, women spoke about their difficulty in explaining what was wrong with them to others. This created problems at work, where employers were sometimes unsympathetic to absences, and within social environments, where women also had role obligations. Having a medical label, therefore, confirmed the genuineness of the symptoms and legitamized (*sic*) the women's inability to perform to their full capacity, providing the sanction required for social support.

At and after diagnosis, it was repeatedly mentioned that there is a problem in terms of a lack of information and hand-over of knowledge to the individuals newly diagnosed with IBD. This is important because giving more control through information is shown to increase well-being and the likelihood of taking prescribed medications. As Gallant (2003: 170) argues:

> Chronic illness self-management has received much attention in the health behavior (*sic*) and health education literature in the past decade. Much of the most prevalent chronic illnesses, such as heart disease, diabetes, and arthritis, entail a significant self-management component, often including regimens of medication taking, physical activity, dietary and weight management, and specific disease-related behaviors (*sic*). An accumulating body of empirical literature demonstrates that successful self-management of chronic illness is related to better overall physical and psychological health outcomes.

This is relevant and there is evidence that upon diagnosis, participants educate themselves and take on significant elements of self-management and control of their condition. This links in with both the quest and restitution narratives described by Frank (1995), as participants search for information and resolution of symptoms and associated problems. For example, Michelle has learned about when she needs to take steroids to stop a flare and has a procedure in place whereby she is able to initiate treatment and has an easy procedure in

place for escalating things to her consultant if required. Graham carries out research on the condition and reads about treatment and feels that this gives him an element of control. Kathy states that she has learned enough to in general be able to successfully manage her condition medically. Tina comments that she makes the decisions regarding her treatment in combination with her medical professionals. The ongoing theme amongst these participants is that they feel a sense of 'control' through this ability.

6.3.3 Experiencing Stigma

Many participants write of issues and concerns around the sharing of their problems with other people. For example, Michelle believes that disclosing her problems to others would put them off seeing her. Frances says that she feels uncomfortable telling other people and that they do not need to know. Jenny talks of wanting to appear the same as everyone else and of the importance of appearing outwardly strong. These people include both those close to them in terms of family members and also those in their close and extended social circle.

The participant narratives appear to raise two distinct strands to this reluctance to talk to other people regarding their IBD. One of the issues lies with how individuals perceive that people will react when talking about and discussing the disease, especially with its reference to bowels and what perhaps many people would class as personal and private body functions. The other strand lies with the way in which some participants have been treated by those around them after sharing their story or after other people have seen the individual whilst they are acutely unwell and suffering from symptoms.

Within society, people are expected to live within certain social rules and norms. There were various incidences of participants being unwilling to talk to others about their condition for fear of people feeling disgust, shame or simply not looking at the individual in the same way any longer and not fitting within these social rules and norms. This fits in well with Becker's (1963:1) argument. Thus:

> ...social rules define situations and the kinds of behavior (*sic*) appropriate to them, specifying some actions as "right" and forbidding others as "wrong". When a rule is enforced, the person who is supposed to have broken it may be seen as a special kind of person, one who cannot be trusted to live by the rules agreed on by the group. He (*sic*) is regarded as an outsider.

More recently, Corrigan (2000: 49) extends this theory, arguing that it is not the label that leads to stigmatisation and people treating a person differently, but that it is the different behaviours demonstrated by someone who has a labelled disease.

Therefore, people who are not seen as 'normal' within society and in the social world may be singled out and seen as different which is the foundation / basis of being stigmatised. This appears to be what several participants were worried about. They believed bowels and toilet habits associated with their disease was a subject that they should not be talking about with other people, or that other people would not, or did not, understand. For example, Tina discusses the misunderstanding about her and her IBD whereby she believes other people have started to feel that she is lazy, rude or can't be bothered with social events instead of it being related to her condition. Sally discusses how antisocial IBD is and that people find it hard to understand. Graham writes that neither family nor colleagues understand and therefore it is not easy to discuss. Thus, participants

tried to keep within what they perceive to be the ‘rules’ and to not become an ‘outsider’.

Goffman gives a similar definition of stigma as an ‘attribute that is deeply discrediting’ and that reduces the stigmatised individual ‘from a whole and usual person to a tainted, discounted one’. Goffman (1963: 3) suggests that stigma may be “discrediting”. This may occur when a disease or something that is not considered ‘normal’ is immediately obvious to outsiders such as blindness or physical deformities. Alternatively, individuals may be ‘discreditable’ whereby the stigmatised condition is not readily observed by other people. Following this argument, it is likely that IBD may be seen as ‘discreditable’, because the condition is not immediately noticeable to the casual observer. Stigma may be seen as a spoiled social identity because it represents deviation away from what society considers normal and acceptable, and the stigmatised person is then treated as different or unacceptable in some way. As discussed above, many of the participants prefer to be private about their IBD in public and to not disclose their condition to other people. This sense of stigma and the possibility of being discredited is not limited to friends and strangers within the participants, but is also a factor in relationships with those close to participants. For example, in the sense of actually being ‘discredited’ Rachel speaks openly. She discusses her relationship with her husband and the reactions she experiences from him regarding her IBD. She speaks of avoiding a stoma so that he doesn’t have to deal with it and the way in which he will not touch her during a flare because he sees her as unclean.

The running theme through this is identity: both in terms of sense of identity and of possibly changed identity. Stigma and identity are clearly linked here. 'Negativism' as discussed by Breakwell (1986: 113) 'involves outright conflict with anyone who would challenge the identity structure'. This fits in well Adams *et al* (1997: 190) who argued that the diagnosis of a chronic illness leads to disruption in many areas of life including future plans, relationships and work and that this is likely to lead to a diminished sense of identity, saying:

> An important modifying factor here is the significance of the illness to the individual, particularly the negative connotations and stigma associated with the condition.

Adams *et al* (*ibid*: 199) go on to argue:

> … when the components which make up an individual's social identity are in contradiction or conflict, he / she will attempt to reconcile attributed social statuses both with each other, and with his / her personal identity. Failure to achieve such a reconciliation is seen as resulting in an unsatisfactory or "diminished" sense of self.

The ways in which participants such as Rachel, Graham, Tina and Sally avoid telling others of their problems and experience problems in relationships with others really highlights these issues. Self-identity interlinked with social identity appeared to be running concurrently with the idea of perceived stigma and the potential for spoiled identity.

6.4 Becoming a Patient

6.4.1 Professional / Patient Interactions

It is important that all relevant parties communicate effectively and are treated as mutually important in effective management of a chronic disease. Indeed, Holman and Lorig (2000: 526) argue:

> Now that chronic disease has become the principal medical problem the patient must become a partner in the process, contributing at almost every decision or action level. This is not just because patients deserve to be partners in their own health care (which, of course, they do) but also because health care can be delivered more effectively and efficiently if patients are full partners in the process... In most cases doctors cannot accurately detect the trends themselves. The patient knows them better, and provides information and preferences that are complementary to the doctor's professional knowledge. In general, the patient provides the individual information and the doctor the general information, and both are necessary for effective management.

When communication breaks down it can be highly problematic and affect the quality of care and subsequently disease outcomes. Communication with health professionals within the participant responses varies considerably. However, there is regular discussion of doctors not listening or on occasion believing the individuals. For example, Sally had a lengthy delayed diagnosis and was misdiagnosed several times. At one point she reports that she was told that she was attention seeking and that it was in her head. This, in all cases led to a breakdown in communication and a decreased sense of trust in treatment and care. The implications of this amongst participants seem to be linked to the levels of perceived stigma and altered identity experienced. This is discussed by Fong Ha *et al* (2010: 38) who propose:

> Effective doctor-patient communication is a central clinical function in building a therapeutic doctor-patient relationship, which is the heart and art of medicine. This is important in the delivery of high-quality health

> care. Much patient dissatisfaction and many complaints are due to breakdown in the doctor-patient relationship. However, many doctors tend to overestimate their ability in communication.

Understanding each individual **as** an individual is important for effective treatment and monitoring. This will range far further than a blood test result or a set of scientific pathology. This is noted by May *et al* (2004: 142) who argue:

> …while the central focus of medical knowledge and practice is on revealed pathology, the consultation needs to take into account a far wider set of conditions and problems, at the centre of which is the patient's own subjective experience of illness.

This shows the importance of catering for the 'whole' person and is likely to therefore involve more than one health professional. This is a view that is - supported by Wagner (2000: 569) who says:

> The delivery of health care by a coordinated team of individuals has always been assumed to be a good thing. Patients reap the benefits of more eyes and ears, the insights of different bodies of knowledge, and a wider range of skills.

The participants appear in general to have better relationships with health professionals as time passes further from their diagnosis. Rachel voices this clearly saying that she is of the strong belief that the more an individual learns over time about their condition and the treatment of it the better the communication with health professionals and the better the outcomes. It can be seen that at this point the chaos narrative is seen less frequently and that the restitution narrative becomes more prominent (Frank, 2000). Michelle describes the way in which it has taken her time to learn about her condition since diagnosis and in time has found the right doctor for her who will listen to her and understands how she works. This is interesting because there is a clear link

back to time and levels of perceived and actual control. Initially it has been seen that there are high levels of disruption and fear. Over time, with increased knowledge and confidence the narratives appear to change. The participants become more confident in their own knowledge and experiences and contribute more towards their health care in combination with the health professionals. This in turn leads to more willingness to take an active part and to have a basic level of trust in their treatment.

6.4.2 Relationships with Family and Significant Others

According to Kulik and Mahler (1989) relationships and support gained within relationships can be absolutely vital to either maintenance or restoration of an individual's health. Gregory (2005: 372) argues 'the experience of chronic illness, for the patient and for the rest of the family, is, quite literally, an on-going lived experience'. This is supported by Gonzales *et al* (1989: 69) who states:

> Clearly, disabling medical conditions such as traumatic injury, kidney disease, multiple sclerosis, coronary artery disease, and so on, pose unique and unusually severe stresses for the person who must adapt his or her sense of self and life style to the limitations imposed by the illness. While advances in medical technology have lengthened patient survival and improved the expected medical course of many of these conditions, there remain concerns about the psychological and interpersonal quality of life available to these patients and their families.

Therefore, another potential area of support (and disruption) is from family and other significant people in the life of the person suffering from IBD. Chronic disease puts a strain physically and emotionally on a person but it can also put a strain on personal relationships. Indeed, Lyons (1999) suggests that the challenges that are faced in a relationship as a result of chronic disease are very similar to the physical challenges faced by the patient. This is highlighted

by participants who report very different results of these challenges. Some individuals have supportive family and significant people whereas others find relationships breaking down as a result of the challenges. For example, Graham, Tina, Sally and Abi all gain support from family or others who are close to them. However, there are other participants who experience problems in their relationships as a result of their IBD. Tina is an example of an individual who has found support but not from her partner whom she says it affects due to not being able to be intimate with him. Lucie's partner left her just before her diagnosis due to her being unable to have children. Rachel reports that her husband is unable to understand at all and just sees her as different to how she used to be and wants the "old Rachel" back. Those individuals gaining support, as reported above, appear to use this as a form of education and empowerment. Those not gaining as much support do not appear to lack in confidence with regard to advocating for themselves but clearly have not necessarily got the support of their partner to do this. So, it is not simply the thought of the disease or the understanding of the disease but it is also the physical symptoms experienced that create problems for both parties.

Badr and Acitelli (2005: 465) propose that 'finances, division of labor (*sic*), social activities, and interaction patterns can change' within personal family relationships due to chronic disease. This is furthered by Gallant (2003: 172) who says:

> … it is reasonable to assume that family members and friends may facilitate the self-management process in a variety of ways, providing, for example, occasional advice, emotional support, tangible support that indirectly facilitates self-management (e.g., shopping for heart-healthy food) and more direct assistance with illness management activities.

Thus, there is a triadic relationship between the individual with a chronic disease, their significant others and medical professionals. These relationships may play an important role in well-being. Kleinman (1986: 37) argues:

> … much of clinical communication takes place in the context of the family and lay referral system… it often involves the family as well as the patient' and 'the target of treatment, then, will be seen as involving considerably more than the patient's body. The doctor will be viewed as only one, and perhaps not the most important, agent of treatment. And the family-patient relationship or family-doctor relationship will be regarded as the 'real' therapeutic relationship.

This demonstrates the possible importance of the negotiation, discussion with, dependence on and relationship with family members and those close to the individual suffering from chronic illness. Although participants in my research do seek support from other individuals and use this to educate and empower within medical encounters, they do not completely support the above. What does seem important in maintenance of health and well-being to the participants is a whole range of factors, not just based on relationships. There is an emphasis on other important factors such as physical activity (Frances and Mark), Michelle and Kathy both mention that just having friends and family around is helpful and Michelle mentions socialising, church and sport. This certainly supports the concept of individual well-being being about more than just the body. But the participants show a greater degree of self-sufficiency and less dependence on others than some of the literature may suggest. . More recently Wolff and Roter (2011: 830-831) argue:

> ...families are not only commonly present, but also engaged in medical visit dialogue during routine physician visits. That family companions were commonly reported to facilitate information exchange within medical encounters suggests their presence and involvement may benefit coordination of care and health care management activities.

However, some previous research indicates that this relationship between doctor, patient and family may not be satisfactory. Locker (2000:87) says '… the medical gaze is frequently a narrow one, concerned predominately with disease to the exclusion of its social and emotional consequences for patients and families'. One participant, Sally, is an excellent example of this. She was given her medication and not told of side effects or that the medication being used was also used as a chemotherapy drug. She says that she doesn't feel in control because she doesn't have a say or a relationship with her consultant. Similarly, Lucie states that she lets the consultant prescribe the drugs and gets her information and support from a pharmacist. Michelle believes that health professionals see patients as individuals who require 'instruction', whether or not it is right for them as an individual.

6.4.3 Mutual Support from Other Patients

One way of increasing knowledge is through support groups aimed at particular individuals such as the NACC (specifically for Crohn's disease and Ulcerative Colitis). This provides not just information, but also the opportunity to meet up with other people who also have the same condition on a regular basis. This is something that is discussed frequently by participants (e.g. Graham, Jenny, Abi and Sally). Davison *et al* (2000: 206) discuss seeking other people with the same condition for support and argues that 'the power of this approach lies in the belief that a collective wisdom is born through the shared experience of participants rather than through the professional training or style of the leader'. This is true of some of my participants. Graham gets his best support from his sister whom he believes understands his situation through shared experience

as she suffers from Crohn's Disease. Tina has found another mother at school who has Crohn's Disease and they rely upon their shared experiences to support each other and to 'normalise' the situation and symptoms. Sally and Abi also rely on family and friends with the condition to gain support.

Coppa and Boyle (2003: 68) support this and comment on the uses of support groups:

> Self-help groups offer a unique form of support based on mutual understanding and the experiential knowledge of members. They constitute a potentially valuable resource for assisting people to manage chronic illness and its impacts.

A more detached and anonymous way of achieving support and education is through online support groups – again, something which was mentioned within my participant group. The sense of anonymity within this avenue of support is discussed by Davison (2000) who examined support seeking behaviour online. He found that some groups of people search for online support because of the need to seek out others with the same condition but prefer to do this online because of the anonymity offered. This is true to a limited extent with my participants. Many participants use the NACC and the groups associated with that. Some do use online forums (and were recruited to this research through these forums). They seem to use online internet forums as an additional resource if required as opposed to a main avenue of support. Michelle uses forums for a quick question of for something she perceives as embarrassing, which she finds helpful as nobody there knows who she is. Certainly the NACC is a more public group who have physical meetings and self education sessions, which my participants appear to use more. This appears to some

participants to be because it is a group of people who understand and are also in the same or a similar predicament (e.g. Sally, Jenny, Graham and Abi).

Huh and Ackerman (2012: 853) researched support received by people with diabetes both in group support situations and online support. Those using online support tended to be younger, professionals who were mid-career. But most importantly, they found that those using either form of support were trying to educate and help themselves in order to take control of their chronic disease and the treatment of it. Certainly the participants in my research who have been noted to use the NACC support groups all speak of learning, education, awareness of IBD and the ways in which they can use this knowledge to help themselves.

6.5 Coping and Control

6.5.1 Control and Choice and Shared Learning

The terms “control” and “choice” appear to be words that are repeated regularly by many of the participants with regard to their treatment and intertwined with their relationships with health professionals and the positivity or negativity associated with their treatment. Many participants put great emphasis upon these two concepts with regard to their treatment and they seem to be linked to positive relationships with their health professionals.

It is likely that an individual’s beliefs and perceptions about their illness and the ways in which they react to the illness may have a profound effect upon the physical symptoms. It is also a learning process. As Bury (1982: 173-174) argues:

> The realisation that medical knowledge is incomplete, and that treatment is based on practical trial and error, throws individuals back on their own stock of knowledge and biographical experience. The search for a more comprehensive level of explanation, a more certain basis of coping with the illness is often along and profound one.

From what has been noted above, increased choices or increased ability to make choices may lead to an increased sense of control. This increased sense of control is likely to lead to not only a happier person –as a patient and an individual - but also a patient who is more likely to take prescribed medication and follow medical advice (Seeman and Seeman, 1983; Makoul *et al*, 1995; Hay, 2010). This seems to be generally true within my participant group. However, there are challenges to this idea. For example, Michelle states that as she has learned about her condition and the medication used to treat it over time, she has become more aware of what is and what is not acceptable to her in terms of treatment and side effects. She says that if she knows that a treatment is not right for her, she will not take it. Rachel is another example of an individual with such an advanced knowledge of treatment she acknowledges that a large amount of time she tells the doctors what treatment she requires and they prescribe as she requests. Therefore, a better understanding of patients' perceptions, what is important to them, and what is not could provide opportunities for early help and intervention before any physical problem becomes increasingly serious. Kralik *et al* (2002) propose that people with a chronic condition who are taking an active role in their healthcare tend to feel empowered and able to have an increased sense of self-identity and have thus have increased control over their condition, and this seems particularly relevant to this point. There seems to be a clear argument here that health professionals

need to listen and learn from their patients in an effort to allow them to take an active role and additional control over their condition.

What is apparent from the data is that much of what was said can be directly linked back to the concepts of identity and control. Participants' sense of identity appear changed and formed as a result of their illness. Perceived stigma, relationships with others, taking on responsibility of treatment and fear all appear to have an impact on identity. Indeed, this fits in well with the previously mentioned work where Kelly (1992: 411) argues that 'identity change is concerned with potential labelling, felt stigma, status passage and of experience of power relations in social institutions'. Also relevant is William's emphasis on the importance of the physical alongside the concept of identity.

The participants' self-identity and level of biographical disruption appear to be dynamic and depending on circumstance at the moment in time and this is linked to their level of coping and control. What is clear is that there is a link between the different narratives and that the participants in this research demonstrate a combination of all the discussed illness narratives. Therefore it is not the case that it is an either / or situation. The way in which narratives are related and the attitudes participants demonstrate towards their IBD show the dynamic nature of and the fluidity of the illness narratives written about. Changing perceptions both as an individual and within relationships with others, changing symptoms and treatment, changing circumstances and subsequent levels of coping and control all appear to have an impact on the illness narratives. A narrative at any given moment is simply a moment in time and are related to the changing levels of coping and control. Over time, both long-term

and short-term the circumstances and the narratives change. Individuals adapt and change their narratives as they gain in experience and knowledge along with coping strategies.

6.6 Conclusion

In this chapter I have discussed many of the themes raised frequently throughout the participant interviews. This has included how health and well-being is understood by an individual with IBD. The main themes discussed were ‘Living with IBD’, ‘Becoming a Patient’, and ‘Coping and Control’ with biographical disruption and illness narratives as a running theme throughout, as they underpin all the findings within the participant interviews and relate too to my experience. These themes and the gathered data of this thesis suggest a number of important conclusions that both add to and challenge the existing thought and understanding of biographical disruption and illness narratives. This is now considered in the next, and final, chapter.

CHAPTER SEVEN: Conclusion

The data I collected and the subsequent analysis of the data produced a number of issues to consider and has implications for further research and policy change in the future. In this chapter I reflect on the data, its significance and its potential influence. I discuss the process of carrying out the research and what elements of the research worked well and what could be done differently if the research were to be repeated. I reflect on what I have learned from the process and the research itself and the implications of it on me as an individual.

7.1 Reflections on the Data

At this point, my main focus is on the participant's stories, yet my own story is relevant also. Here I reflect mostly on the experience of the 16 'other' participants and then conclude with reference to my own experience .

Participants generally wrote very lengthy responses to each of my questions and gave me far more detail than I had ever expected. This not only included details about their IBD but also how they felt about their condition and how it affected their life and relationships with other people. These narratives were all different, and affected by differing circumstances, both static and changing.

The depth of information given to me may be in part due to the method of interview. Through the use of email the participants were perhaps more able to say what they wanted with less embarrassment or fear of disclosure. Meho (2006: 1289) argues:

> ...email interviews reduce, if not eliminate, some of the problems associated with telephone or face-to-face interviews, such as the interviewer/interviewee effects that might result from visual or nonverbal cues or status difference between the two... e-mail may safeguard against possible loss of face among some people when they describe potentially sensitive events, experiences, or personal characteristics... In short, in many cases e-mail facilitates greater disclosure of personal information, offering further benefits to both the researcher and participants.

Participant accounts concerned a considerable amount of factual information but participants also discussed the tension that their IBD had created between them and significant others. They talked in depth about problems they had encountered with health professionals and the effects of their IBD on their personal relationships. They also wrote about how any problems and issues affected them in terms of how they felt and the emotional and psychological impact of chronic disease. They not only wrote of the changes and disruption in their life as a result of their IBD but also the ways in which they coped with these disruptions to what they might want or expect from their life.

Well-being

The participants placed emphasis on many different factors affecting their health and well-being, including changes in diet and exercise, socialising and going to church. However, commonly research participants encountered problems in both paid and unpaid work.

A common theme amongst research participants was either changing the kind of paid work being carried out or changing the way that they worked. For example, starting to work part-time instead of working full time, in order to be able to earn money whilst suffering from a chronic disease with unpredictable

symptoms on a day-to-day basis. Unfortunately, despite equality and disability laws, several participants experienced disciplinary action against them as a result of their repeated absences from work due to being unwell or, in one case, hospitalised.

Unpaid work within the home also was affected by the symptoms of IBD amongst participants. Children were mentioned as a theme by participants with problems ranging from a feeling of inability to look after the children through to being unable only when in flare and handing over the reins to another family member during these times.

This multi-faceted understanding of well-being and the disruption that can be caused overall supports Kelly (1996: 247) who argues ‘there are few accounts of chronic illness which do not acknowledge that basic to the experience of that illness is the disruption of the normal and usually desired routines of everyday life’

There are few guidelines to help people deal with these problems and very little recognition of them within NHS literature. Further understanding and recognition of the broad encompassing nature of well-being by health professionals could ease some of the burden on their patients, reduce biographical disruption and positively alter narratives.

Stigma

Stigma was found to play a role in many of the participants’ lives. Many participants voiced a concern around sharing their problems or discussing their

IBD with other people. One concern was how the individual perceived other people would react to discussion of a personal body function with a related fear of subsequent rejection. Other participants had reported directly suffering from discrimination or a bad reaction when talking about their IBD with other people. In an attempt to appear 'normal' and not an 'outsider' as described by Becker (1991: 1), many participants voiced a reluctance and unwillingness to discuss their IBD

Amongst research participants, coping strategies seemed to be inter-linked with a general goal of making the IBD less of an 'issue' and hiding / covering its presence so that other people were unable to detect it. Participants overwhelmingly seemed to want to appear 'normal' and avoid any discussion or opportunity for anyone to have an opportunity to devalue or stigmatise them. This can be seen as an attempt to normalise the situation or to create the least amount of (biographical) disruption possible. However, as discussed, this may be impossible amongst those close to an individual with IBD.

An important area of further research is the difference between how individuals who are newly diagnosed with IBD view their chronic disease and how much they share with others, compared with those who have had the diagnosis longer. It would be interesting to explore how much of the lack of sharing information with others is based around learned experience relating to embarrassment and stigma, and in turn if this is an attempt to reduce disruption to the life which the individual is trying to lead. It would also be beneficial to explore these concepts in relation to other chronic diseases – for example,

diabetes, arthritis, HIV and other often ‘hidden’ diseases which may not be immediately obvious to those who are unaware of the condition, as in IBD.

Fear

Fear was a much reported issue which appeared in several guises. First, was the fear experienced before and around the time of diagnosis. It was noted that the word ‘cancer’ was mentioned many times and it seemed to be one of the biggest fears surrounding diagnosis. In some cases this was the immediate fear and in others it was mentioned that this fear was in part due to the extensive investigations and slow diagnostic process. The Government campaigns around the symptoms of bowel cancer have raised awareness of the symptoms, but with that awareness comes fear of symptoms that may be very similar or even identical in other diseases such as IBD. Several participants feared cancer prior to diagnosis and suffered the symptoms described by the Government campaign. They then went on to speak of their relief after diagnosis that they did not have cancer despite their symptoms.

As mentioned, fear was sometimes related to delayed diagnosis. Delayed diagnosis seemed to be a very common factor amongst my participants, and it was something I experienced myself. Diagnosis took a great deal of time for the majority of them. There seems to be some structure for the treatment and tests required when the diagnosis is actually made, but very little guidance for health professionals in the diagnosis of the disease. Participants were given all sorts of diagnoses prior to their diagnosis of IBD, ranging from gastroenteritis, urine infections, piles and the illness having a psychological basis.

This is an interesting area that does not seem to have much coverage. Further research could lead to the creation of a checklist and/or guidelines for general practitioners. This checklist should alert general practitioners to certain symptoms, especially when in combination, to the idea that what they are seeing could in fact be IBD (as opposed to numerous other conditions) and that it would warrant further specialist tests and interventions. This could change clinical practice and reduce associated fear and stress in those awaiting diagnosis which in turn may have an effect on the symptoms being experienced.

After diagnosis, it seems that a different kind of fear may be present, which is more related to the treatment and involvement in the treatment. This has been addressed in many ways through the guidelines produced for the treatment by health professionals of IBD. It puts the emphasis upon giving the individual increased choice and control of the treatment of their IBD. The data analysis demonstrates that lack of knowledge and education around the symptoms and treatment of IBD leads to a feeling of lack of control and subsequent fear and stress. The guidelines address this and suggest that people should be given different sources of information in order to educate.

Fear has been shown to be caused by uncertainty, lack of knowledge and education around a subject area and anxiety about what is happening physically to the sufferer of IBD. The guidelines that are in place aim at empowering individuals suffering from IBD. The guidelines encourage and give advice to enable individuals to take a more active role in their disease management and also their understanding of the disease through making resources available.

The participants in my research regularly reported feelings of fear, anxiety, lack of understanding of how they are being treated and not being given the options that are advised within the guidelines. Further research might investigate why guidelines are not always being followed, leading to uncertainty and anxiety amongst those being treated.

Participation in Healthcare and the Expert Patient

The large majority of the participants seemed to be very active, independent and knowledgeable about their health and the treatments they required. This is something that many of them openly acknowledge is learned over time through their own education and increase in their own knowledge as they experience the symptoms and treatment of their IBD. From the data is appears that patients with a larger knowledge are more likely to take control and to feel in control of their IBD. These are also the individuals who are more likely to get help when they need it and understand when that time is. Patients with a greater knowledge have also been shown to be more likely to take prescribed medication than those who do not feel in control or part of the decision making process.

The Expert Patient Programme is a structured programme, put in place by the UK government. Anything that educates people with chronic disease and puts them in a position of knowledge and corresponding control is a good thing although arguably the educative element of EPP does not acknowledge the complexity of the experience and the self-education that some undertake. The amount of education and knowledge an individual possesses has an influence upon their relationship with health professionals. The term ‘control’ is a theme

that was raised several times by participants. The research suggests that control is a fundamental element of how an individual copes with their IBD and how they feel about it. Participants did not feel that they were listened to enough by health professionals and reportedly did not always have enough control over their circumstances. This is an area that would benefit from further research both specific to IBD and also with regard to other chronic diseases.

Support

Mutual support was very important to participants. This support may come from others within the family who also have the condition through to support groups, specifically created with the focus of IBD. The NACC support groups were said to be of great help providing both resources and mutual support:

Another source of support is from families and others of significance to the individual. This was important for many participants, but there was evidence that the diagnosis of IBD may sometimes negatively affect relationships and cause tension both with significant others, including children. As such my research offers a challenge to research suggesting that family and friends provide much of the help (Kleinman, 1986; Lyons *et al*, 1995; Gallant, 2003; Dolan *et al*, 2008; Wolff and Roter, 2011), and further research is needed in this area.

There were reports from the participants of relationship breakdown with health professionals who did not listen to them and/or not give adequate information about treatment or diagnosis. However, other participants reported easy access to consultants and the ability to liaise easily with regard to treatment. Overall,

these individuals appeared to be the most positive about their IBD and took greater levels of responsibility and control in their condition and its treatment.

Overall, the most significant issues arising from the research are those of control and choice. As described, there are many factors which affect control and choice and changes in these factors have an effect on well-being and ability to live life with a chronic disease. Further research could specifically explore control and choice with reference to the areas discussed above and determine the extent of the links. This in turn could have an impact on the way in which people are treated by health professionals and the way in which chronic disease is treated on a policy level.

Biographical Disruption and Illness Narratives

Throughout the research, biographical disruption and illness narratives have been a core sociological concept and are of critical importance in all the areas that have been discussed. The PhD relates chiefly to these concepts and their interaction with the other areas. All the changes in the participants lives and the way in which they are or have dealt with them are related to these concepts. Narratives constructed by individuals as responses to the biographical disruption, shaped by their own circumstances and resources, provide new insights into understanding these lived experiences.

What is immediately obvious from the participant accounts is that there is fluidity within the narratives and the related biographical disruption, depending on disease activity and personal circumstances. There are examples throughout of all the narratives described by Frank (1995), namely the restitution narrative,

the chaos narrative and the quest narrative. These appear to be closely linked to the level and type of biographical disruption being experienced at the moment in time. Further research in the area could examine more closely the precipitating factors regarding changing narratives in IBD and the effect on health and well-being. I would suggest that this could be done through a series of interviews over time. This could have implications on treatment and patient participation.

I have personally had experience of many of the areas and themes discussed above. Certainly, when I was first diagnosed I had much less willingness to discuss my IBD than I do now. I perhaps felt that I might be judged or that it was not something that ‘should’ be discussed. Whereas with more knowledge and experience I no longer have these feelings. The diagnosis itself was long and protracted. I endured several incorrect diagnoses and treatments. My main feeling was not of fear (as discussed by many of the participants) but more of frustration at the feeling of not being listened to and not having a diagnosis. Without that diagnosis I could not be treated appropriately, and I was unable to recover. In terms of work, my research itself was delayed because of my health. I was unable to work consistently due to being unwell with repeated hospital admissions. My narrative changes, depending on circumstances at a particular moment in time. There are times where my life is more settled, there are times where there is great uncertainty and others where I am working hard to get information and treatment to resolve issues.

7.2. Summary of Implications for Further Research and Policy Change

As discussed there are several areas of further research which could potentially lead to policy change and improved experience for those living with IBD. In summary these are:

1. Further research should be carried out on a larger scale with regard to the time it took to reach a firm diagnosis and subsequent treatment. If the results of this PhD research are indicative of a general problem, then national guidelines could be looked at, potentially changed and implemented. The implications of this are large. It could significantly help people who potentially have IBD psychologically, not least in terms of quicker specialist diagnosis and treatment, which may possibly mean that less treatment will be required therefore saving money for the NHS. The development of a system for general practitioners to recognise the symptoms of IBD in a timely fashion and therefore potentially reducing fear and anxiety in the diagnostic process due to diagnostic delay is one possible development

2. My research has shown that treatment guidelines for IBD are not always being followed and this, as demonstrated here, leads to fear, anxiety and feelings of loss of control. More research is needed to see if this is a general problem or specific to this study. If more widespread, it would be interesting and useful to know the reasons why guidelines are not being followed, and whether it is because health professionals are unaware of them or because they choose not to follow them for some other reason.

3. ‘Control’ and ‘choice’ were repeatedly brought up as themes by participants throughout the research on which this thesis is based. More in-depth knowledge of this area could be used to guide and dictate guidelines and treatment plans in order to help individuals in the best way possible.

4. Throughout the research, the main sociological themes have been related to biographical disruption and illness narratives. What has been very apparent is that there is great fluidity between and within the two concepts, depending on circumstance and situation. Further research both within IBD and chronic disease in general would be useful to examine the causes and impact of the changes experienced and what can be done to support individuals suffering from IBD to minimise disruptive changes and to enhance health and well-being.

7.3. Theoretical and Methodological Developments

There is little research in the area on which this thesis is based. This thesis is, to my knowledge, unique in terms of the subject area and the approach it takes in terms of utilising auto/biographical and online research methods. Using a reflexive, auto/biographical approach, grounded in the experience of individuals living with IBD (Charmaz, 2001; Jones, 2002), I accept that I did enter the research process with some pre-conceived ideas and I have attempted to reflect on these and their significance to the data collected.

Much of the literature I read highlights the need for some theoretical development, as previous discussion of IBD has very much focussed on the specifics of the medical experience. For example, the research by Baumgart

and Carding (2007) explores the causes and immunobiology of IBD and Walld (2011) specifically researches the relationship between IBD and socioeconomic variables. The research by DeRooy *et al* (2001) examines what the concerns of individuals with IBD are, but does not then carry out further research into the reasons for these concerns and the other aspects which may play a role in concerns such as knowledge, experience, fear and emotions.

Many of the studies were conducted several decades ago. With changes in treatment, the NHS, and an increase in the expert patient / lay expertise it is worth re-examining some of the core areas.

With this in mind, my research adds to knowledge and understanding of individual perspectives of chronic disease and IBD. I have explored how people feel and how this may affect their disease. This thesis attempts to give some clarity and understanding about the interaction between the ways in people think and behave, and the impact of this on their disease. It gives a social perspective on the issues raised and the possibility for using this understanding in the future as a part of disease management and treatment experience. Further research jointly linking the work of Bury (1982) and Frank (1995) to this area would give greater insight and understanding into the area of research and give an opportunity to increasingly positively influence the sense of well-being experienced by individuals.

My research methodology is unique in this area of research. To my knowledge, nobody has carried out research in the area of chronic disease and IBD utilising auto/biographical methods and interviewing participants online through the use

of email. This approach enabled participants to reply to my questions in their own time and with no pressure on them to either answer questions or to answer within a set time frame. This ensured a 'relaxed' process and as a result I elicited a great deal of in-depth information. The inclusion of 'myself' in the analysis and data presentation adds a further unique dimension to the PhD.

7.4 Personal Reflections on Carrying out the Research

The process of carrying out the research was a long one although very fulfilling for me. As well as managing my own IBD, I also got married and had two children whilst studying for my PhD. Additionally, I was diagnosed with another very serious long-term illness and had many hospital admissions. I suffered a cardiac arrest, and have recently been prescribed chemotherapy medication. IBD and my other health difficulties played a role in my ability to study and to work predictably over the course of my doctoral studies. There were some lengthy periods of time when I was well, but there were also many periods of time where I was unwell. Surrounding the flares of my IBD I was having to take very strong medications and I found that in particular the morphine I was prescribed at one point made it almost impossible to work due to tiredness and sickness. However, and very importantly, my IBD gave me some understanding and insight into not only the subject area, but also the lives of the participants which other people would not have. Given my personal interest and understanding of the subject area it was important not to let my own story get in the way of the analysis and overshadow the results of the research. I made a conscious effort to ensure this did not happen and that each participant contributed to the research with their own voice. I also attempted to ensure that

I was honest about my own history and experience, allowing my own voice to speak within the research where it was relevant.

The research process went mainly as I expected. What did surprise me was the depth of detail the participants sent to me in response to the research questions. They included a lot of detail, much of it was very personal. I expected a lot of factual information but not as much on emotional issues. Of course, this depth of material made the research far richer and meaningful. The fact that participants described emotion in depth meant that it was something that I had to deal with on a personal level and as a researcher. Generally I did not find this too difficult or too uncomfortable, and because of my own similar experience, I did hold a level of empathy and sympathy towards the problems that some of the participants described.

One particular participant's story had quite an effect on me. Rachel's account was written from the perspective of a nurse who suffers from IBD. She was so clearly very knowledgeable but also appeared to be very vulnerable. She had a husband who appeared to make her life very difficult in terms of support as he was unable to deal with the symptoms and changes in his wife. When I first read her account I found that I was quite emotional and touched by her reply. I also found it quite difficult to read, because although she had a lot of knowledge she seemed to be suffering considerably both physically and psychologically and the way in which she wrote her responses, although matter of fact in many places, seemed very raw. I saw some similarities between her and myself. We both are able to use medical terminology with regard to our treatment and have a very strong sense of what we want and need. However, beneath the exterior

of being bright and breezy in most situations there is something more going on, which most people do not see. I am however fortunate to have very good family support which sadly Rachel reports as her weakest area.

Given more time and resources it would be interesting to return to the participants and carry out more in-depth interviews in order to follow their experience over time and explore in further detail the areas already mentioned as requiring further research. It would also be interesting to look at their narratives again, at a later point in time to see changes in their illness narratives and what has caused these changes over time.

The way in which I recruited my participants was interesting insofar as I did not recruit 'patients' from a hospital environment and therefore did not just focus on the medical experience. I was interested in the life that participants led outside of the medical arena and the impact of their IBD on 'normal' life. Conducting the data collection via the Internet was both positive and negative. Email correspondence gave participants some control over participation both in terms of thinking time and what they did and did not disclose. Arguably, it also made the experience of involvement less emotionally distressing. However, it is unlikely that my group is representative of all individuals with IBD, not least as it is limited to people who access support groups. If I had been able to attend support groups and recruit people face-to-face, would I have discovered similar? And if I was able to access people via other means how might this have affected my analysis? I do not have the answer to these questions and more research with a wider range of individuals utilising a broader range of methods would broaden our understanding still further.

The research has really opened my eyes to the huge range of problems and emotions other people experience in relation to their IBD. I felt quite humbled by many of the responses, and realised that I had taken a lot for granted about my support structure at home. Although my IBD is problematic and causes disruption in my life, many participants had suffered far more than me and many of them did not have the tremendous amount of support available to them which I am fortunate enough to have from my family.

The participants have also influenced and educated me with regard to treatment and decision making with my own disease. My approach has changed slightly, in terms of increased knowledge through their responses. I know more about treatments and how they affect individuals in real terms rather than text book terms. This has left me as a perhaps more demanding and opinionated patient, but it has also helped me to make a move away from being treated with steroids. I have now got an agreement that apart from in critical situations, steroids will not be used and I will be using biological therapies as an alternative. Before this research took place I did not even realise that this might be a possibility. The research has therefore had a big effect on my health and well-being including my relationship with health professionals. Indeed, I changed consultant during the research process to a consultant who was mentioned several times by research participants as being very good. I feel very privileged to have carried out this research on a subject that interests me and which means so much to me.

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