

Experiences of Acceptance and Adjustment for people living with  
Inflammatory Bowel Disease

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## ABSTRACT

**BACKGROUND:** Inflammatory Bowel Disease (IBD) is an incurable, chronic condition that is known to impact the physical and psychosocial well-being of those living with it. Evidence consistently demonstrates there is an association between increased disease activity and psychological distress. Moreover, psychological concerns affect people's ability to cope with the illness. Little research has examined the lived experiences of people with IBD and how they make sense of adjusting to their condition. The aim of this study was to offer a nuanced and detailed perspective about how people experience living with, accepting, and adjusting to IBD, with the view to provide evidence to complement the qualitative repertoire of research, and broaden our knowledge about adjustment for people with IBD.

**METHOD:** A qualitative approach using semi-structured interviews was employed to examine the experiences of six adults living with IBD (three with Crohn's and three with Ulcerative Colitis). A purposive sample of four females and two males were included in the study, aged between 26 and 82 years. Interviews with the participants were audio recorded, transcribed and analysed using Interpretative Phenomenological Analysis (IPA).

**RESULTS:** Two superordinate themes emerged from the analysis: *Lack of control: IBD grabs mind and body* and *Separation vs. Integration: An ambivalent relationship with IBD*, encapsulated by a master theme of *'Positioning Self: In relation to self, body and IBD'*. Superordinate themes and associated themes are presented and illuminated with verbatim extracts from the participants' accounts. The findings reveal that acceptance and adjustment is inextricably linked to notions of self and identity.

**CONCLUSION:** People experience IBD as a threat to identity, thus people manage and adjust to this by actively positioning themselves as separate to illness, or integrating it within themselves. For people living with IBD, the relapsing and remitting nature of IBD presents sufferers with periodic challenges that shape how they relate and respond to threats, difficult situations and experiences. In view of this, they adjust time and time again, and position themselves differently according to how they experience their illness. These findings are discussed in relation to clinical implications and suggestions for further research.

## CHAPTER 1: INTRODUCTION

### 1.1 Overview

This chapter begins with an overview of Inflammatory Bowel Disease (IBD) and psychological perspectives of IBD, and how these ideas inform current psychological treatment. The chapter will then provide an overview of how IBD impacts the physical and psychological well-being of those living with the disease. Following this, the concept of psychological adjustment is introduced and the reader will be provided with a context for understanding this before being led to explore wider societal narratives and meanings of adjustment to chronic illness, including the importance of examination of patient experiences. The chapter will end with a review of the current qualitative literature exploring experiences of living with IBD. Following this, a summary of the research and proposed questions.

### 1.2 What is Inflammatory Bowel Disease?

Inflammatory Bowel Disease (IBD) is a chronic health condition affecting approximately 240,000 people in the UK ( $\approx 400$  per 100,000) (IBD Standards Group, 2009). IBD is collective term used to describe inflammatory autoimmune diseases affecting the gastro-intestinal tract. The two most commonly known IBDs are Ulcerative Colitis (UC) and Crohn's Disease (CD). In UC, disease is limited to the large colon while CD can affect any part of the gastro-intestinal tract<sup>1</sup>.

IBD is associated with periods of remission and recurrent relapses or "flares" of physical symptoms, which may include, abdominal pain, weight loss, fatigue, frequent bowel movements and bloody diarrhoea. There is currently no cure for IBD and physical symptoms typically require long term use of medications that are often associated with complicated side effects. Historically IBD was a severe disease associated with high mortality rates. IBD has the potential to be life threatening, particularly in severe cases. There are risks of complications such as acute colon distension, perforation of the colon, fistulae, and colorectal cancer<sup>2</sup>. IBD is distinct from the gastrointestinal complaint Irritable Bowel Syndrome (IBS), which is a common functional disorder of the gut that is conceptualised as a 'medically unexplained' physical syndrome (Deary, Chalder, & Sharpe, 2007). Although some

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<sup>1</sup> See Appendix 3 for a diagram representing the affected areas in both conditions.

<sup>2</sup> See Glossary of Terms in Appendix 2 for more details of these complications.

reported physical symptoms of both overlap, IBS is not typically associated with bloody diarrhoea or risk of complications.

Although there is no identified cause for IBD, some research suggests that psycho-neuro immunological mechanisms play an aetiological role, and that stress may influence the course of disease (Santos et al., 2008). As such, psychosocial factors are believed to exacerbate symptoms. This will be discussed further below. Although lacking in specificity, it is mainly accepted that aetiology is likely to be a combination between genetic, immune and environmental factors (IBD Standards Group, 2009) and it is best to conceptualise IBD from a biopsychosocial perspective (Drossman, 1998).

### **1.3 Management of IBD**

Most patients are referred to hospital clinics for evaluation and diagnosis, and reviewed at regular hospital clinics (Mowat et al., 2011). Treatment for IBD typically includes traditional pharmaceutical intervention; including, anti-inflammatory medications, corticosteroids, and immunosuppressant and biologic medications. In severe acute cases, participants may require admission to hospital on an inpatient basis to receive intensive pharmaceutical treatment. Surgery is indicated when the disease fails to respond to long term medical treatment, or in emergency cases, such as when complications arise (NACC, 2001). The lifetime costs of living with IBD are reported to be comparable to other major health conditions including cancer and heart disease (Luces & Bodger, 2006). Thus, IBD is a serious condition with financial implications for the National Health Service (NHS).

The clinical guidelines support a holistic approach for the management of IBD, with due care to acknowledge both the physical and psychological impact of IBD (Carter, Lobo, & Travis, 2004; Mowat et al., 2011). Psychosocial support is considered beneficial in improving patient's quality of life and well-being (Carter et al., 2004; Mowat et al., 2011) and that access to a psychologist or counsellor should be included in services for IBD (IBD Standards Group, 2009). There is a clear demand from stakeholders for psychological input as part of the clinical management for IBD (Engel et al., 2012) and there is expressed interest from consultants for counselling services to be offered in their hospitals (NACC, 2001). The consensus is that psychiatric and psychological support should be made available when psychological issues are present (Mowat et al., 2011).

However, there seem to be difficulties implementing psychological services for people with IBD. According to the report carried out by the charity National Association for Colitis and Crohn's

(NACC<sup>3</sup>) in 2001, clinicians faced dilemmas in finding suitable clients to refer for counselling. In order to implement psychology services within this setting, counselling needs to be understood and embedded in the structure of the services available to patients, and good communication between counsellors, professionals and patients is the key to its success (NACC, 2001). There are no specific guidelines within the British Society of Gastroenterology or National Institute for Health and Clinical Excellence for evidence-based psychological treatment for IBD. As such, the current status of delivering robust and tangible psychological services to these patients seem in its infancy and rather idealistic.

#### **1.4 IBD from a psychological perspective**

Claims that psychological factors have a role in the development of the disease, and influence the cause and severity of IBD, has led to the proliferation of psychological research, which has mainly been concerned with exploring the relationship between psychological distress and symptom exacerbation, and the impact of psychotherapy on IBD.

The literature consistently demonstrates that IBD activity is closely related to the psychological states of patients. Increased disease activity is associated with increased anxiety and depression (Fuller-Thomson & Sulman, 2006; Graff, Walker, & Bernstein, 2009; Graff, Walker, Clara, et al., 2009; Porcelli, Leoci, & Guerra, 1996). Furthermore, IBD continues to impact on psychological well-being even when in remission (Dudley-Brown, 1996; Tanaka & Kazuma, 2005). A recent review of studies exploring this relationship indicated that there is no consistent evidence to suggest whether psychological factors precede disease onset or relapse (Graff et al., 2009). There appears to be a cyclical and self-perpetuating relationship between biological and psychological pathways, that is, stress may exacerbate symptoms which may provoke more stress (Duffy et al., 1991; cited in Dudley-Brown, 2002).

Given psychological factors can be considered sequelae of IBD, the study of depression and anxiety in people with IBD is important when considering remediation of psychological factors, with the view to improve disease activity and vice versa. However, the lack of consensus around how IBD is conceptualised from a psychological perspective may affect how it is researched, discussed amongst professionals and indeed treated. In the clinic, consultants and nurse specialists are often faced with patients reporting difficulties related to their illness. They notice, for example, that patients

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<sup>3</sup> The Crohn's and Colitis UK is the working name for the NACC



complain of gastrointestinal symptoms despite being “medically well controlled”, that is, no observable pathology<sup>4</sup>. Medics subsequently identify these patients as experiencing psychosomatic problems associated with anxiety or depression. It is typically at this point in the trajectory that patients will be referred for psychological support.

## **1.5 Quantitative research into psychological treatment for IBD**

The notion that psychological and somatic factors are interlinked in IBD has led to the development of different psychotherapeutic interventions for people with IBD. Thus, the aim of psychotherapy is to influence the somatic nature of the disease and/or improve the psychological functioning and quality of life of the patient. In order to provide a context for the current state of psychological approaches to IBD, the results of systematic and Cochrane reviews into psychological interventions for IBD will be described. Due to the scope of this paper it is not possible to describe in depth the details of each intervention study outlined in the reviews.

### *1.5.1 Effectiveness of psychotherapy for patients living with IBD*

The research evaluating the effectiveness of psychotherapy for IBD is multifarious in terms of therapy objectives and approaches to the intervention (Timmer et al., 2011). These differences may be attributed to different theoretical understandings of the association between psychological factors and IBD. There are studies exploring the efficacy of Cognitive Behaviour Therapy (Mussell, Bocker, Nagel, Olbrich, & Singer, 2003), psychodynamic psychotherapy (O’Connor, 1964; Jantscheck, 1998), Supportive Psychotherapy (Kunsebeck et. al , 1987; in Timmer et al., 2011), Supportive-expressive group therapy (Maunder & Esplen, 2001), Behaviour Therapy (Schwarz & Blanchard, 1991), Group Training programme (Larsson et al., 2003), Integrated Psychosocial group therapy (Oxelmark, Magnusson, Lofberg, & Hilleras, 2007), Stress Management (Garcia-Vega & Fernandez-Rodriguez, 2004; Milne, Joachim, & Niedhardt, 1986), Mind-Body therapy (Elsenbruch et al., 2005), and self-management and educational programmes (Kennedy et al., 2004; Waters, Jensen, & Fedorak, 2005).

According to two recent reviews examining the efficacy of psychotherapeutic interventions, there is no evidence that one psychotherapeutic approach is superior to another (von Wietersheim &

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<sup>4</sup> According to the clinical experiences of Consultant Gastroenterologists involved in this study

Kessler, 2006; Timmer et al., 2011). Moreover, there is no evidence for the efficacy of psychotherapies for patients with Inflammatory Bowel Disease *in general* (Timmer et al., 2011). There is weak evidence that psychotherapy directly impacts on the disease course, and there are inconsistent results in relation to psychological improvements, which may be partly attributed to heterogeneity in outcome measures used. The intervention studies were heterogeneous in the therapeutic focus, mode of intervention delivery (i.e. group or individual based), inclusion criteria and outcome assessments. All studies were of low methodological quality and had high risks of biases, for instance, lacking control groups, appropriate follow-up duration and blind assessment. In view of the above, the claim that there is no evidence for psychotherapy for people with IBD requires further evidence, owing to the notion that a lack of an observed effect is not equivalent to a lack of effect. Nevertheless psychotherapy positively influences how people deal and cope with their illness (von Wietersheim & Kessler, 2006; Timmer et al., 2011) and it is beneficial for those who need it<sup>5</sup>. However further inquiry is warranted to understand the experiences of ‘subgroups’ that may benefit from psychological intervention, and to understand which therapy is most useful.

With regards to the latter, it is useful to review the literature to evaluate existing psychotherapeutic interventions available to people living with chronic illness. Acceptance Commitment Therapy (ACT) (Hayes, 2004) is increasingly used in clinical health settings, and there is preliminary evidence for its usefulness for patients with chronic pain (Dahl et al., 2004). Chronic pain is comparable to IBD in that patients experience debilitating physical symptoms with psychosocial implications. ACT does not seek to cure or control pain symptoms. ACT is particularly interested in the concept of “experiential avoidance”, which is how a person tries to avoid unwanted thoughts or physical sensations. ACT interventions involve changing behaviour by changing the way a person *experiences* their thoughts, feelings and sensations, by encouraging people to observe their private experiences with openness and willingness. In order to ascertain whether people with IBD would benefit from this type of intervention, further evidence is required to understand how people experience living and relating to their disease.

In summary, whilst systematic reviews are generally accepted to be the best method for providing evidence of the most effective interventions in current practice, it is important to address wider questions, such as why people with IBD experience psychological problems and how they have arisen (Kemp et al., 2012). Qualitative research can help to explore these questions by obtaining rich and in depth knowledge about the concerns of people living with IBD. If experiences and stories of

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<sup>5</sup> Defined by those with psychopathology, mental stress or dysfunctional coping techniques (von Wietersheim & Kessler, 2006).

illnesses are considered and integrated into clinical care, IBD can be viewed, treated and managed in a more holistic way.

## **1.6 Experiences of Inflammatory Bowel Disease**

During flares physical symptoms include but are not limited to, experiences of frequent and often bloody diarrhoea, abdominal pain, extreme tiredness, systemic issues, weight loss and malnutrition (Mowat et al., 2011). Frequent trips to the toilet are often associated with a sense of urgency and/or incontinence. Physical symptoms can have a deleterious effect on the psychosocial well-being of the individual with IBD as it can lead to embarrassment, pain and fatigue which consequently impact on social and personal relationships, and work (Casati et al., 2000).

Reviewing the empirical literature, Casati et al. (2000) identified eight categories of health-related concerns of people with IBD, including, body image, lack of energy, loss of control, isolation and fear, not reaching full potential, feeling dirty and lack of information from the medical community. Psychosocial concerns are considered as important as coping with physical symptomatology (Guyatt et al., 1989). The unpredictable nature of the illness, including its unknown aetiology presents the sufferer with social and psychological difficulties, and contributes to psychological distress (Casati, Toner, de Rooy, Drossman, & Maunder, 2000; Drossman et al., 1991) and are highly influential in terms of affecting people's ability to cope with their illness. It is important to address and integrate psychosocial concerns into the clinical management and treatment of IBD (Casati & Toner, 2000). Furthermore subjective experiences of people with IBD is an important outcome measure in the treatment of IBD (Casati et al., 2000; Maunder et al., 1997).

## 1.7 Psychological adjustment

It is important to introduce the concept of adjustment, which is a term often used interchangeably with 'adaptation' and 'acceptance' (e.g. Charmaz, 1991; 1995). Lazarus' (1969) early ideas of adjustment have since been extensively researched and developed in the psychological study of chronic illness. In their article, Stanton et al., (2007) examined processes that contribute to people's adjustment to chronic illness. In defining what it means to adjust to chronic disease, the authors state that:

*"a) chronic disease requires adjustment across multiple life domains, b) adjustment unfolds over time, and c) there is marked heterogeneity across individuals in how they adjust to chronic illness" (Stanton et al., 2007; p. 567)*

In Stanton et al.'s (2007) theory, adjustment is multifaceted and has five related conceptualisations, including, mastery of disease-related adaptive tasks, preservation of functional status, perceived quality of life in several domains, absence of psychological disorder and low negative affect. Moreover, the theory suggests that adjustment is a dynamic process and individuals perceive or make sense of adjustment differently (Stanton et al., 2007). Owing to periods of relapses and remissions as characterised in IBD, it can be argued that adjustment may not be a linear and stable process for these patients.

### 1.7.1 Health-related quality of life and psychological adjustment to IBD

In the IBD literature, there is no definitive conceptualisation of adjustment. Similarly to the chronic illness literature, adjustment is typically viewed as the absence of psychological distress and/or positive health related quality of life (HRQL) (Kiebles, Doerfler, & Keefer, 2010). The latter, HRQL, is an inclusive multi-dimensional term comprising physical, social and all aspects of psychological functioning, such as well-being and perception of health status (Wolfe & Sirois, 2008). HRQL is often used to assess patient's subjective concerns of living with IBD (Drossman, 2001), illness outcomes and psychological adjustment.

However, the argument is that the measurement of adjustment (and therefore the concept) may reflect presence (or absence) of symptomatology only. The most commonly used and validated measures of HRQL, such as McMaster IBDQ (Cheung et al., 2000) and Rating Form for Inflammatory Bowel Disease Patient Concerns (RFIPC; Drossman et al., 1991) were developed by primarily

exploring negative experiences. Moreover, the former assesses for generic social and emotional problems only, for example, assessing the frequency of feeling 'upset' or 'happy' on a Likert scale (Cheung et al., 2000). Beliefs, perceptions and experiences in relation to emotional problems, and *how* patients experience living with the disease are considerably limited in this concept of adjustment (Kiebles et al., 2010).

According to the framework proposed by Kiebles et al. (2010), adjustment to IBD is a complex, dynamic interplay of outcomes indicative of adjustment and many other clinical factors. Furthermore that psychological adjustment is a construct far beyond singular medical and psychological components of adjustment (e.g. depression and anxiety). The author suggests that future research to develop this framework should focus on the cognitive, emotional and behavioural contributors of adjustment to the nature and course of IBD. This research highlighted that understanding adjustment from a biopsychosocial framework is critical for the management and advancements of holistic care for people living with IBD. Furthermore that there is a clear need to further our understanding of the experiences of psychological adjustment for people living with IBD.

### *1.7.2 Moving beyond quantitative measures of subjective experience*

Recent studies have demonstrated that lived experiences of people with IBD are not reflected in routine assessment measures, such as the RFIPC (Stjernman, Tysk, Almer, Strom, & Hjortswang, 2010). Furthermore, using content analysis of text, Wolfe and Sirois (2008) demonstrated that patient's subjective experiences of "health related quality of life", were not reflected in routine HRQL measures such as the SF-36 and IBDQ. The measures failed to include experiences of a cognitive nature, such as excessive attending, and self-regulation (referring to aspects of control). The authors suggest that current literature lacks emphasis on how people make sense of their perceptions of control and their response to threats of control (Wolfe & Sirois, 2008). Given the chosen methodology, the study lacks depth in lived experiences. However, the findings reveal that it is "critical to continue examining how the patient's themselves live and frame their experiences with IBD" (p885), that is, not necessarily from a negative position. This view is shared by Dickson et al. (2008) who states that it is crucial to conduct longitudinal qualitative research to fully understand the processes underlying adaptation to illness.

## 1.8 Social construction of Chronic Illness

So far, this paper has presented the empirical literature investigating concerns of people with IBD and psychological adjustment with a focus on examining quantitative measures. This is primarily in order to provide the reader with a context of how adjustment is currently conceptualised within the IBD community and to highlight limitations and gaps in this knowledge. Measures provide a means of classifying observable phenomena into categories which are useful in increasing knowledge and understanding about overall disease trajectories, prognosis and treatment across populations of people. However a scientific, positivist approach to understanding human experience is arguably more reductionist and loses sight of how individuals make sense of their experiences.

Quantitative research holds a different epistemological position to that of research exploring subjective experiences of people living with IBD. From a postmodern perspective, adjustment can be considered a social construction, in that the phenomenon of 'adjustment' is influenced and constructed by societal and cultural meanings and discourses (Burr, 2003). For chronic illness and IBD, there are dominant discourses around the negative impact of illness, as seen in the development of measures of HRQL, utilizing open-ended questions about 'worries' and 'concerns' (Drossman et al., 1991). It is interesting to explore social and cultural discourses informing the increasing development of subjective research in the area of IBD by considering this within the context of chronic illness.

According to Lawrence (1994, cited in Bury, 2001) from the turn of the 19<sup>th</sup> century, in medicine there has been increased interest in 'norms' and statistical deviations, independent of particular experiences. With the rise of the biomedical model and discourses around individual pathology, came the diminishment of a holistic view of patient's stories and how they make sense of their own experience (Bury, 2001). One of the key processes leading to the renewed interest in patient experiences was the increased impact of chronic physical and psychosomatic illness (Strauss, 1995; Bury, 1991, 1997). The focus is on management and care, in exchange for treatment and cure (Gerhardt, 1989; cited in Bury, 2001). This may well be the case for recent discourses around Inflammatory Bowel Disease, as a life-long condition with no known cure.

These ideas may explain how measures of quality of life and biopsychosocial well-being, with associated norms and cut-off points of 'abnormality', became the dominant paradigm. In view of this, it is important to locate individual experiences within societal and cultural contexts. Therefore,

it is useful to look beyond using quality of life measures and towards subjective experiences of living with chronic illness.

### **1.9 Adjustment and concept of “self”**

In the works of Bury (1982, 2001) and Charmaz (1991, 1995), adjustment is conceptualised differently. Illness is seen as a disruption of the sense of wholeness of body and self (Bury, 1982) and as such, identity, normality, acceptance and adaptation to chronic illness are inextricably linked. According to Charmaz (1995), ‘adapting’ is one way of living with bodily impairment and illness. Other ways include ignoring it, minimizing it, struggling against it, reconciling self to it and embracing it (Charmaz, 1991). Through ignoring or minimising their illness, patients attempt to preserve the sense of self and unity with their bodies that they had prior to the illness. Reconciling the self with illness involves acknowledging the illness and it is likened to a sense of tolerance, in that the illness and associated symptoms is acknowledged and managed. In this phase, people decide to live with it and attempt to accommodate it. This seems closely linked to traditional concepts of adjustment, in that changes are made to accommodate the illness and there is a sense of ‘coping’ with it. Similarly to this, Bury (1982) views chronic illness as a biographical disruption. According to this theory, a loss of self is a fundamental challenge that patients face and in order to adjust to illness, one must re-establish a sense of identity.

### **1.10 Qualitative inquiry into living with IBD**

It is useful to examine the literature to gain an understanding of psychological adjustment to chronic illness in general. However, it is not known whether there are issues or experiences related to adjustment that are specific and limited to those people that live with IBD. There is currently limited qualitative research in this area and as a methodology, qualitative research is often overlooked in the field of gastroenterology (Vanderheyden, Verhoef, & Hilsden, 2006).

There are only several studies exploring the lived experiences of those with IBD. Although there have been studies focussing on subjective patient experiences, many of these used self-report survey methodology (Drossman et al., 1991). Furthermore, there are several studies mixing people with IBD and those with IBS, so the results are limited in their claims about living with IBD (Fletcher, Jamieson, Schneider, & Harry, 2008; Schneider & Fletcher, 2008; Schneider, Jamieson, & Fletcher, 2009). Participants in these studies are arguably not homogenous because IBS is typically associated with physical and psychosomatic symptomatology that is clearly differentiated from IBD (Simpson & Dearden, 2012).

A recent meta-synthesis of six qualitative research studies examining subjective experiences of IBD sheds light on the experiences of people living with the disease (Kemp et al., 2012). Of particular importance are issues around attempting to maintain normality and 'striving to thrive'. However the fear of incontinence and negative consequences associated with IBD places restrictions on people's lives, thus they feel detained by their disease. Moreover people live with a constant sense of tension between these positions, conceptualised as "push and pulled: a compromised life"; people push to be normal but IBD pulls them back.

Since Dudley-Brown's (1996) early study of three individual's experience of IBD, the humiliation and fear of incontinence has been consistently reported as a major factor in living with IBD (e.g. Kemp et al., 2012; Cooper et al., 2010). Moreover there are profound effects on family, social and work life, in part due to feeling unable to live a 'normal' life (Dudley-Brown, 1996). Consistent with the quantitative literature there are also important issues of living with uncertainty and feeling out of control (Kemp et al., 2012; Cooper et al., 2010; Daniel, 2002; Dudley-Brown, 1996). Evidence suggests that perceptions of control enhances patients adjustment to IBD (Dorrian, Dempster, & Adair, 2009; Hall et al., 2005; Cooper et al., 2010). Using a systematic framework approach, Cooper et al. (2010) explored IBD patients' beliefs of personal control. Interestingly they found that some patients viewed being unable to control and predict the disease as distressing, while others did not. According to the authors the key to patients feeling more in control of their life and their condition is an ability to reconcile beliefs about personal control, that is, balancing beliefs about what they are actually able to do and what they feel they ought to do, in order to gain quality of life. Moreover it was important to feel in charge of IBD, rather than being controlled by the disease process. Controllability and coping strategies were closely linked to patients knowing how their body reacted to their illness and identification of flare ups (Cooper et al., 2010; Burger, 2005; cited in Kemp et al., 2012), maintaining normalcy and acceptance of IBD within the individual's life (Cooper et al., 2010; Hall et al., 2005; Pihl-Lesnovska et al., 2010).

In relation to the latter, using a grounded theory approach Hall et al. (2005) illuminates some of the difficulties that people with IBD face with acceptance, such as a sense of "fighting" to gain control of the illness. Furthermore, maintaining the appearance of health related normality to self and others is important to people with IBD. The authors commented on the prevalent use of combat like language and that "health related normality" is something to conquer or to gain control of. This is consistent with the theoretical concept of struggling against the illness (Charmaz, 1991) and objectifying the body in order to preserve the sense of unity with the self and body and preferred identity (Charmaz,



1995). In Hall et al.'s (2005) study, the authors present an argument that those who cope with the illness yet show determination to fight the disease show evidence of acceptance and adaptation. It is not clear how people make sense of this fight, whether it may be likened to a fight *against* or *with* the illness. If the former, it can also be argued that concepts of struggling against and attempts to conquer the illness with the view to obtain normality are related to experiential avoidance and destructive normality (Harris, 2006; Hayes, 2004), thus interfere with acceptance.

Being the only known qualitative studies to have been undertaken in the UK (Hall et al., 2005; Cooper et al., 2010), these studies are particularly relevant to the context of treatment for IBD in the UK as there is an increased move towards offering patients choice and effective self-management strategies (Mowat et al., 2011). Increasing our knowledge of experiences of personal control and the importance of reconciling personal beliefs is useful in developing clinical services, such as considering the role of specialist nurses (Cooper et al., 2010). However owing to being largely informed by a theoretical framework, Cooper et al.'s (2010) study followed a deductive process of analysis, thus it lacks depth in the types of experiences explored and misses out on important meaning making processes.

Participants included in Hall et al.'s study (2005) were those who prior to the interviews rated themselves as having low health-related quality of life, according to the UK IBDQ (Cheung, Garratt, Russell, & Williams, 2000). Thus at the interview participants may have been biased to attending to negative experiences. It would be useful to verify whether the proposed framework would be applicable to other groups of people. It is also important to note that while grounded theory is a valuable approach in deriving theoretical frameworks at a sociological level, it typically lacks depth in interpretation at an idiographic level (Smith et al., 2009). Using Interpretative Phenomenological Analysis, Burger's (2005; cited in Kemp et al., 2012) study may supplement this framework with nuanced, detailed knowledge about the phenomenon of living with IBD. However, at the time of writing this current research, Burger's study remains unpublished and it was not possible to gain access to this article.

The review highlighted that further qualitative inquiry is required in relation to the impact that incontinence, fear and behaviour has on the individual (Kemp et al., 2012). Moreover there is a need to gather in depth knowledge about the experiences of living with IBD, and importantly, the meanings that people attached to them. This would be beneficial in enhancing knowledge about

living with IBD, for example the meanings people attribute to incontinence. Moreover it would further our understanding about experiences of acceptance and adjustment to IBD in general.

### **1.11 Summary and rationale for research**

Inflammatory Bowel Disease is an incurable, chronic condition that impacts the physical and psychosocial well-being of the patients and their families living with it. Evidence suggests that emotional concerns affect people's ability to cope with their illness and are considered as important as coping with physical symptoms. There is consistent evidence that psychological distress is associated with disease activity. It is clear that there are identifiable gaps in our knowledge about IBD, particularly in terms of identifying how to treat patients who are experiencing psychological distress and gastroenterological problems, in the absence of observable disease pathology. More evidence is needed in identifying characteristics of patients who might benefit from psychotherapy and indeed the most appropriate intervention. In light of this, there has been an increased focus on exploring subjective experiences of living with, and adjusting to IBD.

The literature demonstrates that adjustment is a complex, dynamic, multifaceted process which incorporates and is influenced by a number of clinical factors. Psychological adjustment is therefore a construct that is far beyond current measures of adjustment variables and warrants further qualitative inquiry. Given that IBD is an uncertain, unpredictable disease that presents itself in idiosyncratic ways, it is increasingly important to examine how the patients themselves make personal meaning of their experiences with IBD.

To date there have been no qualitative studies specifically examining the experiences of adjustment for people with IBD. Previous qualitative research exploring experiences of living with IBD highlighted themes including conflict between striving to thrive and being detained by disease. The aim in this current study is to uncover themes in relation to acceptance and adjustment with the view to broaden knowledge about this framework. The objective is to offer nuanced and complementary knowledge about adjustment and acceptance, which may help to contextualise the quantitative literature and shed more light on individuals experience at a micro level. With increased knowledge, it may help to answer wider questions such as 'why is there a problem?' and 'how has this arisen?' with the view to inform appropriate approaches for psychotherapeutic interventions (Kemp et al. 2012).

## **1.12 Research questions**

The main research question is: How do people experience living with IBD?

This question will be explored through the following, specific research questions:

- (i)* How do people living with IBD experience acceptance and adjustment to their condition?
- (ii)* How do people living with IBD relate to their condition?

## CHAPTER 2: METHODOLOGY

### 2.1 Overview

In this section, I will discuss the rationale for using a qualitative approach. I will then provide the reader with a rationale for the selection of Interpretative Phenomenological Analysis (IPA) amongst other approaches. Following this, the design and context to the research, including recruitment processes, ethical considerations and analytic procedures will be described. An overview of principles used to evaluate quality in qualitative research will also be presented, with details of how this research meets these criteria. Finally, I will state my own position as a researcher and my relationship with the subject matter.

### 2.2 Rationale for qualitative methodology

The primary aim of this research is to broaden our understanding of living with Inflammatory Bowel Disease (IBD), and how people living with IBD experience, and make sense of acceptance and adjustment. A qualitative approach was considered in keeping with the study's aims, with its focus on the lived experiences of individuals. Furthermore, a qualitative approach can provide rich insight about experiences of a given phenomenon, such as meaning making of behaviours, emotions and experiences (Vanderheyden et al., 2006). While quantitative methods of inquiry are useful in developing knowledge across populations of people, they are limited in their ability to capture the essence of an individual's experience. Qualitative research has generally been overlooked in the area of gastroenterology (Vanderheyden et al., 2006), and although there are a handful of studies exploring the lived experiences of IBD, they generally lack depth of interpretation and meaning making. Consequently, there is a need to develop more detailed and nuanced information at a micro-level, with the view to provide complementary knowledge to the area of acceptance and adjustment to IBD.

In light of the above, Interpretative Phenomenological Analysis (Smith et al., 2009; Smith & Osborn, 2008) was chosen as the preferred methodology for this research. Owing to its firm philosophical connections to phenomenology, hermeneutics and idiography, IPA is not only a means of analysing data, but it is considered a methodology in its own right (Cassidy, Reynolds, Naylor, & De Souza, 2011). In this section I will provide an overview of these philosophies and why IPA is most suited to meeting the objectives of the study.

IPA is phenomenological as it involves a detailed examination of lived experiences, and explores in depth, individual's personal meaning and sense-making of an event or object (Smith & Osborn, 2008). In this current study, the focus is on individual's personal perception of the experience of living with IBD, and how they make sense of this, in the context of adjusting to this illness. Therefore, a phenomenological approach focussing on the lived experiences of people with IBD, was most suited to meet the study's aims. IPA is also recognised as a helpful method in exploring issues in the personal experience of health and illness (Smith et al., 2009).

Congruent with its philosophy of idiography, IPA focusses on the *particular* and therefore examines and makes claims based on individual cases only (Smith & Osborn, 2008). This focus fits well with the objective of the study to offer detailed and complementary knowledge about adjustment and acceptance, which may help to contextualise the quantitative literature. Furthermore, while IPA is largely a constructivist approach, in that it sees individuals as making meaning through perceptions of their experience in the world, it is also interested in contextual factors, such as how social constructions influence their construing of the world, which is in keeping with my epistemological position (see Section 2.11). IPA's aim is not to generalise findings across populations, but is more concerned with transferability, that is, the ability to resonate with readers' own clinical and personal experiences.

Hermeneutics is intrinsically related to phenomenology, as in order to understand lived experiences, one also needs to interpret. According to Heidegger (1962; cited in Smith et al., 2009) hermeneutics, or the theory of interpretation, is at the heart of humanity and we cannot not interpret. As IPA researchers, we enter into a double-hermeneutic, whereby the researcher is attempting to make sense of the participant making sense of their experience. A triple hermeneutic also exists whereby the *reader* is making sense of the researcher making sense of the participant (Smith et al., 2009). As such, IPA acknowledges the inevitable influence of the researcher's own beliefs, assumptions and contextual factors on the process of interpretation. The aim of IPA is not to produce an account based on an 'objective truth', as it only claims to access a version of it through participant's narrative account, as it is co-constructed with the researcher (Smith et al., 2009). Therefore, the account, and the phenomenon itself, is intrinsically bound by the dialogic encounter between the researcher and participant (Gadamer, 1990). In light of this, it is important to be aware of, and contextualise my own position, whilst acknowledging that these 'fore-conceptions' may not be illuminated until later in the interview or analysis process (Smith et al., 2009).

### **2.3 Consideration of other Qualitative methodologies**

In this section I will explain reasons for why IPA was selected over other qualitative methodologies, including grounded theory, discourse analysis and narrative analysis (NA). Grounded theory is often considered to be the main alternative method for IPA (Smith et al., 2009). Typical aims of grounded theory research are to develop theoretical level account of a given phenomenon, on a much larger scale of individuals. Consequently, it often makes claims at a higher conceptual level than IPA. It was considered that the power and usefulness of IPA is in its micro-level analysis, and would therefore add more detailed and complementary knowledge to the current qualitative evidence base of IBD (Smith et al., 2009).

Discourse Analysis (DA) was considered less appropriate than IPA because of its critical focus on the structure of language and its role in constructing social reality. Moreover, as DA largely ignores individual involvement in constructing reality, including their perceptions and experiences of a given phenomenon (Willig, 2012), it was not considered appropriate in meeting the aims of this study.

Owing to strong intellectual links between IPA and NA, the latter was considered as an approach for this current study. IPA and NA share concerns with the importance of context and the construction of narrative as a meaning making endeavour (Smith et al., 2009). However, narrative methodologies are more concerned with the process and structure of story-telling, with careful analysis of the function of that narrative within a particular context and how this evolves over time (Smith et al., 2009). However, as Smith et al. (2009) highlight, constructing a narrative is one way of making meaning. IPA is more concerned with hermeneutics, that is, interpretation of the content and meaning of narratives for a particular person in a particular context, thus IPA positions itself from a more constructivist approach. This was considered more in keeping with the aims of the study, by attempting to enter the participant's psychological world and understand their own realities.

## 2.4 Design

### 2.4.1 Sampling

Participants were selected using a purposive sampling method, which is an approach typically used in qualitative research (Barker, Pistrang, & Elliot, 2002). Using homogenous purposive sampling, participants were selected on the basis that they could provide insight into a particular experience or phenomenon; that is, they represent a perspective rather than a population (Smith et al., 2009).

Congruent with an idiographic approach, IPA studies are typically conducted on small sample sizes. According to Smith et al. (2009), there are no guiding principles regarding appropriate sample sizes for IPA research as this largely depends on the level of analysis, richness of individual cases, and existing operational limitations and constraints. However, Smith et al. (2009) note that typically between 4 and 10 interviews are employed in doctorate research. For this current research it was decided that 6 to 8 interviews would be an appropriate number for the level of proposed analysis, and in keeping with operational limitations.

To ensure homogeneity of the sample, participants had to meet the following criteria:

- (i) Participants must have had a formal and established diagnosis of IBD for at least two years<sup>6</sup> (i.e. Crohn's Disease, Ulcerative Colitis or Indeterminate Colitis), as evidenced by relevant diagnostics and/or observable pathology. This was in order to ensure that participants have experience of the researched phenomenon.
- (ii) Participants must be at least 18 years old. Owing to differences in life roles and experiences attained over time, children are likely to experience IBD differently to adults. Inclusion of children and adolescents would therefore reduce homogeneity in critical ways.
- (iii) Participants must be fluent in English. This research relies on participant's use of language to make sense of experiences and the meanings placed on these. This relies on the researcher having a good understanding of the verbatim language being spoken by the participant and to understand issues that are unspoken. An interpreter would be in conflict with IPA's double-

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<sup>6</sup> During the first few years, the disease can be unsettled, so two years post diagnosis was reasoned as an appropriate time to allow the disease process to establish itself.

hermeneutic approach to interpretation, as the inclusion of an interpreter would add another layer to the co-construction of the encounter.

- (iv) Participant must have no previous colorectal or pouch surgery. This criterion was in place because it was felt that individuals who have undergone surgery would experience living with IBD differently compared to those who have not<sup>7</sup>. In order to maintain homogeneity of the sample, those who had undergone surgery were excluded.

#### 2.4.2 *Recruitment Setting*

Participants were recruited from an outpatient gastroenterology service at the Luton and Dunstable (L&D) Hospital in Bedfordshire, which is part of the Luton and Dunstable University Hospital NHS Trust. The gastroenterology department runs a county-wide service that provides diagnosis and treatment for people with disorders and diseases of the stomach, duodenum and small and large bowel (colon). The gastroenterology team consists of specialist consultants and nurses. Recruitment for this study was conducted in collaboration with Dr Matthew Johnson, Consultant Gastroenterologist at the L&D Hospital, and the team of IBD specialist nurses. In order to conduct research at this site, ethical approval was obtained from the Local Research Ethics Committee (LREC) in Hertfordshire. Further details of this process are provided in Section 2.6.

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<sup>7</sup> For those with Ulcerative Colitis, surgery is curative, in contrast to Crohn's Disease, where it is not. For those with CD, surgery is indicated in order to minimise the impact of disease (Mowat et al., 2011). Situations when individuals with Crohn's or UC undergo surgery may include when they personally elect to undergo the procedure due to unresponsive pharmaceutical treatment, or in an emergency as a response to complications of the disease. As such, it can be considered that this group alone are heterogeneous in their experiences.



### 2.4.3 *Recruitment process*

Participants attending outpatient clinic appointments for regular review were considered for this study. Potential participants were identified by the gastroenterologist or IBD nurse specialists who were overseeing the clinics. During the patient's clinic appointment, the consultant or nurse specialist approached suitable patients with brief information about the study. Potential participants were provided with a Participant Information Sheet (PIS) that had my contact details contained within it. Potential participants were encouraged to contact me for more details about the study and if appropriate, to arrange a convenient time and date to meet for interview.

I also attended the outpatient clinic on approximately four occasions. Subsequent to being initially approached by the consultant or nurse specialist, interested participants gave permission for me to join them in their clinic to introduce the study in more depth. The potential participants were provided with a PIS and they were informed that they could contact me to arrange a time and date to meet for interviews. However, the majority of participants preferred to book the appointment whilst they were present. With respect to these participants, they were reassured that they could change their mind or cancel the appointment at their will.

There were approximately 10 people who met the criteria and showed interest in taking part. Of those, 8 participants elected to take part in the interview. Two participants decided to cancel the interview beforehand; one, who suffered additional chronic back pain was concerned about their ability to manage the hour long interview, and the second cancelled due to work commitments.

## 2.5 Participants

There were six participants in total, as described in Table 1 below. Participants have been given pseudonyms in order to protect their identities. Of the six who participated, half of them were diagnosed with UC and half with CD. Two participants described their ethnicity as British Indian, and the rest were of White British ethnicity.

*Table 1. Description of participants included in the study*

Pseudonym	Gender	Age	Ethnicity	Disease Type	Time since official diagnosis (years)
David	Male	82	White British	Ulcerative Colitis	6
Linda	Female	50	White British	Ulcerative Colitis	14
Pauline	Female	56	White British	Ulcerative Colitis	22
Arun	Male	39	British Indian	Crohn's Disease	10
Iris	Female	78	White British	Crohn's Disease	2
Riya	Female	26	British Indian	Crohn's Disease	10

## 2.6 Ethical considerations

### 2.6.1 Process of ethical approval

Ethical approval was granted from the Hertfordshire Local Research Ethics Committee (LREC). Local approval was granted from the Research and Development (R&D) Department at the Luton and Dunstable University Hospital NHS Trust. Subsequent to receiving ethical approval, a minor amendment of the protocol was submitted to the LREC so that participants could be provided with parking reimbursements, if applicable. The most recent versions and up to date documents to support this are provided in Appendix 4.

Shortly into the recruitment process unexpected difficulties emerged. Firstly, some suitable participants declined to take part because they felt that they had no problems living with the condition, and considered that talking about IBD was unnecessary. Secondly, the majority of suitable participants were attending the clinic for 6 monthly or annual reviews so were not typically seen regularly. Consequently some declined participation because they considered returning the clinic to be an inconvenience. In view of the second difficulty, a decision was made to submit a substantial

amendment to the LREC for participants to be given the option to be interviewed at home or at the clinic. However, in the time between making necessary arrangements for submitting the amendment and notifying the R&D department, several participants expressed interest in taking part. The decision was to terminate the proposed substantial amendment and interview participants at the clinic. This decision was evaluated by considering the time constraints imposed by previous delays in recruitment, and the option to wait for the amendment and interview participants at home. Overall, it was considered that it was preferable to interview participants as soon as possible, thus they were seen at the clinic only.

### *2.6.2 Informed consent*

Potential participants were provided with the PIS (see Appendix 6) at least 24 hours prior to the interview, to allow participants time to fully consider their decision to take part. My contact details were contained within the document so that participants could ask specific or generic questions about the current study and research in general. Prior to consent procedures, the PIS was reiterated verbally to participants, including the aims and objectives of the study, what the study involves, the benefits and risks of taking part and that they have the right to withdraw at any time without giving a reason. Participants were given opportunities to ask questions. Participants provided their consent by signing a consent form prior to taking part (see Appendix 7).

### *2.6.3 Confidentiality*

In order to maintain confidentiality and anonymity, participants were given pseudonyms, and all data containing personal identifiable information about the participants was anonymised or removed from the transcripts. Participants were informed that all data collected in relation to the study will be stored on a password protected and encrypted computer, in accordance with data protection principles. Participants were informed that all information obtained as part of the research remains confidential and separate from the clinic team. Furthermore, that if participants declined to take part, that it would not affect any care they are currently receiving.

### *2.6.4 Minimising distress*

Due to the nature of the questions asked, some participants may have felt distressed or upset during, or after the interview. Due care was taken to minimise the impact of distress on participants. Drawing on therapeutic experiences developed as a Trainee Clinical Psychologist, I remained alert and sensitive to the participant's needs and adjusted questions accordingly. All participants were

given written information and resources for relevant support services, as documented in Appendix 8. All participants were provided with space to debrief at the end of the interview. However, if participants felt they were affected by any issues raised in the interview, they were provided with extra time to talk through any difficulties.

## **2.7 Patient Participant Involvement**

A patient representative was involved in constructing the interview schedule. A list of potential questions was presented to the representative and these were screened so that they could be understood, and were appropriate in tone, clarity and brevity. A mock interview was conducted with the representative so that they were afforded the opportunity to answer the questions to assess for appropriateness. In collaboration with the representative, questions were added and amended when necessary, and placed in an appropriate order.

## **2.8 Procedure**

### *2.8.1 Interview Schedule*

This study used individual semi-structured interviews to explore participants' personal meaning and sense making, in line with guidance on the conduct of IPA research (Smith & Osborn, 2008; Smith et al., 2009). Semi-structured interviews enable researchers to keep areas of interest and specific questions in mind, however, the direction of the interview is led by participants' responses. Subsequently the researcher is free to probe and pursue other areas of interest or concern, which perhaps may not have been planned for, but are pertinent in exploring the research question. The interview schedule was constructed based on recommendations in the literature (Smith et al., 2009), and in collaboration with a patient representative as described above.

Areas of interest to cover in the interview included experiences of diagnosis and treatment, how people described their relationship with IBD, impact of IBD on how they (and others) viewed themselves, and how they make sense of 'adjustment'. Finally a question was included that asked participants to elicit a metaphor to encompass their experiences of IBD. Metaphor is an important way that people make sense of their experience (Smith et al., 2009; Mair, 1977; cited in Hermans, 2003) thus it was felt that the use of metaphor fitted well within a phenomenological approach and would deepen participants' understanding of their experience. An experienced IPA researcher was also consulted in order to provide feedback on the suitability and relevance of the questions in

shedding light on the researched phenomenon. The interview schedule is presented below in Fig 1. The schedule with full prompts is provided in Appendix 9.

<u>INTERVIEW SCHEDULE</u>	
1.	Can you tell me a little bit about your IBD?
2.	What treatment are you currently having?
3.	How do you feel about what you have to use?
4.	What place does IBD have, in your life at the moment?
5.	How do you make sense of 'acceptance' of IBD (open question)
6.	How would you describe 'good' times with IBD?
7.	How would you describe 'bad' times with IBD?
8.	What would be for you a positive development?
9.	How do you think your life would be, if you did not have IBD
10.	How do you think / feel about yourself?
11.	Has having IBD changed the way you think or feel about yourself?
12.	Has having IBD changed the way others think about or feel towards you?
13.	How do you see yourself in the future?
14.	If you could use a metaphor or a thing to describe IBD, what would it be?

*Fig 1. Interview schedule*

Prior to the interviews, I familiarised myself with the interview schedule by conducting a pilot interview with a colleague who had previous experience of chronic illness. By preparing this way, I was able to adopt a more informal, conversation style to facilitate discussions with participants. Although all interviews were guided by the interview schedule, the order and direction of each were dictated by participants' responses and pertinent areas of interest voiced by participants were also explored.

### *2.8.2 Context for interviews*

The interviews took place in a clinic room at the L&D Hospital. Participants were interviewed alone in a quiet room in order to reduce interruptions and noise. The initial plan was to interview participants in a counselling clinic room. This room, equipped with sofas, was considered appropriate in providing a naturalistic and comfortable setting for interviews. However, due to room availability, it was only possible to interview 3 out of the 6 participants here. The remainder of the interviews were conducted in a clinic room that was designated for medical outpatient

appointments. Participants were interviewed during one scheduled appointment. Interviews lasted between 40min and 1hour 15min.

### *2.8.3 Recording and transcribing participants' experiences*

The interviews were audio recorded and transcribed verbatim by myself. In IPA, transcription is typically at the semantic level, that is, all words spoken by the participant and interviewer are recorded including significant pauses, stammers, and false starts of words or sentences (Smith & Osborn, 2008). Utterances of the participant and I were recorded as well as significant non-verbal information that were explicitly remembered.

## **2.9 Analysis**

Interpretative Phenomenological Analysis was used to analyse the data informed by Smith and Osborn's (2008) and Smith et al.'s (2009) approach. I also attended a one-day practical IPA workshop, facilitated by experienced IPA researcher Dr Rachel Shaw, to further develop my analytic skills.

As IPA involves a double-hermeneutic approach, a reflective diary was kept in order to record personal reflections and observations throughout the research process. I endeavoured to reflect on strong reactions about how I felt towards participants, memorable expressions made by participants, and a sense of their stance towards the researched phenomenon. By engaging in this, I could reflect on the process of interviewing, and increase my knowledge about the individual's experience. Supervision was sought to facilitate this reflective process, and to check the plausibility and coherence of the exploratory notes and subsequent emerging themes.

Each stage of analysis is described below, however it is important to note that although these appear as definitive, linear steps, the analysis ensued a more circular process. As described by Smith et al., (2009), IPA typically involves a hermeneutic circle of examining specific parts to represent the meaning of the whole, whilst contextualising and understanding parts, within the whole. This process occurred on a micro level, for example specific sentences or words were examined to represent meaning of the paragraph or transcript as a whole. Simultaneously, sentences were contextualised by the whole of the transcript. This circularity also occurred at a more macro level, such as understanding one interview as a part within the context of the whole, i.e., all six transcripts,

and so on. As such, the stages of analysis often occurred in parallel with other processes, within the context of the hermeneutic circle.

### 2.9.1 *Stages of analysis*

The first stage involved immersing myself in the data in order to become as familiar as possible with the account. The transcript was read several times and the audio transcript was listened to whilst reading the transcript, on one or two occasions. Particular attention was paid to the voice and tone of the participants and how these related to the spoken words.

Exploratory notes were documented using the left hand column of the written transcripts. Descriptive comments concerning the phenomenological content were noted, for example, descriptions of the participant's experiences. Interesting use of linguistics were also commented upon, such as repetition of words, fluidity and coherence of sentences. Finally, higher level interpretative and conceptual comments were noted, which included more abstract concepts that helped to make meaning of the account.

The next stage involved developing emerging themes. This included noticing paraphrasing and observing how the exploratory notes were connected or associated with each other. In developing emerging themes two processes of iteration ensued. Firstly, an initial list of possible themes were noted in the right hand margin of the transcript and then typed up chronologically, in the order they appeared in the transcript. Secondly, where initial themes represented a similar experience or meaning, they were clustered and renamed and a final list of emerging themes was drawn up (Smith et al., 2009). Using abstraction the final list of emerging themes were clustered together and given a superordinate name, staying as close as possible to the spoken words of the participant (Smith et al., 2009). In order to ensure that the themes still related to the spoken words of the participants, they were constantly checked against the transcript. Following an idiographic approach (Smith et al., 2009) analysis was on a case by case basis, so the processes described thus far were repeated for each transcript, before moving onto the next, and so on. As it was inevitable that subsequent analyses were influenced by what has previously been found, it was important to be aware of these ideas, whilst allowing new themes to emerge (Smith & Osborn, 2008).

Once all cases were analysed separately, connections and patterns were explored across the different cases. Attention was paid to the themes that seemed prominent and where one theme identified in one case shed light on themes identified in another case. A final list of themes with

associated subordinate themes was then drawn up and represented in a table (see Results). The list of themes, along with superordinate and subordinate themes, were translated into a coherent narrative account illuminated with direct quotes from participant's accounts. This narrative provides a framework for understanding experiences of living with and adjusting to IBD.

## **2.10 Issues of quality and validity**

Owing to differences in aims and epistemological positions, qualitative researchers argued that quantitative and qualitative methods cannot be subjected to equivalent evaluations of rigour and credibility (Smith et al., 2009). This led to the proliferation of concepts of quality in the qualitative community, which are framed as flexible and contextually specific and more congruent with qualitative research aims (Tracy, 2010). Smith et al. (2009) favour Yardley's (2008) "four principles" approach in assessing quality, therefore this was deemed appropriate for this current study. Yardley's (2008) principles are sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. Below, I will state how this study meets these criteria.

### *2.10.1 Sensitivity to context*

Sensitivity to context can be demonstrated through situating the study in a relevant context, by examining existing literature and the material obtained from participants (Smith et al., 2009). As discussed in the Introduction chapter, there is a clear gap in the literature for more idiographic approaches, thus sensitivity to context was demonstrated by the very selection of IPA methodology. Furthermore, sensitivity to context was demonstrated through the relevant selection of participants, as shown in Section 2.5. By adopting a conversational style in the interviews participants were facilitated to feel at ease, and therefore were more likely to have been open with their experiences. Commitment to the participants' experiences and sensitivity to their own context is evidenced in the audit trail in Appendix 10. I have endeavoured to show sensitivity to the data by conducting an in-depth analysis and illuminating findings with verbatim extracts, thus giving the participants a voice (Smith et al., 2009). Finally relevant literature will be referred to in the Discussion section, therefore anchoring the findings in the context of theory and substantive research.



### *2.10.2 Commitment and rigour*

According to Yardley (2008), rigour refers to the thoroughness of the study and the commitment of the research to good quality data collection and analysis. Rigour was provided by the appropriateness of the research design, which was developed in collaboration with a patient representative. An example of a transcript has been included in Appendix 11 to demonstrate the style of interviewing and appropriate levels of probing. I attended a one-day practical workshop to further develop skills in phenomenological and interpretative coding, so that my analysis could move to a higher level of interpretation. To demonstrate credibility of findings, peer review was conducted where a supervisor and two psychology colleagues independently audited parts of a transcript to evaluate the plausibility of emerging themes.

### *2.10.3 Transparency and Coherence*

According to Yardley (2008), transparency refers to how clearly each stage of the research process is described in the write-up. To ensure transparency, details of the careful selection of participants, construction of the interview schedule and how the analysis was performed has been detailed in Sections 2.5, 2.8 and 2.9 respectively. I also demonstrated a commitment to self-reflexivity by stating the challenges faced and how I learned from this in the Discussion section. Coherence refers to how well the research presents a coherent argument and how well the themes hang together (Smith et al., 2009). Yardley (2008) suggests that coherence also relates to how well the findings of the current study fit with underlying theoretical assumptions of the approach used. Evidence of this is therefore included in the audit trail in Appendix 10.

### *2.10.4 Impact and importance*

Impact refers to the ability of the findings to resonate with readers, and how well this can be transferred to their own practice and knowledge of the phenomenon. To this end, I have endeavoured to produce an interesting and evocative narrative of the findings, and I have outlined explicitly the clinical significance of this research in the Discussion section.

## 2.11 Self-reflexivity

In line with transparency and a commitment to self-reflexivity as described above, I will state my position as a researcher, including my epistemological stance and a context to my own experiences, including my relationship with the subject matter.

I am a 29 year old white British woman and I born and brought up in England, primarily living in East Anglia. I am a daughter, a sister and a fiancée. I currently cohabit with my fiancé in our own house. I have worked in the area of psychology for several years and am currently a Trainee Clinical Psychologist in my third year of the Doctorate in Clinical Psychology (DClinPsy). I have been excited by and engaged in the course philosophy of social constructionism and constructivism.

I consider my epistemological position as a critical realist with tenets of constructionism, that is, I believe a reality exists, but that every individual constructs and makes sense of their *own* reality, as shaped by societal and cultural discourses. This position has largely been developed from my own past experiences of neuropsychology and clinical health, in that I personally cannot deny the presence of a reality because by doing this, I believe it is also denies the presence of physical, felt phenomena. However, I firmly believe in phenomenology, in that everyone makes sense of their own experiences.

I was diagnosed with Ulcerative Colitis 9 years ago at the age of 20. During this time I have experienced four relapsing episodes, or “flares”. From my perspective the diagnosis and years subsequent to this have had a profound effect on me. I feel that certain processes have been central to my personal adjustment to IBD and my relationship with it. IBD became a significant part of my life over the years and I have remained open and honest about my personal experiences with it. Prior to conducting interviews, the patient representative was consulted about their views about how I could manage potential self-disclosure as a peer researcher. Following our discussion, it was considered that self-disclosure would be most appropriate at the end of the interview, in the debrief section.

## CHAPTER 3: RESULTS

### 3.1 Overview

This chapter presents the results of the Interpretative Phenomenological Analysis of the six participants' accounts of living with, and adjusting to, Inflammatory Bowel Disease. Through the analysis, two superordinate themes emerged, *Lack of control: IBD grabs mind and body* and *Separation vs. Integration: An ambivalent relationship with IBD*, encapsulated by an overarching master theme, *Positioning self: in relation to self, body and IBD*.

In this chapter, the superordinate themes and constituent themes are presented (as shown in Table 2 overleaf), illuminated with verbatim extracts from the participant's accounts. A diagrammatic representation of the hierarchy of these themes is also presented (see Fig 2). The account presented does not capture all aspects of the participants' experiences, as the themes were selected for their relevance in addressing the research questions; *how do people experience living with IBD*, as explored using the questions *how do people with IBD experience acceptance and adjustment* and *how do people with IBD relate to their disease*. Furthermore, it is recognised that this account is a subjective interpretation of participant's experience in line with a double-hermeneutic approach (Smith et al., 2009). Therefore, this account is not proposed as a full and definitive truth, but offers one possible account of how people with IBD experience living with, accepting, and adjusting to IBD.

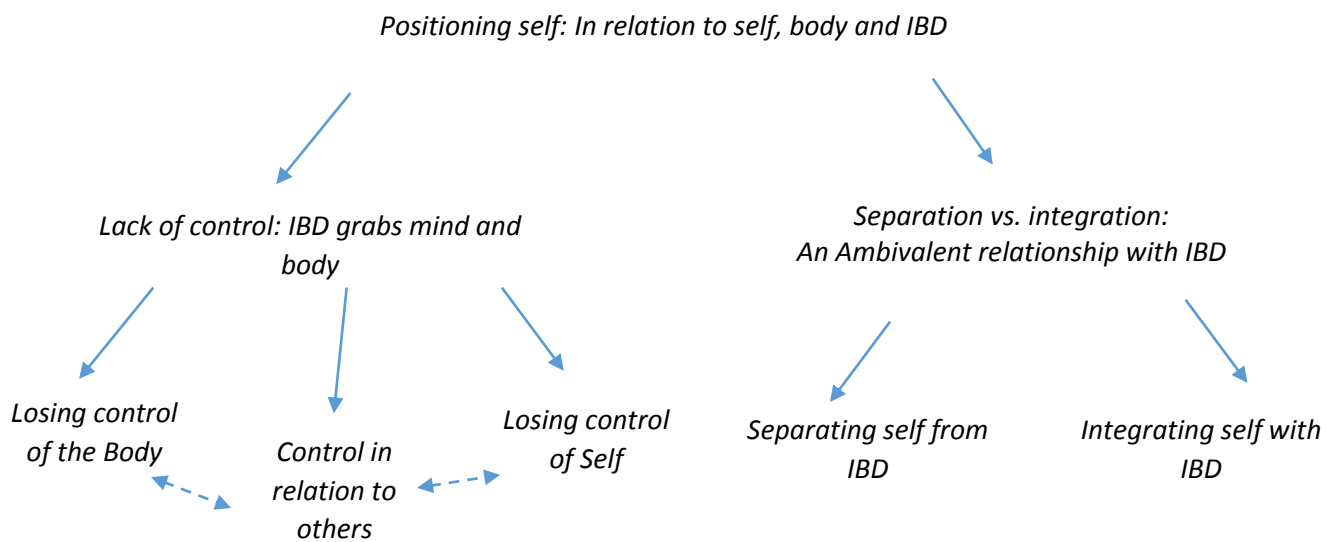


Fig 2: Diagrammatic representation of the themes emerging from the analysis. Dashed arrows indicates that the themes are interrelated

Table 2. Presents the themes (including the overarching master theme) and subthemes that emerged from the six participants' accounts.

<b>MASTER THEME: Positioning self: In relation to self, body and IBD</b>	
<b>SUPERORDINATE THEMES</b>	<b>THEMES</b>
Lack of control: IBD grabs mind and body	Losing control of the body
	Losing control of self
	Control in relation to others
Separation vs. integration: An ambivalent relationship with IBD	Separating self from IBD
	Integrating self with IBD

### 3.1.1 Presentation of results

The verbatim extracts selected to illustrate the themes have been edited for ease of reading. Minor hesitations, false starts, and utterances such as 'err' and repetitions of words have been removed when appropriate. Words that have been added, where it is pertinent in understanding the extract, are presented in square brackets. Where text has been omitted, this is indicated by [...]. Pauses in the dialogue are indicated by ... or (*pause*), for short (less than 2 seconds) and long pauses respectively. Participants have been given pseudonyms and all names referred to in the extracts have been changed, in order to protect their identities. I have provided the reader with a brief pen portrait of the participants<sup>8</sup>, in order to bring them alive and to situate them within their contexts.

#### David

David is an 82 year old white British man who was diagnosed with UC 6 years ago. He has a history of significant physical illnesses, including cancer and heart attack. For the past 18 years he has been caring for his wife at home who sustained a stroke, paralysing her on one side.

#### Linda

Linda is a 50 year old white British woman who was diagnosed with UC 14 years ago. She has a grown up son and currently lives with her husband. After having her son, Linda left work to be a stay at home mother. Since her children left home and following her diagnosis of colitis, she did not return back to work.

#### Pauline

Pauline is a 56 year old white British woman who was diagnosed with UC 22 years ago. She divorced from her husband a number of years ago. She has two grown up children, a son and a daughter from this marriage. Pauline currently lives at home with her partner, Michael.

#### Arun

Arun is a 39 year old British Indian man who received a formal diagnosis of CD 10 years ago, although had been experiencing symptoms for 10 years prior to his diagnosis. He has a wife and two young sons. He and his family are strong believers in the Hindu faith. He is currently employed in a position at a business specialising in electrical goods.

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<sup>8</sup> A useful suggestion from Dr Rachel Shaw at the IPA training course (Shaw, 2012)

### Iris

Iris is a 78 year old white British woman who was diagnosed with CD two years ago. Iris cared for her husband until his death from dementia two years ago. Her daughter and son-in-law also sadly died within the past two years.

### Riya

Riya is a 26 year old British Indian woman who was diagnosed with CD 10 years ago at the age of 16. For several years as a child, Riya lived with her grandparents in India. Riya returned to the UK to receive education. She currently lives with her husband and works within the medical profession.

## **3.2 Positioning self: In relation to self, body and IBD**

Experiences of living with IBD were often interpreted in the context of identity, given participants often made sense of IBD in relation to themselves. This master theme is comprised of participants' experiences of relating to, and positioning themselves with their illness, self, and their body. This master theme is defined by a number of important issues, which were embedded throughout participants' accounts, and shaped how they experienced IBD, themselves and their body. This master theme was experienced differently, and thus shaped participants' positioning in different ways. Participants' experiences of 'positioning self' was influenced by: the experience of feeling isolated with an odd, alien condition; wider discourses around social stigmatisation which is termed 'poo taboo'; participants' experiences of feeling tormented by uncertainty and a lack of understanding; finally, gaining perspective over time. Therefore these issues are essential in representing the master theme, and are pertinent in shifting and shaping participants' experiences of living with, adjusting to and subsequently accepting their illness.

How participants' positioned themselves in relation to their illness was influenced by a sense of isolation. Isolation captures the loneliness, difference, and disconnectedness experienced by participants, from their friends, families and even others with IBD.

Unlike the group as a whole, two British Indian participants described feeling different from their families, and this appeared to be distressing for them. At the time of diagnosis, no-one in their families had experienced the illness. Within the Indian culture, there is a collective sense of identity, which is in contrast to Western individualistic concepts of identity (Dwairy, 1997). With the onset of an unknown illness, this was perceived as a threat to their identity and consequently shaped how they conceptualised the illness, and themselves with it.

*"It's a very, a very unusual condition, coz there's no real history of this in my family, everyone's kind of ok [...] no-one's really suffered from anything like this" (Arun)*

*"you don't feel normal... don't feel human anymore" (Arun)*

Arun believed that IBD was a genetic, hereditary condition. Given there was no previous family history of IBD in the family, this left him confused and feeling isolated. In order to manage this sense of difference in his family, he took the position of gaining control, by trying to find a cause of the Crohn's that made sense to him. When Arun discovered that as a child, while living in India, he contracted Tuberculosis (TB) and had a history of juvenile Rheumatoid Arthritis, he sought answers for whether these conditions could help to explain his condition.

*"...TB TB TB....now this is you know, I'm different to everyone in the family, no-one's got this [Crohn's Disease], so let me look into TB..." (Arun)*

Similarly to Arun, no-one had experienced Crohn's Disease in Riya's family, so IBD was an alien, odd condition. Owing to the condition being unknown, Riya positioned herself and her body as odd and alien. As a result, she separated herself from the illness by overlooking the condition, which is discussed in more depth later in the chapter. With the discovery of others having the same condition, including those in her family, came relief that she was not 'abnormal' or odd for having the condition.

*"It was the very first time anybody ever heard of it, even I, nobody else had ever heard of it was just like this completely alien medical condition that's come in, you know, nobody knew anything about it" (Riya)*

*"I found more and more people are actually having this diagnosed and I felt okay I'm not the only one having this odd disease it's not actually odd anymore..." (Riya)*

Riya had an ambivalent relationship with IBD, which she describes using the metaphor of a yo-yo. This in part is symbolic of the tension between being close to, and separate from her family, which is represented in the following extract:

*“It’s [...] like a yo-yo I suppose, so at times when we’re really really close to it, that’s when I’m taking the medications and we’re trying to get on the right track and then when the yoyo is down its more like, I don’t really care what I have, so it’s more like a yo-yo....” (Riya)*

Consider Riya’s use of relational concepts of ‘we’ and ‘I’ in making sense of her relationship with IBD. She positions herself closer to IBD when it is a collective effort with her family, and there is a sense of withdrawing from IBD when she feels more isolated as an individual. Thus, her sense of isolation from her family influences her positioning with IBD. Moreover, unlike the other participants, Riya did not report having ‘normal’ IBD symptoms, adding to the feeling that she was wrong or abnormal from others.

*“[I’ve] not had any flare up, touch wood, so I feel normal, and that’s why I can’t relate to [people with IBD] so that’s why I feel hit and miss” (Riya)*

There were also underlying feelings of difference to others with IBD, due to the idiosyncratic nature of the illness.

*“I do think it is obviously different for everybody coz I think even some people’s symptoms aren’t necessarily quite the same”. (Linda)*

IBD was also seen as an illness that is isolated in itself because it is hidden and unknown, making people feel that they are the only ones suffering, which is distressing.

*“...it [IBD] is an isolated thing. Until you come to hospital and see everybody that’s here for the same thing, and.... yea you’re isolated basically” (Pauline)*

Other participants’ sense of isolation was mainly in relation to their social lives. This is partly linked to the socially unacceptable nature of IBD, discussed next. Some participants described isolating themselves because of feeling too unwell, or for fear of being judged by others for having an unusual illness. The sense that no-one really knows how you feel increases the sense of isolation and frustration.



*“When I’m not well anyway, I tend to just [...] kind of shut away you know, I’m at home and I don’t go out when I’m very ill” (Linda)*

*“I used to be worried about like, what if people ask me ‘why do you not eat chillies’, and then I’d have to explain what’s wrong with me, and what if...you know at that time people at that age would just react like ‘oh my god, what kind of thing have you got?’” (Riya)*

*“No-one knows how you feel. No one. They can’t possibly imagine what it’s like either” (Pauline)*

‘Poo taboo’ is conceptualised as a prevailing discourse within culture and society, whereby the experience of IBD and its characteristic physical symptoms is viewed as embarrassing and socially undesirable. Participants’ experiences were interpreted to mean they felt stigmatised by their condition, in part because of the inappropriateness of ‘poo talk’. There is a tendency to avoid and discard the existence of bowel movements, which in turn may shape how people position themselves in social and intimate relationships, and how they engage with the illness itself, such as rejecting it as unwanted and undesirable.

Dominant discourses surrounding poo talk are described below. Even within these extracts, I noticed how participants attempt to conceal full details, through the utterance ‘*blah blah blah*’, and in Iris’s extract, by her pause after ‘*you know, about...*’, thus demonstrating the prevalence of unsaid dialogue about the condition.

*“...you don’t come out of the toilet and say ‘oh my god, blah blah blah’. [...] It’s not a topic that comes under discussion if you’re sitting having a coffee with anyone! (laughs)” (Pauline)*

*“You wouldn’t talk about it like I’m talking to you...because I don’t think people want to know really, you know, about...I think there’s something about bowel movements that aren’t very pleasant you know” (Iris)*

The impact of stigmatisation pervades into social and family relationships, adding to the sense of isolation. As an older lady, in her generation there were prevailing stereotypical norms and expectations about not disclosing personal health matters to the male gender. In keeping with maintaining the appearance of a healthy normality, Iris took the position of hiding her illness.

*“I wouldn’t talk to them [grandsons] they’re too young and of course, male (snort laugh). I wouldn’t talk to them about it, they probably don’t even know I’ve got it really” (Iris)*

Participants described that by appearing ‘fine’ to others, the disease itself is invisible. The extract below represents ambivalence, where Pauline wants to disclose details of the condition, in order to dispel the perception of normality to others to feel understood and validated. However she is silenced by the immense shame and embarrassment of the physical symptoms associated with the disease, so takes the position of not talking about it.

*“...in my head I’m screaming, ‘I’m not actually fine!’ But it’s the same thing, you’re not gonna go into detail about what’s going on with you because it’s something that you don’t talk about. And something probably that I don’t want to talk to people that I don’t know... [...] well no, even my best friend I don’t want to talk about all that stuff” (Pauline)*

David also demonstrates the fear of stigmatisation as a consequence of public incontinence. Referring to having ‘an accident’ as having ‘fouled myself’ evocatively suggests that this would be construed as a disgraceful act.

*“... touch wood I’ve never had an accident, where I say an accident, (raises voice) fouled myself, out of my home [...] and I’ve had a couple of accidents at home. Well it’s the right place to have ‘em in my opinion.” (David)*

A number of participants related to themselves as having something wrong with them. As a result, they took the position of hiding their illness for fear of judgement, special treatment, or feeling different. For Riya this was also at a deeper level, where she wanted to hide her illness from judgement from herself as well as worrying about becoming a burden to others.

*“whilst I was on holiday I didn’t want to be thinking that I’m not well [...] and I didn’t want people around me thinking that I’m not...erm... there’s something wrong with me... [...] because then they’ll obviously start worrying, ‘oh well what’s wrong’ ”*  
(Riya)

The fear of stigmatisation and embarrassment experienced by these individuals has an adverse effect on intimate relationships. Within these quotes is an inherent sense that IBD influences how people position themselves in relation to others. In particular, that others are perceived to lack understanding.

*“...when you’re ill [...] it’s not a very nice thing so yeah, [...] when you’re obviously not at your best (laugh) from that point of view and in and out of the toilet, you do feel dirty and [...] you just don’t feel nice.”* (Linda)

*“I’m not looking for anybody else and I couldn’t imagine having anything like that with anybody really [...] yeah, it’s too personal”* (Iris)

Most participants described struggling with uncertainty and a lack of knowledge and understanding. The latter refers to participant’s own appraisal of the illness, and perceived responses from others. People positioned themselves with striving for information and certainty, or disengagement from the disease, which in turn shaped how IBD was integrated into themselves.

For some participants, uncertainty, such as lack of information from the medical community, was extremely tormenting, so they chose to strive for answers and a sense of certainty.

*“It [process of diagnosis] was absolute torment, because I wanted to know exactly what I’ve got”* (Arun)

*“...what I found hardest was not knowing and couldn’t get an answer as to why. Coz you would be like ‘tell me what I can do’ [...] tell me not to eat that or drink that, or*

*do eat that and do drink that you know, and then I'll do that, but when they can't tell you, [...] it's like 'arragghhhh' " (Linda)*

Even with diagnosis there is uncertainty, as there is no clear information about treatment, prognosis or cure.

*[Doctors said] you've got ulcerated colitis [...] but then, that's it. There's nothing else do you see what I mean? There's nothing." (Pauline)*

Iris was different from others, in that she did not know what to expect from a flare up. This uncertainty appeared to concern her, particularly in the context of her acute disease onset. Similarly to others above she tried to choose the position of gaining certainty, but the answers may have left her more uncertain and reluctant to seek further information.

*"I don't really know what to expect [from relapse]. Erm, do I get pains? ...I don't get pains, not normally. I know that when I had it the first time, I was in a lot of pain, and I lost a lot of blood. Well is that what I should expect if I had a relapse? I don't know. That's something maybe I should ask. I think I did ask once but I don't think I got any reply. I said how would I know if I was having a relapse? And they said oh you would know! (laugh)." (Iris)*

She also found the unpredictability and uncertainty around incontinence more difficult to manage.

*"...when it happens [being incontinent] you don't know it's gonna happen. I wish somebody would be able to tell me. But yeah, you don't know when it will happen" (Iris)*

Riya was also unlike the others because she lived with uncertainty about the validity of her diagnosis, given she denied experiencing symptoms on a day to day basis. Riya seemed confused about the relapsing remitting nature of IBD. With the absence of tangible physical symptoms, her condition was not a reality for her. Thus she took the position of rejecting the diagnosis and was 'non-adherent' with medications.

*"It leaves me in a quite confused state on a day to day basis that's hence why I wasn't taken any of the medications" (Riya)*

Many participants also described a pervasive lack of understanding from others, including friends, families and medical professionals.

*“My GP was pinging me back and forth a little bit. Saying, oh, it’s just a viral it’s just a viral. But he’s not taking it seriously that I’ve got diarrhoea [and] a little bit of constipation” (Arun)*

For Linda, she was frustrated by others not being able to take the disease seriously because of a lack of lived understanding. Again, as indicated by *“you feel like sort of saying to people”*, her frustrations do not get voiced.

*“But you know, you feel like sort of saying to people ‘no, it’s not that [stomach bug] it’s really not, it is so much worse you know’ ” (Linda)*

This master theme also captures how participants relate to their experience of living with IBD in comparison to past experiences. Previous experiences of illness and adversity seemed to shape how participants positioned themselves with their IBD. David’s IBD seemed to be put into perspective in relation to multiple illness experiences, stories of survival, and role adaptations. In the context of these previous experiences, the impact of IBD was minimised.

*“Anything, IBD, cancer of the throat (laugh), what else have I got? I got Thyroxine, what do you get for that. Under active thyroid (laugh). What I’ve got don’t compare with that stroke [wife experienced]”. (David)*

For Iris, the experience of multiple bereavements changed her perspective of IBD towards a position of acceptance, as she made sense of the illness in relation to her past experiences.

*“And my daughter died the year after and then my son-in-law died 6 months later so within 2 years I lost them all [...] (voice cracking and tearful) I suppose because of that, maybe I didn’t worry too much about what was wrong with me really” (Iris)*

*“...[deep breath out] maybe in a way, that’s made me accept what I’ve got, you know what I mean?” (Iris)*

Others alluded to gaining perspective and making sense of their condition through hindsight, or by comparing experiences over time. These relational comparisons suggest an ability to reflect on

earlier experiences and a process of learning over time. There is a sense that participants position themselves differently with their illness, where do not fight it and they *do* care.

*“I remember in the early days I used to sort of, struggle [to force self to go out]”  
(Linda)*

*I think for me, because I was only young, I used to fight it instead of giving in to it  
(Pauline)*

*“Initially I think I used to just...when I was at Uni and stuff, I don’t think I really cared that much” (Riya)*

### **3.3 Lack of control: IBD grabs mind and body**

This superordinate theme captures the prevailing lack of control experienced by all six participants. The theme title is described eloquently by Pauline:

*“...if it [flare up] goes on for a long time, then obviously it starts to get hold of you in your mind and your body...” (Pauline)*

As implied within this extract, there is a sense of feeling out of control of both body and mind. This theme encapsulates both feelings of despair, helplessness and the pain and suffering experienced within the *body*, but also how this impacts on participant’s sense of *self* and their identity. Most participants described feeling that IBD has changed them as a person in some way, which was synonymous with their feeling out of control as these changes were generally unwanted and perceived as a threat to identity. How participants manage this threat is explored more in the theme of *Separation vs. Integration: An ambivalent relationship with IBD*.

In this section, there are three overall themes; *losing control of the body*, *losing control of the self*, and *control in relation to others*. Each theme is comprised of a number of important subthemes and the meaning of these for each participant is explored.

#### **3.3.1 Losing control of the body**

There were two major subthemes in relation to losing control of the body, including, *living with pain and suffering* and *burdened with a body you cannot control*.

### Living with pain and suffering

In all of the participant's accounts there were experiences of pain and suffering within the body. However, most participants reported these experiences as prevalent at first onset of the disease, or during subsequent flares.

Iris recalls the painful and shocking experience of the onset of Crohn's Disease, which for her was acute and severe. She was diagnosed with Crohn's Disease a few days after the first onset of symptoms.

*"One day I was out shopping and I got this awful pain and err [...] I got myself home eventually, but by that time I was pouring with blood [...] down below. And I was so shaky and distressed, I didn't know what to do and I was in pain, so I dialled 999. The paramedics came and then they took me to hospital and then I just passed out" (Iris)*

For the other participants, their symptoms deteriorated over time until they were helpless and debilitated. Some also described a long wait before being assessed at hospital and subsequently diagnosed.

*"I was just doubled up with pain I couldn't drive, I couldn't walk I couldn't do anything [...] and from there it took a year before I was actually seen at the hospital."*  
(Pauline)

Arun describes a particular flare, which resulted in an admission to hospital, as being the worst experience of his life.

*"...it was probably the worst time I've ever experienced. I mean I was going to the bathroom 25 times a day, losing blood continuously, and I lost a lot of weight as well. It was 2 weeks I think I was in that ward, and I lost about 2 stones, straight away".*  
(Arun)

*"it was difficult to see and even get up out of the bed coz there was a lot of pain, a lot of spasms going on, there was a lot of... like tight clenching pains in my stomach"*  
(Arun)

Arun took the position of gaining control by making meaning for a cause. He made sense of his suffering as being a form of punishment from God.

*“He [God] is making me suffer and I have never done anything wrong to him, you know I have never harmed, never murdered anyone” (Arun)*

The experience of IBD as painful pervades into treatment and investigations. In David’s account, he described the process of having a diagnostic sigmoidoscopy<sup>9</sup>. He also describes how prescribed medication failed to work. The tablets were not properly digested and were excreted whole, thus he experienced a period of suffering prior to them working. The two extracts demonstrate that treatment and investigations are experienced as intrusive and unpleasant.

*“I mean it is quite a sensitive area you know, [...] he puts it up [sigmoidoscope] as far as he can I suppose, but it’s err... not painful, but it’s tender, if you know what I mean and it makes you jump occasionally.” (David)*

*“I think they went through me for a little while. But... once they were in me long enough, they did kinda calm the bowels down but it all went over quite a long-ish period” (David)*

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<sup>9</sup> A sigmoidoscopy is a procedure where a doctor or nurse looks into the rectum and sigmoid colon using an instrument called a sigmoidoscope. It has a camera and a light at one end of the instrument. This allows the doctor or nurse to see the lining of the rectum and sigmoid colon.



### Burdened with a body you cannot control

This subtheme captures the despair that participants experienced as a result of perceived endless pain and suffering. These experiences culminate in feeling like the body is completely out of one's control. This theme is poignantly captured in the following extract.

*"I mean at points I just felt so ill...it was almost like tell me I'm gonna die, because I [exasperated laugh] in a way, I really felt that bad that I either thought I was dying or I wanted to die" (Linda)*

Pauline described a process of deterioration where she eventually felt helpless and out of control of her own devices.

*"As time went on into the months I just got worse and worse until eventually I was just in bed I couldn't do anything" (Pauline)*

Participants described how during disease activity, they have no control over their body. Furthermore, that they positioned themselves as separate from the body, because the body takes over.

*"Coz...you know [...] when you're having a flare up you don't feel in control of your own body, do you?" (Linda)*

*"...your body, I don't know, [your] body's just amazing it just takes over, and so you go through the processes..." (Pauline)*

Pauline used the metaphor of a black cloud to make sense of her colitis. Colitis was conceptualised as an overarching external influence that takes control of her. She tried to take the position of gaining control, but this did not work.

*"...the black clouds following you about everywhere and you're not gonna get away from this. This is, this is it, this is what is happening to you erm... when you're having a flare up, it doesn't matter what you do, how you eat..." (Pauline)*

As mentioned, in Riya's account, she denies reports of physical symptoms. However, her regular blood tests indicate the presence of inflammation and bleeding within the bowel. Riya feels confused about her body, and struggles to grasp what is happening. The following quote suggests she perceives her body is so out of control and 'bad' that it negatively impacts on having a child.

*"think the negative is is.....erm, it's, it's erm... the scary thought that in case, like, obviously I want to have a baby, and then in case something goes wrong because of my body being bad...(quietens voice and becomes teary eyed)" (Riya)*

For four of the participants, the threat of, or actual, incontinence, brings with it deep shame and demoralisation. As described later in this section, having no control of the bowels has a profound influence on participant's sense of self. Incontinence is synonymous with losing part of their identity that is perceived as 'good' and 'in control'.

David's account suggests that IBD is an uncontrollable and messy disease. Even with the support of a commode placed next to his bed, it was not enough to prevent his incontinence.

*"I couldn't get out of bed and the commode was there and you just couldn't hold it. So it was all over the place." (David)*

Iris disclosed her despair of not being able to find a toilet when it is required. The extract also suggests that with the loss of control comes a sense of sadness.

*"And when you know you really want to go to the toilet and maybe you can't. I do... I do find it... (sigh) I wish I had more control over the bowels. [...] that's the hardest thing I think. I wish I had erm... I've got some control but I haven't got enough control really" (Iris)*

Arun describes a sense of torment, rather than sadness. In the following extract, Arun demonstrates the demoralisation of the disease, in his use of the word 'nappy'.

*"yeah [it is] a bit demoralising, everybody else is enjoying their lives, they're able to you know go to like the cinema, without having to keep a nappy with them or something like that" (Arun).*

Arun is a man whose young children had only recently transitioned out of nappies. His meaning of incontinence was interpreted as infantile, and as such, extremely humiliating and emasculating, thus affecting how he positioned himself as a man and father. As a result of his lack of control, he experienced despair so severe that he felt as if he could no longer live. He was so troubled by his disease that he found it difficult articulating the experience.

*"it's a very tormenting disease, it, it, it, torments you with horrible... you wanna sit there in the meeting and you're holding it like 'go, go, go you've gotta go and then you run." (Arun)*

*"you know I just wanna throw everything in the bin, you know, sod my life and err (laugh) sod everything....I mean I even told my wife, I really don't want to live like this you know this is terrible, cause I can't even control you know, when I go to the bathroom". (Arun)*

Pauline described a similar experience to Arun. She shuddered whilst recalling the experience thus indicating a prevailing shame and humiliation of *'messing myself'*. The dialogue trails off as if she cannot bear to think about it any longer.

*"...I've had 2 lots [flares] which was the worst ever where I just messed myself all the time, [...] the first time that happened I was... (shudders) oh my goodness...that was so bad. That was so (3 second pause)..." (Pauline)*

### 3.3.2 *Loss of control of the self*

This theme has clear similarities to the theme above, in relation to how participants experience a threat to their sense of themselves, through the loss of control of their body. This theme is comprised of three subthemes; *the threat to self and identity*, *IBD transforms who I am*, and *conflict of selves: who am I?* Most participants related to their bodies and minds as separate entities, thus this subtheme captures the experience of losing control over one's own sense of self and identity. How participants manage this overarching loss of control of the self is interesting and will be discussed further in the superordinate theme *Separation vs. Integration: An ambivalent relationship with IBD*.

#### *The threat to self and identity*

All participants experienced IBD as a threat to their identity, including, how IBD is experienced as taking away their life, or having a more intrusive role. The accounts described by Arun and Pauline were interpreted as a loss of identity through the experience of IBD and incontinence. Pauline found it difficult articulating the experience and eventually concluded that incontinence takes away who you are.

*"I dunno, I don't know how to explain it [incontinence]... it's just like, it just takes away all of you". (Pauline)*

For Arun, the ability to have control over the body is seen as central to being 'normal', thus in the absence of control, it makes him feel insecure and positions himself as no longer human.

*"umm...you don't feel normal.. don't feel human anymore, aahh I think that's the word, not really human, no longer in control with your normal habits, so, when you're no longer in control of your own devices you feel insecure, yeah" (Arun)*

Linda and David made sense of IBD as being an inconvenience, as it restricted them from living their normal lives. For Linda, this meant that her life was being stolen:

*"It's like, uurrghh, I've got to get myself well now before I can do this this and this, you know. It's like [...] to me it's like taking chunks of my life" (Linda)*

While David similarly related to IBD as an inconvenience, or, a *'pain in the backside'*, this was largely because it restricted him from maintaining his role as a carer for his wife. The experience of IBD was seen as unwanted and intrusive because of the regular review appointments and routine pathology collections necessary in managing the illness. These were seen as *'extras'* in his life, not *'givens'*.

*"I was going to the toilet and I had to take a sample to the pathologists this morning, so I mean, that's another job I had to do this morning. That's not easy, with my eyes, and your thing, (laughing) you know! You know, anything extra is a pain in the backside."* (David)

For Linda, her sense of identity was threatened with the mention of surgery during her last hospital admission. She described that the option of surgery had never previously been alluded to, and that this was a huge shock. In this extract, Linda provides me with a sense of her imagined future with IBD, and how this does not include having surgery. The mere mention of surgery was experienced as a significant threat to her imagined future self. Moreover, the experience cast a shadow of doubt in her mind about her *'taken for granted'* ability to recover.

*"[nurse] said something to me about...when the doctors come round [...] they might mention surgery or something... and that's when I really did like... [makes a 'korrr' sound] I almost burst into tears coz I never saw myself getting to that point where that would even be an option, I don't, you know, there's no way I'm going down that route, you know, I wouldn't have to do that"* (Linda)

*"I kinda took it for granted that they will always be able to put me on steroids and I'll be fine"* (Linda)

Pauline describes the realisation that IBD will always be a part of her life, which was interpreted as a threat. Prior to the interview, she had never discussed her experience of colitis in depth, and certainly not in relation to her emotional experience. This section of the interview had a profound effect on both Pauline and I. She appeared to gain insight into the chronicity of the condition while providing her account, as she slowly and thoughtfully spoke out loud the realisation that IBD will *'always be there'*. It was a touching experience to witness with her.

*“I’m never gonna be rid of it... does that...(3 second pause) It’s always gonna be there...It’s always gonna be there...It’s ruined my life...and that just... makes you think...” (Pauline)*

Arun’s account differed from both Linda and Pauline’s, as he experienced a threat to his identity in relation to how he viewed IBD. In Arun’s account, he described the somewhat disheartening experience of meeting someone else with Crohn’s Disease who alluded to a lack of hope in relation to living with the disease.

*“well I said to him that, ‘I’m sure there’s gotta be all kinds of new things coming out, new kind of treatments, new hope coming round the corner’, and he walked out and he looked at me and he says, ‘I’ll tell you one thing about Crohn’s, there’s just no hope’, now I, its stuck in my head, that just stuck in my head”. (Arun)*

Arun identified himself as a hopeful person who always had faith in finding answers, seemingly regardless of his multiple let downs of finding a resolution and cure for the disease. This experience had a huge effect on him, as the sense of no hope remained with him for days after the event, whilst he appeared to make sense of its meaning. This experience was interpreted as a major threat to his sense of identity. Instead of retreating into a state of hopelessness and despair, it spurred him on look for ways of managing this, by taking the position of striving for answers and having faith.

*“[my bosses] know the only person who can handle mission impossible is Arun, so they phone me. [...] I said to my boss, that guy [with Crohn’s] really put me in a right spot there he said there’s no hope, and you know me, you know there’s nothing that’s impossible, [...] I, we can achieve anything, there’s absolutely nothing in this world that can’t be explained you know, so I think that spurred me on to do the research, I’m that kind of guy, once I’m into it I never stop, till I find the answer.” (Arun)*

### IBD transforms who I am

In four of the participant's accounts, there were ideas that IBD transforms how they think, behave and ultimately, who they are. Thus, there was a sense of feeling out of control of how they viewed themselves, because this change was generally perceived as unwanted. Arun's and Iris's accounts are somewhat similar as both allude to IBD having transformed their personalities within a social context.

Arun described feeling that both the disease, and the medication used to treat it, changed who he was. Arun was the only participant to talk directly about treatment as a loss of control of self.

*"I think it's a combination of not just the condition, but I think the addition of the steroids, I think the steroids also changed me in personality a little bit" (Arun)*

Iris noticed how her friends perceived her differently, because she was bossier.

*"(laugh) somebody said to me yesterday, [...] 'oh you are bossy' and I said no I'm not, and they said 'yes you are', and I said 'no I'm not, I'm just independent' (laugh)". (Iris)*

For Arun, this change was extremely unwanted. I will take the reader through how I interpreted how Arun makes sense of his account of being transformed. In the first extract, Arun describes how Crohn's drains life out of you and encompasses it in negativity. When analysing this, I had a poignant vision of the petrifying 'Dementors' from the Harry Potter book series (Rowling, 1999).

*"I think the Crohn's... [...] just depresses you, it just makes you feel...not anger or anything or such, it just puts you in a spiral down of negativity for yourself, and everything else around you, so, you'd walking around but you'd have a very solemn face, a very unhappy approach to everything, if you're talking there's no life in you to talk" (Arun)*

Arun goes on to explain the immediate effect of taking steroids, in that there is an external source taking control of your mind. Furthermore, that this transforms him into an unwanted, aggressive person.

*"...you can feel it pretty instantaneously, once you've taken it, that something is twisting your head a little bit" (Arun)*

*"...I would say steroids makes me into a more kind of aggressive person" (Arun)*

He was able to reflect on this experience after he was withdrawn off steroids.

*"I'm a completely different person [off steroids], I mean my mind is calmer. I feel as if I've come down from some kind of hilltop. The air pressure was worse and I can [now] breathe." (Arun)*

In the next extract Arun describes how the steroids are antagonistic in their healing role. This was interpreted as Arun taking the position of evaluating a 'psychological cost, physical benefit' dilemma to treatment. However, when he describes how the Crohn's and steroid use affected his mood and personality, he presents like a spectator, observing the changes happen to himself. There is no mention of 'Arun', and his own role in the unfolding of this transformation. It suggests an overwhelming lack of control, or, conversely, a complete lack of ownership.

*"I think your immune system is compromised, for your psyche, your mind, and at the same time you're physically battling yourself, so these two are conflicting sometimes. Once you've been doing Crohn's for many years, I think the two fight, so steroids will physically help you, but they will also psychologically put you right down on the bottom floor, and then you kind of try pick yourself up and that makes it worse, that makes the condition worse, it breeds it with itself". (Arun)*

The reader may notice Arun's interesting use of the action 'doing Crohn's'. It made me question whether Crohn's is something you 'do'. This can be interpreted that over the years, Crohn's has become a job to him, in his search to find a resolution. Furthermore, he alludes to attempts to get himself better, as making the condition worse.

In Pauline's account she described the impact that multiple flares has had on her confidence. This experience relates to the previous subtheme of loss of control of the body, as for Pauline, her experiences of incontinence, and her confidence in herself, are inextricably linked. She describes attempts to build her confidence, which appears to be a degenerative process, for the aftermath of each flare is deterioration in confidence in her sense of self.



*“I suppose [experience of IBD has] chipped away at my confidence... [...] that’s probably the hardest bit, your confidence goes in a big way. Erm... and to keep losing your confidence and then have to try to rebuild it again, it becomes less and less. I don’t feel like I wanna bother anymore” (Pauline)”*

In Riya’s account, she portrays IBD as transforming her into a weaker person. This was interpreted as illness being synonymous with an impaired, bad body. However there is a sense that she now positions herself differently with IBD and no longer feels weak.

*“in the last few years its changed, but before, I used to see myself as a little bit more weaker” (Riya)*

During this part of the interview, Riya embedded this sentence swiftly into another one, and effectively, changed the subject. On consulting my reflective journal, there was no mention of my interpreting a sense of her feeling weaker as a result of IBD. It was not until I transcribed the interview that I noticed how this seemed to be a really important factor in how Riya previously made sense of, and positioned herself with IBD. Unfortunately the meaning of this was not elaborated. On reflection, this could be interpreted as avoidance of portraying herself this way, thus perhaps I inadvertently colluded with this sense of avoidance.

#### Conflict of selves: who am I?

For four of the participants, they conceptualised themselves as living with two selves. There were different meanings of this between the participants. Due to the relapsing nature of IBD, participants’ experiences were interpreted as a sense of conflict between ‘self in remission’ versus ‘self with a flare’, or as we saw above for Arun, between ‘self on steroids’, versus ‘self not on steroids’.

In Pauline’s account, there was a sense of not knowing who you are, because when she is going through a relapse, the deterioration is a slow process. The consequence is that when she becomes well again, she gains a sense of perspective of herself and becomes confused about who she was when she was unwell, but still able to ‘carry on’ her life. It is interesting that Pauline appears to want to compartmentalise the ‘good’ part from the *bad* part of herself, which is interpreted as attempts to separate herself from IBD. However, the slow process of illness progression makes this very difficult and confusing for her.

*"I don't remember ever feeling as good as I feel now. I felt so bad...It's just like finding which part is the good you, and which parts the bad. That's hard". (Pauline)*

Similarly to Pauline, Arun described a conflict between a good and bad self. In his account, he described living with two sides of himself, when he was taking steroids on and off, for 8 years.

*"I didn't recognise myself for about 8 years, I'm pretty sure there were two sides of me which are very difficult to, to kind of...dissect" (Arun)*

Living with two sides to him was a huge struggle for Arun, because of the immense shame that came with an 'aggressive' personality, conceptualising himself as being like Jekyll and Hyde. Furthermore, his family rejected this new self, as indicated by his wife imploring with him about what was 'wrong'.

*"My wife said to me 'gosh, what's wrong with you, why are you shouting unnecessarily?', and [...] I wouldn't feel I was shouting. But I was conveying a point that was very strong and I wouldn't have it any other way, and that's not normally like me [...] it was like Jekyll and Hyde". (Arun)*

Riya's account is different from others, although she still portrayed a sense of two selves, in that there is a 'normal' versus 'abnormal' self. Riya only experiences the presence of IBD when it is evidenced by blood tests or diagnostic tests. Consequently, the 'abnormal' part of her is completely internal and therefore invisible.

*"The thing is, what's also quite difficult, [is] because externally I feel, I'm completely normal, but it's all inside which is difficult for me to see" (Riya)*

Similarly to Riya, Linda experiences a conflict between two selves. Linda lives normally in between her flare ups and she makes this distinction throughout her account. Linda takes the position that she does not have colitis all the time. Thus for both Linda and Riya, IBD requires measured, physical, observed symptoms as evidence for it to be 'real'.

*"...in between the flare ups, you, I wouldn't know, anyone else wouldn't know there was anything wrong, coz that's the thing with it, your body is fine in between..." (Linda)*

*“when I say to people I’ve got colitis, I say, ‘well I haven’t got it right this second’ (laughs)” (Linda)*

### 3.3.3 Control in relation to others

In this theme, the lack of control in relation to others is explored, such as a lack of agency and dependency on external sources. This includes relying on support from friends and family, the medical profession and medical treatment. This theme is comprised of the following subthemes: *relinquishing control, having an advocate for control and others living IBD with you.*

#### Relinquishing control

There were periods where participants experienced such intense despair and helplessness, that they took the position of surrendering control. In Linda’s account, she explains how her friends sympathised with her having to be admitted to hospital for intensive treatment to manage her flare. However, Linda explains that while being admitted is always the worst possible outcome, at times, she becomes so desperate that she begs to come to hospital.

*“...you get to a certain point, you feel so ill you’re kinda begging to come in to hospital because you know that as soon as you’re in hospital and they sort of hook you up, you’re gonna...it happens very quickly you start to feel better” (Linda)*

This account is congruent with other participants’ experiences. For Pauline and Linda, there is a sense that when they feel out of control of their bodies, the only solution is for doctors to take control on their behalf. I noticed how both participants used the word ‘*obviously*’ in how they make sense of this. There seems to be no other choice thus participants are left feeling helpless and disregarded as agents in their own recovery.

*“...you’ve got other people sort of taking control of you, you know, and obviously you have to let them do that” (Linda)*

*“...obviously you just go the doctors and they take it from there really” (Pauline)*

Arun's and Iris's experiences represent alarming distress with the onset of an acute flare, or disease onset. For both, in a state of desperation, they look for the symptoms to be contained by others, within a medical frame of understanding the illness.

*"I was losing a lot of blood again this time things were out of control. And I said to err [nurse] and [gastroenterologist] and the Drs here, what do I do?" (Arun)*

*"I didn't know what to do and I was in pain, so I dialled 999. And erm they kept, the paramedics came and then they took me to hospital and then I just passed out" (Iris)*

### Having an advocate for control

IBD is conceptualised as taking control of all aspects of participants' lives, and participants expressed wanting someone to take control *for* them, not *from* them. This subtheme relates to the importance of participants having support from a person advocating on their behalf.

Being in hospital alone and feeling threatened with the notion of surgery, Linda felt frightened and out of control of her own treatment and recovery. This was interpreted as a sense of mistrust about the surgeon's intentions, and that Linda is desperate to be involved in the decision making so that she feels she has control of her own future. The extract below illuminates the comfort and relief that Linda felt, having the IBD nurse specialist inform her of potential decisions in a transparent way.

*"...you obviously feel out of control [...] coz everything's being done to you, so it's nice to have someone that makes you feel a bit more in control coz you think, oh I can always ask [nurse] or speak to [nurse] [...] just what they're [consultants] thinking [...] as far as your treatment and different things like that..." (Linda)*

As Riya was only a teenager when she was diagnosed, her parents were involved in helping her to make decisions, with the view to gain control over her condition.

*"When I was diagnosed yeah my parents would look after me, like, you know, you have to eat this this is good for you" (Riya)*

However, for Riya there appears to be a prevailing sense of preferring others to look after her, rather than attempting to gain agency herself, as her husband continues to make some decisions for her.

This was interpreted as a source of comfort and support. However, because of the position she takes in overlooking and avoiding the condition, Riya may inadvertently draw others into a caring role for her.

*“He [husband] knows I need to eat healthy foods and that kind of stuff so he just makes sure I am eating all the healthy stuff” (Riya)*

Arun speaks about the importance of having support from medical staff to gain control over the condition. Arun’s quest for answers to finding a resolution for his condition led him to access information from journal articles and a second opinion via a private medical practice. Arun decided to trial pharmaceutical interventions, one of which is typically prescribed to HIV patients to help fight infections. For this to be prescribed required strong support from his GP.

*“I said to my GP look I need your help here, I need your support, what I want to do is I want to trial [drugs]. My GP is very very open minded cause he saw me suffering, so he said to me you know this is too much now, we’ve got to do something about [this]”. (Arun)*

This experience was interpreted as being highly validating for Arun, and that he had support from others in his attempts to manage his own condition.

#### Others living IBD with you

The final subtheme is in relation to support received by others. All participants perceived that having consistent, supportive care from others is pertinent in being able to manage the lack of control of their body and themselves.

For Linda, this incorporated support from her family and the medical professionals. It was important that her family members live the IBD with her, so that they fully understand her ordeal.

*“I mean my family and that have seen me when I’m ill and stuff so they, they know what I’m going through” (Linda)*

Similar to her experience of the specialist nurse acting as an advocate for control, Linda relies on the nurse as a source of comfort and trust. Iris and Pauline also both emphasised the importance of having someone to speak to, to voice their concerns and share their experiences. The experiences

are interpreted to mean that participants take the position of striving for understanding from others, in order to feel validated and connected.

*"[nurse] is like my go to person that if I'm not feeling well [...]. I know she's there for me, she'll do her best to sort things as it were, so I think that's very important, that people have someone that they can really trust" (Linda)*

*"I think it's important that there are people on board that can talk about it. I mean if I come across anybody in the year that have said... I've got IBD... I will say oh right, what is it, what have you got? [...] And then I'll talk about it, and then they'll talk about it, and you do feel better" (Pauline)*

In Linda's and Iris's accounts, they indicated a need to be known as a person. Linda wanted to be known for *her*, not her disease. This can be interpreted as her sense of who she is, is separate from their illness. Conversely, Iris likened being known as a person, to the doctors knowing about her personal and medical history.

*"They [consultants] know my disease, but they don't know me" (Linda)*

*"They [GP] don't know you as a person. And I think that's a big disadvantage really, erm...because if they know you, they know your history, they know your medical history and your personal history. But the [GPs] don't....so by going to [gastroenterologist] I feel he knows me a lot better than my GP does" (Iris)*

Two participants expressed a sense of insecurity about losing this support, thus demonstrating a significant attachment to their relationship with medical professionals.

*"If you've got a good doctor, you hold onto them! (laughs)..." (Iris)*

*"It's nice having someone that is familiar that you've dealt with before and they know you and they've seen you before, and yeah, so definitely helps. I hope she doesn't retire any time soon! (laughs)" (Linda)*

### 3.4 Separation vs. Integration: An ambivalent relationship with IBD

This superordinate theme captures participants' experiences of an ambivalent relationship with IBD, whereby the illness is either separated from their sense of identity, or else it is integrated into themselves. While this may perhaps be perceived as a bipolar construct, participants appear to position themselves somewhere across the two constructs, so it could be viewed as more of a 'continuum' of experience. However, this is not conceptualised as a linear process of progression, where the end point is that IBD is integrated into oneself, or accepted, as most participants appear to position themselves differently throughout their experience of living with IBD. This superordinate theme aims to capture the participants' experience of how they relate to their illness, and how they make sense of adjusting to their illness.

#### 3.4.1 Separating self from IBD

This theme encapsulates participants' experience of disconnection from IBD. In their accounts, all participants experienced a sense of disengaging or minimising their illness, in an attempt to separate themselves from the illness, and retain their healthy identity. This theme suggests rejection of the unwanted, unhealthy self. This section will provide the reader with how participants' experienced this process.

Referring back to Linda's experience at hospital, when surgery was mentioned, for her, it was important to avoid thinking about it and carry on as normal in order to diminish the threat to her imagined future self.

*"Once I was well again, and I was out of hospital and I got back into my normal routine, I never really thought about [surgery] again" (Linda)*

Moreover she takes the position of avoiding thinking about IBD as she perceives thinking about it to be unhelpful.

*"I didn't want to be one of these people that were like, 'ooh, I've got this, therefore, I can't do this, and I can't do that... and... I've got this terrible disease. Coz I think, like with everything, if you dwell on it, you can let it affect you and ruin your life" (Linda)*

Similarly to Linda, Pauline tries not to think about it. As described above, Linda and Pauline position themselves as only having IBD during a flare, so it does not play a large role in their life when it is in remission. The assumption is that by thinking about IBD, it is allowing it to affect you, which would ruin your life. Consequently, in order to prevent IBD becoming a significant part of their life (and therefore ruining it), it gets avoided and pushed aside during times of remission.

*“I don’t really think about it that much. When you don’t have a flare up you don’t sort of think about it too much, but when I talk about it, and think it’s a life thing, it’s not ever gonna go away, it’s always gonna be there in some form or another, then I get angry, I suppose”. (Pauline)*

In the following extract, Pauline was tearful in response to thinking about the impact that colitis had on her marriage. She finds it difficult talking about IBD because thinking about it increases insight into the impact of the disease, which is seen as threatening. It is easier not to think about it, so that she can retain her healthy identity.

*“This morning I got up and was thinking I don’t know if I wanna talk about it, because if you talk about it, it makes you think about things doesn’t it? [...] and what’s gone on in your life and.... although you cope with it and you live with it, it’s a real debilitating illness.” (Pauline)*

Riya took the position of separating herself from IBD as a form of protection for her preferred identity. I asked her how she had felt about taking part in the interview and talking about her experiences.

*“I probably wouldn’t like to [talk about it] regularly because then it would be reminding myself... and I wanna be strong and I just wanna have [...] a normal life, not having to think about [it].” (Riya)*

Similarly to Pauline and Linda, Riya’s experience was interpreted to mean that talking and thinking about IBD is not helpful, because it threatens the ‘normal’ self. There is a sense that participants cannot live a normal life with the continual presence of IBD. Thus, separating themselves from the illness by avoiding it, is seen a way of adjusting to the illness.



Most participants talked about their body and mind as separate entities, thus IBD was often externalised. At times this was as a useful strategy, because by separating the illness they were more able to relate to it. However in Pauline's account, as mentioned, she made sense of colitis as a black cloud. This was conceptualised as an external object that she cannot grasp, but prevails above her, permeating into her mood and body. Thus IBD can be seen as separate to her, but somewhat intangible. The extract below further illustrates her separation from colitis. The extract is interpreted to mean that expressions of sympathy are directed towards her colitis, not her, which is seen as avoidance of a perception of weakness, and needing sympathy from others.

*"[my children] they're much more sympathetic towards....towards the colitis if you like" (Pauline)*

Other participants took the position of minimising the impact of IBD, which was interpreted as disconnecting from the severity of the disease in order to avoid the threat to themselves. Participants often compared themselves to others with IBD and believed that others are worse off than them.

*"I feel terribly sorry for the young people that have got it. [...] That's absolutely awful for them, to have to have it when they're so young. And to have to go through the whole of their lives with it" (Iris)*

*"I see all these older people... I just feel so bad for them, [...] I think oh if this is happening to me, how the hell does it affect them?" (Pauline)*

Riya minimised the impact of IBD in order to avoid the threat to herself.

*"...if I was telling you that oh I've got Crohn's... errr I don't know I can't really describe anything. I'd just say okay, I've got Crohn's I take medications for it but its fine I don't really feel anything about it...." (Riya)*

As mentioned, Riya's relationship with IBD was ambivalent. I will remind the reader of the quote used earlier.

*"It's [...] like a yo-yo I suppose, so at times when we're really really close to it, that's when I'm taking the medications and we're trying to get on the right track and then when the yo-yo is down its more like, I don't really care what I have, so it's more like a yo-yo...." (Riya)*

The yo-yo is 'down' when Riya takes the position of disconnecting or separating herself from IBD to protect her collective identity, because she perceives her illness as 'odd'. Riya particularly struggled with feeling a burden to others and she did not want to be treated differently. Riya told me that within her family culture, food plays a significant social role. By being served different foods, it may have reminded of her difference, or *unequal status*, within her family and peers, thus threatening how she viewed herself within her family.

*"I think that's the one thing that I would like to change, is that people don't treat me differently. In any other way, people do treat me as equal, I think it's just in terms of the food they treat me like 'oh, no you can't have this, you can have this' " (Riya)*

Riya's rejection and overlooking of the diagnosis may be perceived as a way of separating and avoiding connection with the illness, as a way of retaining her 'normal' identity.

*"the blood tests suggest that I have got the symptoms still, of Colitis or Crohns, but I've never felt that I have got the symptoms" (Riya)*

However, she contradicts herself in her account, by her suggestions that she had to avoid eating certain foods, in order to prevent symptoms. It can be seen that Riya does not *fully* reject the diagnosis, and she wonders what is 'normal' for her. This uncertainty is represented by her yo-yo, her push and pull towards IBD.

*"...or am I just in denial that I don't get the symptoms because my body is used to it as a day to day thing? But I don't think it is just normal, it's quite confusing but I don't know (laughs)."*

Throughout his account, David struggled to remember names of medications and other medical jargon, which might be expected given the complicated terminology associated with the illness. However, the term IBD did not seem to resonate meaning for David. While there were instances throughout his account consistent with not thinking about his illness, it was surprising to me that he seemed to take a dismissive position towards the term.

*"I don't think it has affected me. Sometimes you get down periods, but that's not down to that IBD, or whatever you call it..." (David)*

This disconnection with IBD was interpreted in line with his previous experiences of illness, as described earlier. Furthermore, his colitis has to be overlooked as a way of protecting his identity as a Carer. He engages with his colitis for what he views as the minimum amount required, and anything surplus to that is seen as an inconvenience.

*"...now I gotta do the shopping, gotta cook everything. Put it to my wife and make it so that, coz she's paralysed on one side she don't use one side, so I gotta cut everything...so my colitis goes in the background unless it's an emergency." (David)*

*"I don't think about it, I haven't got time to think about it, I take me pills regularly. And err come and see Tracey the least possible times, every 6 months." (David)*

Five participants experienced a sense of fighting to retain their healthy identity, through forcing themselves to carry out 'normal' activities, and maintain their social identities. The following extracts present participant's experience of battling against their IBD.

*"I used to fight it instead of giving in to it. I used to ermm... make myself get up and, make myself do the cleaning and try and do the normal things that everyone does" (Pauline)*

*"I kind of forced myself to go [to the zoo], thinking I'm not gonna let it, sort of defeat me" (Linda)*

Arun related to his Crohn's as an enemy to terminate, to get out of his body.

*"Crohns, yeah, I think when I was going through it I was thinking it was my enemy, it's a really vicious thing, that's there for me". (Arun)*

*"I was finding it very difficult to live with myself [...] you look in the mirror and you're not really the person you want to be [...] you were a healthy person probably about 10-15 years ago [...] I don't really want to be, I don't know what this is, I want to take it out, whatever it is" (Arun)*

### 3.4.2 Integrating self with IBD

The final theme represents participants' experiences of engaging with IBD, and integrating it into themselves and their lives. All participants experienced this in some way, however experiences differed in their meaning and how people relate to their illness when they are engaging with it. Due to the relapsing nature of IBD, there is a sense that participants engage and disengage periodically, as a way of adjusting to the condition.

Participants experienced becoming more attuned to their bodies, which is a temporal and learnt process. Participants described not only being able to listen to their bodies, but they adapted themselves accordingly. Hence to represent the reciprocity of this relationship, I have used the term *attune* rather than *attend*.

*"[having IBD has] made me more aware of myself. (annunciates each word carefully) I've had to learn to listen to what my body is telling me to do. Whether I've got a flare up or not, that's still what I do, so in one way, that's the good thing that's comes out of it". (Pauline)*

By attuning to her body, Pauline was able to understand her body, and think in a solution focussed way, about what works. Thus, it is more than just noticing what happens to the body.

*"... it's getting a focus, [...] think about what's making you feel better, mentally and physically. And that's, that's what I've learned really, over the last, probably over the last year" (Pauline)*

At the heart of Iris' experience is a desire to retain her identity as an active and social person. However she takes the position of incorporating her Crohn's as part of this, as there is a sense that being 'normal' involves listening to her body.

*"I want to continue, to keep going you know, in the way I was before, as I say, I'm quite an active person, I belong to a club and I'm on a committee...so, you know, I would like to continue to do that, provided I rest when I need to rest" (Iris)*

Similarly for Linda, her experience has taught her to be aware of her body, and to understand when something is 'not right'. By taking this position, she feels more confident in being able to control and manage her colitis.

*"I'm kind of very attuned to it (laugh) coz obviously [...] I have to look out for these things so I'm just so aware of how my body is feeling in that regard, I just kinda know if something is not right" (Linda)*

David took the position of learning about his body so that he could identify when best to carry out his duties. David alluded to coping with IBD. I asked what this meant for him, to which he replied 'well, you get used to things, don't ya?' As seen below, this entails an understanding of his bodily movements, so that he can gain control of his life.

*"Well you get used to it, usually I'm alright in the mornings [...] I try to do everything I can in the mornings because I know it will be reasonably stable." (David)*

Participants also alluded to engaging with IBD as a way of gaining control over the illness. When they were faced with a threat to their identity, participants attempted to understand their illness to gain certainty. Riya's experience was interpreted as IBD threatening her imagined future of being a mother. As such, she chose to engage with IBD, and to become 'strong' and motivated to accept help.

*"...I've got this aim, I wanna have a healthy future, that's probably why [I'm accepting help]. In the past I wasn't even thinking much and it was more just myself and now it's about our family in the future [...] I don't want anybody to get hurt because of me, kind of thing [...] I'm really willing to do the right stuff that is needed to". (Riya)*

In order to feel in control, Riya needed to understand and feel confidence in her diagnosis. In order to do this, she took the position to get closer to IBD and make it visible. Her decision was to undergo three diagnostic tests simultaneously, so that she could get a picture of her condition.

*“I feel quite strong [when I’m closer to IBD] to the point that like I am at the moment, for example. I want to have this diagnosis done in April and I want to start from then... okay it’s like a new start, this is the diagnosis and I want to get better.” (Riya)*

Similarly to Riya, Arun’s experience was to integrate Crohn’s into his life by striving for answers. He took the position of gaining certainty as a response to his sense of duty to others.

*“...the only way to finding the answer to this is to find out yourself. You know there must be something in all of this that can find the answer”. (Arun)*

*“...the driving force is trying to keep yourself going not for yourself.... It’s really not about me anymore, I have got 2 little ones that need me, so the driving force was to be for them and for my wife really”. (Arun)*

Arun’s journey was a particular struggle. He experienced a conflict between two selves; his ‘Jekyll and Hyde’. He felt tormented with uncertainty and shame about his unwanted self. Furthermore, he perceived his God to hate him, believing that he was being punished. However, it was important for Arun to find personal meaning with Crohn’s, as this enabled him to find a different relationship with it. He perceived IBD as being a test in his life; a test which he had to pass. Arun conceptualised his experience as a Bhagavad Gita, which in Krishna law represents a battle between good and evil. However, Arun alludes to his Crohn’s as being the manipulator of the battle, not the ‘evil’ to defeat. His good and evil was how he perceived himself and his interaction with others. Thus essentially, he was battling himself, and eventually he was able to make peace with himself.

*“although I feel I’ve done a lot of bad things by saying a few bad words to people and somewhat, but I also know there’s a positive in that because it’s gonna help me to mature, learn things, so this was my test in a way, what we call, in Krishna it’s called a Bhagavad Gita. This is my Bhagavad Gita, my battle between good and evil, and maybe I’m coming up to the end of it, it’s coming to a close. And if it isn’t, then I*

*will continue with it you know, I'm more than happy to carry on with it, so it's taken a good long time to realise that". (Arun)*

By positioning IBD with his faith he was able to reconnect with God. This was a very touching moment for me. Within this extract, the reader can see that he appears to speak to God when he says 'you won't let go of me'.

*"The reason why god is saying to me in my head that I hate him is because you won't let go of me (small laugh), and that's the reason why I keep saying I hate him, because the more I hate him the more I'm actually trying to get close to him." (Arun)*

Crohn's now plays a larger part in his life. By viewing it as a test, finds personal meaning with it, and sees it in a more positive light.

*"Now, I'll be honest it's very calm [part in my life] right now, I think right now it's telling me to try and help others" (Arun)*

This chapter ends with two participants' experiences of reconciliation, whereby IBD is accepted as part of their lives. This has not been deliberately discussed at this point to represent an end point to 'achieve'. However, from participants' perspectives there is a sense that this is a calm and peaceful place to be.

For Iris reconciliation meant that she had incorporated Crohn's into her life and she has made adaptations as to who she is. She was confident and assertive in doing so, regardless of social pressures to conform or keep up appearances of normality.

*"I've learned to say no, a lot more the last 2 years, whereas before I was very easily talked into things. I was very compliant and I think that you just have to take control of your own life. Does that sound funny? Yeah, I think I have over the last couple of years, I've taken control and that person [friend] was probably right, I am more bossy (laugh)." (Iris)*

I asked Iris to describe IBD, and this extract represents her position of accepting the illness, and encapsulates the theme of integrating IBD into the self.

*"...it's something that's there, but you can't get rid of, because it's incurable. You're gonna have to learn to live with it. [...] it's no good fighting it, you've just got to... well you've just got to take advice and [...] take whatever tablets come along if they are going to help and you just got to accept it really. It's part of you isn't it? It's part of your body and it's not going to go away, you know. So...does that explain it?" (Iris)*

Similarly to Arun, Linda's experiences were interpreted to mean a sense of acceptance of the illness as part of who she is, yet remaining hopeful for improvement. For these participants, 'hope' and 'acceptance' are not mutually exclusive.

*"I just think of it as something that happens, that I get from time to time and yeah, it's just I just see it as part of me". (Linda)*

*"I know people as I say that have had it and they've come through it, and they've had no symptoms and they're not on any drugs and... so I know there's hope that that might happen to me, but if I have to take something for the rest of my life then I will". (Linda)*



## CHAPTER 4: DISCUSSION

### 4.1 Overview

This study aimed to examine experiences of living with IBD and to uncover themes in relation to acceptance and adjustment with the view to broaden knowledge about this framework. Six participants' experiences were examined through the use of semi-structured interviews, and analysed using Interpretative Phenomenological Analysis (IPA). The results section provided an overview of the themes as illustrated by participant's verbatim extracts. Whilst this was presented in a logical sequence many of the themes interlinked. In view of this, in this chapter all findings will be presented together, and explicated with regards to addressing the research questions.

This chapter begins with an overview of the key findings of the study relative to the research questions of *how do people experience living with IBD*, *how do people living with IBD experience acceptance and adjustment to their condition*, and *how do people living with IBD relate to their condition*. These findings will be discussed in relation to the current evidence base, including how the study adds knowledge to the existing theoretical and research literature. This chapter will then consider the significance and clinical implications of the study, suggestions for further research, and a critical appraisal of the study. Finally the chapter will end with a personal reflective account.

### 4.2 Consideration of the main findings in relation to existing theory

#### 4.2.1 *Experiences of living with IBD*

The findings from this study illustrate that IBD is painful, stigmatising, and intrusive to life. There are major issues about living in a world of uncertainty, and humiliation and despair about living with a body that cannot be controlled. Themes emerged about participants taking their disease and recovery for granted, and they reported not feeling understood or taken seriously by others. The notion of IBD restricting normal functioning and generating a pervasive loss of control is consistently reported in the literature e.g. (Casati et al., 2000; Cooper et al., 2010; Drossman et al., 1991; Kemp et al., 2012). Furthermore consistent with quantitative literature, IBD is shown to impact on both the emotional and physical well-being of those living with IBD (Casati & Toner, 2000).

The findings revealed that themes of living with IBD influenced how participants positioned themselves, in relation to their sense of self, their body and their illness. In their theory of the 'dialogical self', Hermans and Hermans-Konopka (2010) assert that self and society are interconnected and shape one's identity. Moreover that people are continuously involved in a process of positioning and repositioning in relation to other people and themselves (Hermans & Hermans-Konopka, 2010). Consistent with this theory, the positions that participants took were shaped by wider external influences, such as isolation, feeling stigmatised, and a prevailing lack of understanding of the disease. Moreover isolation and a lack of understanding from others also shaped participants' positioning towards others, such as in social and intimate relationships. Lastly, participants positioned themselves according to previous experiences through processes of gaining perspective and comparisons over time. Consequently, the themes shaped how participants related to the illness and how they subsequently managed and adjusted, to live with the disease.

In all participants' accounts there were issues of living in isolation with a condition perceived as undesirable and stigmatising, demonstrating that these are key experiences of living with IBD. This finding is consistent with the existing literature (Hall et al., 2005; Kemp et al., 2012). In their accounts, participants in this current study described feeling isolated from friends, family and even others with IBD. Through feeling isolated, participants actively took the position of separating themselves from the illness in order to preserve their healthy self and identity. Arun and Riya worried about being perceived as different and odd within their families, and a fear of burdening them. According to Charmaz (1983), burdening others increases a sense of deficiency and dependency on others, which in turn fosters a loss of hope, and is related to losing part of themselves. This is consistent with participants' reports of perceiving themselves as weaker, or that there is something 'wrong' with them because they have an illness. In order to preserve a positive self-image, it is important to maintain past obligations from relationships and social activities, and to not make one's identity solely about the illness (Bury, 1982; Charmaz, 1983).

It is important to consider this finding in the context of ethnicity. Riya and Arun, who both described themselves as British Indian, construed IBD as alien and odd because there was no previous experience of it in each of their families. They perceived themselves as different to their family members which was confusing and distressing for them, and appeared to shape processes of adjustment to IBD. Non-western cultures emphasise the importance of collective identities rather than individuated 'selves' (Dwairy, 1997). This may call into question the relevance of Charmaz's (1983) theory of isolation as a loss of *self* in understanding the experiences of people living with IBD

from non-western cultures, particularly as the data were collected in North America. Nevertheless, IBD could be considered to undermine a sense of collective identity, because of the uncomfortable feeling of difference associated with the illness.

Most participants actively isolated themselves from friends, due to physical restrictions, or for fear of embarrassment and judgement. According to Charmaz (1983), isolation and identity are interrelated as identity is a relational concept developed through social encounters. As such social isolation fosters a loss of self (Charmaz, 1983). All participants described that IBD restricts their normal social functioning due to a loss of bodily control, feeling too unwell, or fatigued, which is consistent with the current literature (Kemp et al., 2012).

Frank (1995) asserts that society expects its *adult* members to have control over their bodies and that if they do not, they are expected to either conceal it, or gain control as soon as possible. A loss of control of the body is stigmatising and societal discourses affirm the view that those without control should avoid embarrassing themselves and others (who bear witness to the 'shameful' act), in order to keep their 'spoiled identity' from public view (Frank, 1995). However far from being a protective strategy, it results in greater cost to individual's self-image as social isolation undermines people's identity (Charmaz, 1983). Therefore living with no control over the body, with embarrassing and stigmatising consequences, can negatively impact on people's identity (Charmaz, 1983). This is consistent with the findings from this current study as there were major issues with losing control, of both body and self.

For people living with IBD the experience of threatened or actual incontinence was particularly troublesome, and was synonymous to losing part of themselves. This is particularly relevant for IBD, given that the illness is associated with physical symptoms that are deemed taboo and socially undesirable. As a result, participants in this study took the position of hiding their 'public' selves, as seen with David, Arun, Pauline and Riya. Pauline declined to disclose her difficulties for fear of embarrassment, or for not being wholly understood. Iris took the position of continuing her normal social activities. However the fear of shame and stigmatisation afforded to potential incontinence, resulted in extreme hyper vigilance of her body.

Arun described feeling insecure in his own existence as a human being, which he attributed to a lack of control of his bodily devices. Furthermore, Pauline described incontinence as taking away who she was. In Dickson et al.'s (2008) study, using IPA to explore the lived experiences of adults with spinal

cord injury, incontinence was considered a major issue and it was frequently viewed as a loss of control of body and self (Dickson, Allan, et al., 2008). Whilst there are theories in relation to restriction of illness as being pertinent in shaping one's identity (Charmaz, 1983), this appears to be a relatively new concept in the IBD literature. The finding that incontinence is considered a humiliating loss of bodily control is however not a new concept, and is consistently reported in the literature (Casati et al., 2000; Drossman et al., 1991; Kemp et al., 2012). Nevertheless, there has previously been less of a focus on the impact of incontinence as a literal loss of control, in losing or shaping person's identity.

Another key finding was in relation to the torment of uncertainty and a lack of information and understanding about the disease. This sense of uncertainty led participants to take the position of striving for information, with the view to gain resolution and a sense of control over the illness. Illness perceptions, such as cause, controllability and consequences of illness are known factors in influencing the choice and engagement of coping strategies (Knowles, Wilson, Connell, & Kamm, 2011) and are important factors in influencing psychological adjustment to IBD (Dorrian et al., 2009). Taylor's (1983) theory conceptualises illness as a threat that undermines a person's sense of control. This explains how participants in this current study positioned themselves with striving for certainty. Moreover the theory suggests that as a response to threat, individuals assert control in other areas of their life. This sense of asserting control was demonstrated by participants who took the position of gaining control of their life through searching for answers, understanding, and by getting to know their IBD.

#### *4.2.2 Identity and adjustment*

As discussed above, losing control of the body can be understood as a loss of identity. For many participants in this study illness seemed to threaten their sense of past, current, and future self, consistent with Bury's (1982) conceptualisation of chronic illness as a biographical disruption. According to this theory, a loss of self is a fundamental challenge that patients face, thus affecting adjustment processes.

Bury (1982) asserts that illness disrupts patient's 'taken for granted' assumptions and behaviours, and that there is a process of rethinking self-concept and biography. In response to the disruption, there is a period of 'mobilising resources', which involves patients adapting their lifestyle, and social and community identity accordingly. Consequently identity is a central component of adjustment to illness, consistent with Charmaz's theory of adaptation to illness (1995). Using the example of Linda,

the notion of undergoing surgery to manage her condition, was seen as a threat to her imagined future identity. She described taking her body for granted in its ability to recover from a flare. The imminence of the threat of surgery afforded Linda the opportunity to rethink her biography and imagined sense of self. However on returning home and re-engaging in normal activities, Linda took the position of retaining her healthy identity by separating herself from IBD, and its threat to her sense of self. This is also related to Charmaz's (1995) ideas about acceptance, insofar as patients tolerate living with illness 'within limits'. Limits are construed as contingencies that are more than patients can emotionally handle; in other words, "I can live with it as long as...". Most threatening to the participants in this study was the notion of surgery, and serious complications such as cancer.

It is important to discuss the impact that a loss of identity had on participants. For many, they described that living with IBD was like living with two selves. Some reported finding it difficult to 'dissect' the selves because they appear to merge together, while others perceived them as distinctly separate. Linda and Pauline took the position of distinguishing between self with flare versus self in remission. Pauline found this challenging because she experienced relapses as a slow deterioration of symptoms, thus the 'selves' merged together. People living with IBD can be viewed as members of a 'remission society' (Frank, 1995) given there is no cure, and it is characterised by periods of relapses and remissions. According to Frank (1995) societal discourses influence the view that people should either be healthy or ill, thus people with chronic illness do not fit into either and overtly adopt two selves. This experience may be somewhat more pertinent for people living with IBD because of the taboo nature of the illness experience. As such participants internalise societal discourses and take the position of rejecting their illness, and self with it, as being undesirable. Thus having two selves may serve as a protective function, in order to preserve the healthy self.

In Charmaz's (1983, 1991, 1995) and Bury's (1982) studies they interviewed patients with chronic illnesses that are differentiated from, and heterogeneous to, IBD. However, both theories provide useful conceptualisations of living with and adjusting to chronic illness. Moreover these theories are consistent with findings from this study, in that acceptance and adjustment are viewed as indissolubly bound with identity. However, it is important to consider how experiences of acceptance and adjustment may be differentiated in those with IBD.

#### 4.2.3 *Experiences of acceptance and adjustment for people living with IBD*

This study revealed that participant's relationship with IBD was inextricably linked to their experiences of adjustment. As such, the question of how people with IBD relate to their illness is also addressed in this section. A major theme from this study was that participants experienced an ambivalent relationship with their IBD, which is conceptualised as *Separation versus Integration: An ambivalent relationship with IBD*. Moreover how people manage this, or position themselves with their illness, themselves, and indeed their body is key in their experience of adjustment. Participants attempted to separate themselves from IBD, or they integrated it within their sense of self. Moreover participants positioned themselves along this 'continuum' in different ways over time. The superordinate theme of 'separation versus integration' relates to the existing qualitative IBD adjustment literature. In Kemp et al.'s (2012) metasynthesis review of qualitative studies, it was considered that individuals with IBD live with a constant tension, conceptualised as "push and pulled: A compromised life", where individuals push to be normal, but the fear of incontinence pulls them back. There are some similarities between themes of 'push' and 'integration', and 'pulled' and 'separation'. However, the review lacks meaning making in terms of how people experience the process of adjustment, and how the contingencies of being 'push' and 'pulled' actually ensues; in other words, who or what is the agent of change? This current study provides more nuanced information about the experiences of adjustment for these individuals. The findings place agency directly back with participants, whereas 'push' and 'pulled' suggests an external, intangible force controlling these positions.

##### *Separating self from IBD*

The theme of separation is likened to a process of active disengagement whereby people minimise, overlook or ignore the impact of IBD on their lives, as a means of what could be described as 'fighting for normality' (Hall et al., 2005). Separation represents the position that participants take in relation to IBD, in order to retain their healthy self. Separating, or disengaging, from IBD seems synonymous with viewing the illness negatively and wanting to get rid of it, as seen in the tension between 'push' and 'pulled' (Kemp et al., 2012). However for people who disengaged from IBD, it was not necessarily a sign of maladjustment or a lack of acceptance. For instance, some participants minimised and ignored the illness, but this did not appear problematic for them because it allowed them to continue their 'healthy' lives. Nevertheless this position is not rigid. Consistent with Kemp et al. (2012), people with IBD adopt different positions according to their experiences with the illness. This is in part uncertain, paralleling the unpredictable nature of the relapsing and remitting illness.

People ignore or minimise illness when other goals take precedence, such as attending to others' needs (Charmaz, 1995). This was clearly seen for David who had little time to think about his IBD and who generally construed the illness as an inconvenience because it restricted his ability to attend to his wife. Minimising or ignoring illness can also be considered an illusion, which according to Taylor (1983) is an adaptive way of adjusting to threat, as it bolsters a sense of mastery, self-esteem, and control over the illness. For participants in this study it also included the illusion of downward social comparisons (Taylor, 1983), whereby others were always perceived as worse off. According to the theory, disconfirming the illusions is not psychologically problematic, because the relationship between cognitions and meaning is flexible so people will find alternative meanings and responses to serve the adaptive function (Taylor, 1983). This helps to explain why participants who experience illness as a threat to their imagined futures, such as when they are threatened with what they might perceive a 'limit' to living with the illness, minimise the threat or find an alternative illusion.

Some participants were uncertain about the validity of their diagnosis. This was particularly so for Riya, as she denied experiencing the symptoms that are 'characteristic' of IBD. This is congruent with Charmaz's (1991) notion of illness as an interruption where illness is viewed as an acute, not a chronic, event. If illness is seen as an interruption the view is that it is treatable and not permanent. Thus, a 'denial' of symptoms may point to uncertainty about the chronicity of IBD. This is further complicated because patients do not construe themselves as ill without experiences of 'real' suffering (Charmaz, 1991). Thus from this perspective, some patients may struggle to accept the permanency of their condition, and instead view it as an interruption to their life.

All but one participant described fighting against IBD. Similarly to Hall et al's (2005) study, participants often used battle and combat language to describe their relationship with IBD. If people relate to IBD as an enemy, implicit in this relational frame is a 'fight to the death' where something will be defeated. It is likened to a need to attack IBD, which interestingly can be viewed as mimicking the pathogenesis of this autoimmune disease.

### *Integrating self with IBD*

Integration is an active engagement with the illness, whereby individuals integrate the illness with the self. Through integrating self with the illness, one outcome is a sense of gaining control over the illness so that life can continue. Participants demonstrated different experiences of engaging with IBD, such as attuning to body, striving for answers and learning about IBD, which are findings consistent with qualitative studies examining patients' experiences of control (Cooper et al., 2010).

However there were also experiences of reconciling self with the illness and accepting the permanency, yet retaining hope. These do not entirely fit with Kemp et al.'s notion of 'pulled', which appears to be more about physical restrictions and fear of incontinence pulling patients close to their illness. In this study participants do appear to more actively engage with IBD when they were experiencing flares. However integration of the illness with self was an active position they took, and for some participants more in line with notions of acceptance.

Integrating self with IBD was also about building a relationship or making personal meaning. In the participants' accounts there were different ways of developing meaning: some took the position of striving for answers, while others appeared to change their relationship with IBD so that it was congruent with their understanding of themselves, their body and their illness. These findings can be interpreted in line with Taylor's (1983) cognitive theory of adjusting to threatening events. Striving for answers and certainty can be interpreted as a response to threat, whereby people search for meaning or causal attributions. According to the model, people also attempt to understand the threat by understanding its implication for the person's life, and restructuring life accordingly. Arun found meaning in his illness by focusing on positive gains, and his Crohn's having a sense of purpose, which was a view more congruent with his faith and family beliefs. However while this model provides a useful framework for understanding how meaning making provides a cognitive function, it seems to overlook the impact of illness on identity, and how this is implicated in adjustment processes.

The findings from this study are consistent with Charmaz's framework of understanding adaptation to impairment (Charmaz, 1995). Using a grounded theory approach, Charmaz identified different ways of living with illness, including: ignoring it, minimising it, struggling against it, and reconciling to it. Through struggling against the illness, people objectify their body and fight against the identification that comes with illness, as it does not fit with their preferred identity. Alternatively they may integrate their ill bodies with self and struggle *with* illness, whereby they show determination to live as 'normal' a life as possible. Both of which are seen as attempts to take control over their illnesses and their bodies. People living with chronic illness experience all these ways of living with impairment at different times, which was consistent with findings from this current study. Furthermore all of these experiences are considered natural and normal responses to different situations. Adding to this framework, the findings from this study indicate that for people living with IBD, the relapsing and remitting nature of IBD presents sufferers with periodic challenges that shape how they relate and respond to threats, difficult situations and experiences. Furthermore



wider discourses around the stigmatisation of physical symptoms associated with IBD, impact on how people position themselves with IBD. Consequently people with IBD adjust time and time again, thus revisit different stages, or 'ways' of adjusting throughout their lives.

#### *4.2.4 Gaining perspective through previous experience and hindsight*

Participants often commented that learning to adjust was a process they learned over time, and they gained perspective and understanding through the use of hindsight. This is consistent with Charmaz's (1991) theory that illness experiences are embedded in time. All participants described their experiences in chronological order. Even prior to the first question participants naturally began at the 'beginning' of their stories, and some participants appeared confused when they 'lost' their place in their storytelling. Narrative is an important component of Interpretative Phenomenological Analysis because we need phenomenology to interpret people's experience, we need hermeneutics to see it, and require narrative accounts of the hermeneutics (Smith et al., 2009). Nevertheless this finding presents possibilities for further qualitative inquiry.

Participants freely used hindsight to reflect on their experiences, and this influenced how participants made sense of their experiences. According to Freeman (2010) hindsight is a form of truth for individual realities and only available in retrospect. Thus experiences seem different looking back than they do in the moment. Participants often seemed to engage in reflections of the past and imagined future. Borrowing theoretical ideas from IPA (Smith et al., 2009), participants may have been engaging in a hermeneutic cycle of their own where they were drawing on the whole (the past and imagined future), in order to make sense of the part (the present) and vice versa.

While hindsight has its uses often participants seemed more distant from thinking about their experiences in the present moment. Participants consistently mourning the loss of healthy selves presents more of the 'perils' of the use of hindsight (Freeman, 2010). However, Freeman (2010) suggests that there is room to both honour the power of the present, and the power of hindsight.

### **4.3 Significance of study**

There are limited qualitative studies exploring patient's lived experience of acceptance and adjustment, and some studies are more deductive in nature, exploring phenomenon through structured theoretical frameworks (Cooper et al., 2010). There are currently no published studies using IPA methodology that have explored the lived experiences of people with IBD. This study provides detailed and complementary knowledge to the psychological adjustment literature in IBD. Moreover this is the first known study in Britain to have included participants from ethnic minority cultures, in exploring how people make sense of their experiences of living with and adjusting to IBD.

Concepts of adjustment in the quantitative literature focus on health related quality of life and measures of psychological disorder (Wolfe & Sirois, 2008). There is less of a focus on perceptions and consequences of personal identity changes, and the meanings placed on this. This study supports the notion that psychological adjustment is a construct beyond singular measurements of medical and psychological components (Kiebles et al., 2010), and it highlights that adjustment should be conceptualised within a broader holistic model.

As highlighted by Knowles et al. (2011), identifying "specific perceptions and coping strategies, especially those that are emotionally oriented, may be critical to effective clinical management" (p2556). Perceptions of illness, particularly around illness as a disruption to people's identity is an important finding that should be incorporated into the quantitative evidence base. For instance, the meaning of feeling 'out of control' is likened to losing one's identity, particularly so for experiences of incontinence. Feeling out of control also impacts other areas of identity, such as one's body being so bad that it impacts on the ability to have a child. Finally, this study has highlighted meanings around management options such as surgery.

### **4.4 Implications for clinical practice**

This study demonstrated the importance for people living with IBD to have their experiences heard. Many participants reported that it was the first time they had ever talked openly about their experiences, particularly the emotional impact on them and their families. Their propensity for talking about their experiences was in stark contrast to their assertions that 'you don't talk about it'. The need to talk to someone at an earlier stage of their illness was highlighted by some participants, particularly around developing practical coping skills and talking to others with IBD. Patients would

benefit from being offered psychological support through individual or group treatment modalities, the latter being so that patients can share experiences with others.

The findings give support for the holistic treatment of IBD within a biopsychosocial model of illness, which takes into consideration people's physical health, emotional well-being and their social contexts. This is especially relevant in services accessed by those from multicultural backgrounds where there may be differences in how people demonstrate distress (Dwairy, 1997). This is likely to influence what concerns patients bring to discuss in clinic appointments because certain difficulties (physical or psychosocial) are seen as more important than others. Consequently it is important that clinicians consider how individuals make meaning from their experiences and what may impact this, such as individual beliefs, family influences or wider societal discourses. Medical conceptions of illness and subjective meanings are complementary and both important for individual's sense of control and adjustment to illness (Bury, 1982).

In this study, participants made sense of their realities and experiences through story-telling and metaphor. According to Mair (1977; cited in Hermans, 2003), metaphor is an important 'structure of human understanding', in terms of how we make sense of the world. In light of this, it is not surprising that some participants in this study naturally conceptualised their experiences through metaphor. However for those that did not, a part of the interview schedule was to elicit a metaphor for their illness. For some, this served as a powerful clinical tool to elaborate and deepen participants' understanding of their experiences. For instance, consider Pauline's metaphor of IBD as a black cloud and how she made sense of this as being ever present and controlling, yet somewhat external and intangible. The feedback elicited from participants suggested that thinking about their relationship with IBD using metaphor was interesting and gave them food for thought. It is important for clinicians and therapists to attempt to understand the patient's phenomenological world through unconditional positive regard, genuineness and empathy (Coulehan, 2003), which are key skills when working with individuals in distress. However this study also demonstrated that using metaphors is a particularly useful clinical tool that can be used in gastroenterology, or other clinical health settings, in order to gain a fuller understanding of how people relate to their illness.

The findings suggest that a psychotherapeutic approach in line with a biopsychosocial model, focussing on issues of psychological adjustment would be beneficial for patients living with IBD. Phenomenological approaches to therapy including some cognitive behavioural therapies lend themselves to this. Acceptance Commitment Therapy (ACT; Hayes, 2004), with its focus on the

phenomenological experience of patients and strong use of metaphor fits within the biopsychosocial model, as non-western cultures often use metaphors to make sense of experiences (Dwairy, 1997).

Whilst many participants used hindsight to make sense of their experiences, there were also participants that seemed stuck in thinking about the past, and conceptualised future. It would be useful to adopt an approach to encourage people to stay in the moment with the view for patients to feel more attuned to their body, and IBD more integrated into themselves. ACT could be a useful approach to address the finding that people may be fused with the concepts of the healthy self (Hayes, 2004). Whilst taking the position of separating from the illness is useful at times, it seems more problematic when participants engage in constant battles against the illness to the extent that this appears to disrupt their daily functioning. This is perceived more in line with struggling *against* the illness, rather than struggling *with* (Charmaz, 1995).

The findings also have implications for how professionals approach difficult treatment decisions. Participants benefit from involvement in their treatment in order to bolster a sense of mastery and control. This is particularly important given the huge impact that a loss of control has on people's identity and self-efficacy. The findings also suggest that of particular importance is how clinicians approach the topic of surgery with patients, indeed any issue around potentially difficult decisions about their health care. It is important to create a safe conversational space for patients to think about management options, including surgery, before the threat is imminent and too threatening. Moreover within this space, to focus on patients' concept of self and their imagined biography with illness in a positive and non-threatening way. The role of a psychologist may be in providing consultation and education to medical students and other professionals in thinking about the psychological impact of these conversations on patients.

Finally it is important to think about the impact of wider societal discourses on illness perceptions, including what it means to lose control of the body, and how people experience living with IBD. It is important to consider what responsibility we have as clinicians in facilitating discussions with clients, colleagues and so on about stigmatising discourses including 'poo taboo'. In his article, Haslam (2012) observes that psychologists have largely embraced other taboos including sex and death, but that excretions are still ignored and one of the most neglected and underrepresented topics in psychology. Haslam (2012) argues that in view of the prevalence of psychological disorders related to excretion and moral judgements associated with corporeality, which are closely tied to emotions of shame and disgust, psychologists need to acknowledge and address its importance.

#### 4.5 Strengths and limitations of the methodology

A strength of this study was in its selection of qualitative methodology in addressing the research questions. In the area of psychological adjustment to IBD, there is a gap in the literature in relation to a lack of depth in the *meanings* that participants place on their experiences, and their own personal sense making. IPA, with its focus on phenomenology and idiography, was considered the most suitable approach for meeting the research aims of developing a rich and detailed account of how people with IBD make sense of their experience and the meanings they attach to them.

It is important to consider the selection of IPA methodology in relation to the study's findings that concepts of identity and adjustment are inextricably linked. Analyses of identity are often seen as narrative endeavours, particularly in relation to notions that identity is developed over time and through interactions with others. However, incorporating narrative ideas into a study using IPA is possible as the approaches are complementary (Smith et al., 2009). Participants' experiences of positioning themselves in relation to illness, self and body, as influenced by societal and cultural discourses, was only part of how people made meaning from their experiences.

Strengths of this research were also in the level of transparency, reflexivity and rigour throughout the research process. The selection of a patient representative was essential in maintaining rigour throughout the design of the study. The representative was involved in compiling the interview schedule, and was consulted about their views on disclosure in peer research. This ensured that the interview process was comfortable, appropriate and relevant. To ensure credibility of findings, a supervisor and two psychology colleagues independently audited parts of a transcript to evaluate the plausibility of emerging themes as derived from sections of transcripts. In social constructionism there is no one truth or reality, so while similar conclusions were drawn between us, and this is valued for assessing for credibility, it does not necessarily add accuracy to the findings (Smith et al., 2009). Member checking<sup>10</sup> was not adopted as a means of validating the findings, which can be critiqued as lacking credibility. However according to Larkin & Thompson (2012), member checking is considered less appropriate in IPA because the approach is interpretative and does not seek to present an objective or definitive truth. Furthermore, given the expansive process of abstraction and iteration of themes across individuals, member checking can be considered counter-productive (Larkin & Thompson, 2012).

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<sup>10</sup> Member-checking, also known as respondent validation is a means of ensuring validity, accuracy, credibility and transferability of qualitative research findings. It involves presenting participants of the research sample to check the authenticity of the work

While there are strengths in the use of IPA, there are also limitations. Owing to the idiographic nature of IPA, it is not possible for the findings to be generalised across populations of people living with IBD. However the findings may resonate for the reader in the context of their own clinical and research practice so there may be transferability in the claims of the research. In view of IPA as an idiographic methodology it is important to ensure homogeneity of the sample. In this study, there were participants with multiple illness experiences so there is the potential that the analysis tapped into other experiences of illness. In addition to this, a possible limitation is the large distribution of ages across the sample of participants; furthermore one participant developed IBD in her late adolescent years. It is important to acknowledge that there may have been additional developmental issues that may have affected participants' experiences of their condition, thus in conflict with the group homogeneity. However as will be the case across any group of individuals, there are likely to be individual experiences of illness, adversity and life transitions and adaptations.

It is important to consider the context for interviews as a possible limitation of the study. All interviews took place in the hospital at which they are seen for regular review. It is important to acknowledge that this context may have influenced the participants' accounts. They may have been biased towards telling narratives of a medical nature. Moreover despite my assurances of confidentiality, participants may have associated the research with the care they were currently receiving, therefore more biased towards reporting positive experiences of care, or avoiding disclosing altogether. As stated in the Methodology section, the plan was to submit a substantial amendment to the local Research Ethics Committee to give participants the option to be interviewed at home. This would have been a preferable option because participants may have felt more relaxed and open in discussing their experiences. Nevertheless, I put due care into making the encounter as comfortable as possible by adopting a laid back and friendly approach.

The inclusion of a metaphor question in the interview schedule was interesting. However the use of this question could be argued as leading participants or a form of intervention, thus influencing participants' sense making of their experiences. It is important to note that prior to interviewing participants, the inclusion of this question in the schedule was carefully considered. The decision was to administer the question at the end, so as not to directly influence participants' sense making throughout the interview. However, given many participants naturally used metaphor to make sense of their experiences, it was not always the case that this question was delivered at the end. Moreover, the use of metaphor in this study demonstrates the potential of using this technique

clinically to obtain depth of meaning. When questions elicited powerful or emotive responses, extra time was offered to participants to debrief and to discuss any important issues that arose for them.

Finally it is essential to consider the possible strengths and limitations of conducting research as a 'peer', albeit undisclosed prior to interviews. For research to be officially 'peer' led, the researcher discloses prior to conduct of the study. This was not the case in this study, as the decision was to disclose as the interviews came to a close. In line with a double-hermeneutic approach (Smith et al., 2009), I was able to use my own knowledge of the subject matter to reflect on my interpretation of the participants' sense making. Thus, a critique might be that this account is deductive and biased towards my preconceived understanding. On the contrary, by using my knowledge and immersing myself into participant's experience, I was better positioned to notice similarities and differences between myself and the participant, in terms of our experiences and the meanings placed on them. Thus, the research actually benefits from a richer and more insightful account. As will be discussed further below, I was surprised by many of the findings, which demonstrates the inductive and emergent nature of the research (Morgan, 2008).

#### **4.6 Suggestions for further research**

There are several suggestions for further research in the area of IBD. This study highlighted a possible heterogeneity in experiences that warrants further inquiry, with regards to cultural differences and previous illness experiences. There are limited studies exploring experiences of IBD in those from ethnic minorities around living with, and adapting to IBD, particularly how this impacts on their sense of identity. It would also be interesting to explore how previous illness experiences tap into factors affecting adjustment to IBD. Further research in this area would increase our knowledge about the impact of illness on identity and subsequent processes of adjustment.

The IBD adjustment literature would benefit from in depth exploration about the impact that wider societal discourses have on patients' narratives of living with IBD. People tell stories to make sense of their suffering and when they turn their diseases into stories, they find healing (Frank, 1995). Therefore, how people living with IBD tell their story, including the structure and form of the language of storytelling warrants further narrative inquiry. It would be useful to explore how participants change their position in relation to their body, illness and self, at different points over time. Longitudinal qualitative inquiry, such as narrative analysis, would lend itself to exploring this further, to provide in depth knowledge about processes of sense making and adjustment over time.

As mentioned above, it is important for clinicians to carefully consider how to approach the option of surgery with their patients. Current research is investigating the usefulness of positive self-affirmation approaches, in presenting kidney dialysis patients the opportunity to rethink their illness perceptions and subsequent behaviours (Wileman et al., 2013). This might be an interesting area of further research in IBD, in terms of how patients can have open and realistic discussions around the topic with their clinician. In view of this, it would also be important to gather clinician's views about conversations about surgery. For the one participant who mentioned surgery in this current study, surgery appeared to be an avoided topic both for her and her clinicians. It would be important to consider if there are parallel processes of avoidance at a service level, and to explore what might be underlying this.

#### **4.7 Personal reflections**

Firstly, it is imperative that I discuss the implications of choosing a research topic so “close to home” (Etherington, 2004). It was important to me to feel passionately about the subject and so that I could continue to learn and develop my interest. Etherington (2004) talks about the usefulness and richness of undertaking research that we are personally involved in, but also about the danger of becoming so caught up in it, that it impacts on us as researchers. Whilst supervision was sought, the processes of completing the research impacted on my health, as I experienced a flare of my colitis. Whether this was due to stress associated with this particular topic is unknown, because unpredictability is part and parcel of IBD. Consequently, the question of whether my health would have been any better had I not chosen the topic is a difficult one, although it may have been slightly easier to manage. The research has taught me that undertaking research of a personal nature requires considerable thought, particularly around the risks that the research might pose to you, as the researcher. I learned to protect myself and the data by finding distance when it was needed, and learned the importance of keeping a reflective journal. Seeking supervision and support from my doctorate peers was also invaluable in reflecting on the process.

Regardless of the stage at which I became ill, it is important to consider how I may have impacted on the research process. Having a personal connection to the subject made me more aware of my experiences, biases and assumptions, so I felt this could explicitly be reflected on; perhaps more than would be the case if I undertook a research topic unrelated to my personal biography. However, I acknowledge that at points during the interviews, particularly if an experience personally



resonated for me, my verbal and non-verbal responses may have impacted on the flow of conversation. The interview can be viewed a co-construction between myself and the participants (Smith et al., 2009), thus it is not presented as an objective truth but as one way of making sense of participants accounts.

I was struck by some of the findings from this study as I had not expected certain themes to be so prevalent throughout participants' accounts. I had expected IBD to be a major part of participants' lives, so I was surprised when some people related to their IBD as almost a non-entity. I was also surprised by how participants described living with two 'selves' and how this was a struggle for them. I had not anticipated this, and it led me to consider themes of identity as being extremely important for this group of people.

Finally, my dual role as a researcher and trainee therapist might have impacted on the interview process. I noticed myself wanting to summarise experiences or provide direct interpretations. I felt privileged hearing the participants' experiences and I hope it has encouraged them to feel more confident in getting their voices heard, should this be important to them.

## CONCLUSION

The aim for this current study was to provide an in-depth analysis of people's experience of living with, adjusting to and accepting Inflammatory Bowel Disease. IBD is an incurable, chronic condition that is known to impact on both the physical and psychosocial well-being of the patients and their families living with it. Previous qualitative research exploring experiences of living with IBD highlighted themes including conflict between feeling detained by disease and striving to thrive. The aim was to uncover themes in relation to acceptance and adjustment with the view to broaden knowledge about this framework.

In exploring this phenomenon, areas of interest included experiences of diagnosis and treatment, how participants viewed themselves with illness, how they thought others perceived them, how they made sense of concepts of adjustment, and how they related to their illness. Participants' experiences were analysed using Interpretative Phenomenological Analysis. The findings revealed superordinate themes of '*Lack of control: IBD grabs body and mind*' and '*Separation versus Integration: An ambivalent relationship with IBD*'. These themes were influenced by the overarching master theme of '*Positioning Self: In relation to self, body and IBD*'. The findings reveal that acceptance and adjustment is inextricably linked to notions of identity.

People manage IBD as a threat to identity through actively positioning themselves as separate to illness, or integrating it within themselves. Integrating illness within themselves related to experiences of acceptance. In relation to the latter, people are seen to accept, or tolerate living with illness within certain limits. For people living with IBD, the relapsing and remitting nature of IBD presents sufferers with periodic challenges that shape how they relate and respond to threats, difficult situations or experiences. As such, for them, they adjust time and time again, and position themselves differently according to how they experience their illness.

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## **APPENDIX 1: LITERATURE REVIEW SEARCH STRATEGY**

### Stage 1: Initial Exploratory Search

The initial stage involved reviewing relevant books held at the Learning Resource Centre at the University of Hertfordshire and database searches using Web of Knowledge and Google Scholar. The initial search terms used were:

‘Inflammatory Bowel Disease’ OR ‘IBD’ OR ‘Colitis’ OR ‘Crohn’s’

AND

‘Psychological’, ‘Emotional’

‘Adjustment’, ‘Acceptance’

‘Psychotherapy’, ‘psychological therapy’

‘Adults’

### Stage 2: Following up references

From relevant articles, key references were identified and followed up. At this time, key authors were also identified and relevant papers obtained. Where key articles were not available to access via the University of Hertfordshire or personal NHS Athens account, authors were contacted directly, asking permission for copies of the article to be sent via email.

### Stage 3: Contacting Researchers in the Field

I liaised with Consultant Gastroenterologists, Clinical Nurse Specialists, Academic Psychologists, and Clinical Psychologists with expertise in the field of Clinical Health Psychology and Inflammatory Bowel Disease. They advised me on relevant books, research articles, journals and other important references and guidance. I also joined the Crohn’s and Colitis UK charity (as a personal member) to be kept informed of latest news, events and up to date research activity in the area of IBD.

### Stage 4: Detailed Review of the Literature over 18 months

Informed by my previous searches, I conducted a detailed review of the literature according to the criteria outlined below:

#### Inclusion Criteria:

- Studies exploring psychological factors in relation to IBD
- Studies that provided insight into subjective experiences of living with IBD
- Studies or reviews examining the efficacy of psychological therapies
- Papers published in English (or where translations were available)
- Peer reviewed Journals

#### Exclusion Criteria:

- Studies of children and adolescents only

#### Dates of Search:

The literature was searched for all articles up to April 2013. Citation alerts were set up associated with key papers to keep me informed of the latest publications.

#### Search Terms:

Using Boolean operators and truncation options to ensure all relevant papers were retrieved, the following search terms were employed:

‘Inflammatory Bowel Disease’; ‘IBD’; ‘Colitis’; ‘Crohn’s’; ‘Crohns’

‘Psychological’; ‘emotional’; ‘psychosocial’

‘Experiences’; ‘lived’; ‘subjective’; ‘narrative’; concerns; ‘personal experience’

‘Adjustment’; ‘acceptance’; ‘adaptation’; ‘coping’

‘Qualitative methodology’; ‘Qualitative’; ‘IPA’; ‘Interpretative Phenomenological Analysis’; ‘Phenomenology’; ‘grounded theory’; ‘lived experiences’; ‘thematic’; ‘constructionist’; ‘constructivist’

#### Search Engines:

The following search engines were used.

- Web of Science / Web of knowledge
- Google Scholar
- Scopus
- Pubmed

### General Web Searches:

Other websites were used to inform other aspects of the study. The following websites were accessed via generic search engines on the internet:

- NICE guidance and guidelines
- Department of Health
- British Society of Gastroenterology
- National Research Ethics Service
- National Association for Colitis and Crohn's

## APPENDIX 2: GLOSSARY OF TERMS

Unless otherwise specified, the information in this section was obtained from information leaflets obtained from the Crohn's and Colitis UK website (NACC, 2011).

A

### **Asacol (Mesalazine):**

Asacol is a type of Aminosalicylic acid (5-ASA) medication. 5-ASA works by reducing inflammation. They are often used long-term to maintain remission, or to treat mild to moderate flares.

### **Acute colon distension:**

This is a very severe complication of IBD. Toxic mega colon is an acute form of colon distension, characterised by a significantly dilated large intestine and abdominal bloating, which can result in septic shock and if not treated, perforation of the bowel. If the condition does not improve, risk of death is significant. ('Toxic Megacolon', 2013)

C

### **Colectomy:**

Surgery to remove the whole of the large intestine only

### **Crohn's Disease:**

Crohn's Disease is a condition that causes inflammation anywhere in the gastrointestinal (GI) tract. Crohn's Disease can inflame any area of the GI tract from mouth to anus.

E

### **Enema:**

Enemas are used to empty the bowel, typically prior to an examination, such as a colonoscopy. Enemas are injected in liquid form to the rectum and colon via the anus.

F

### **Fistula:**

An abnormal channel or passageway where tissue from one organ grows and extends to other organs, usually within the abdominal region

I

### **Ileostomy (or stoma):**

After surgery, the surgeon brings out the end of the small intestine through an opening in the wall of the abdomen called a stoma

**Immunosuppressant medication:**

Drugs to lower the immune system. They are referred to as 'second line' treatment, so are prescribed when 5-ASAs are not able to control the inflammation.

**Inflammation:**

Inflammation is the body's reaction to injury or irritation and can also cause redness, swelling and pain

**Inflammatory Bowel Disease:**

IBD is collective term used to describe inflammatory autoimmune diseases affecting the gastro-intestinal tract. The two most commonly known IBDs are Ulcerative Colitis and Crohn's Disease.

P

**Perforation of the intestine:**

Perforation of the intestines is a tear in the wall of the small or large intestine. This results in the potential for bacterial contamination of the abdominal cavity, which is known as peritonitis. ('Gastrointestinal perforation', 2013)

**Proctocolectomy:**

Surgical procedure where the whole colon is removed, together with the rectum and the anal canal.

**Pouch surgery:**

Involves two operations. Firstly, the whole colon and the rectum is removed, leaving the anus. An ileostomy is created to allow the site to heal. Following this, another operation is undertaken to remove the ileostomy and an internal pouch is created so that stools can be passed normally.

S

**Sigmoidoscopy:**

A sigmoidoscopy is a procedure where a doctor or nurse looks into the rectum and sigmoid colon using an instrument called a sigmoidoscope. It has a camera and a light at one end of the instrument. This allows the doctor or nurse to see the lining of the rectum and sigmoid colon. It is typically used to as a diagnostic procedure for IBD.

**Steroids (Corticosteroids):**

Steroids are used in IBD to treat acute attacks in both UC and CD. They work by reducing the redness, pain and swelling caused by inflammation. They can be administered orally, topically or intravenously.

U

**Ulcerative Colitis:**

Ulcerative Colitis is a condition that causes inflammation and ulceration of the lining of the colon and rectum, which make up the large bowel or intestine.



APPENDIX 3: DIAGRAM OF INFLAMMATORY BOWEL DISEASE

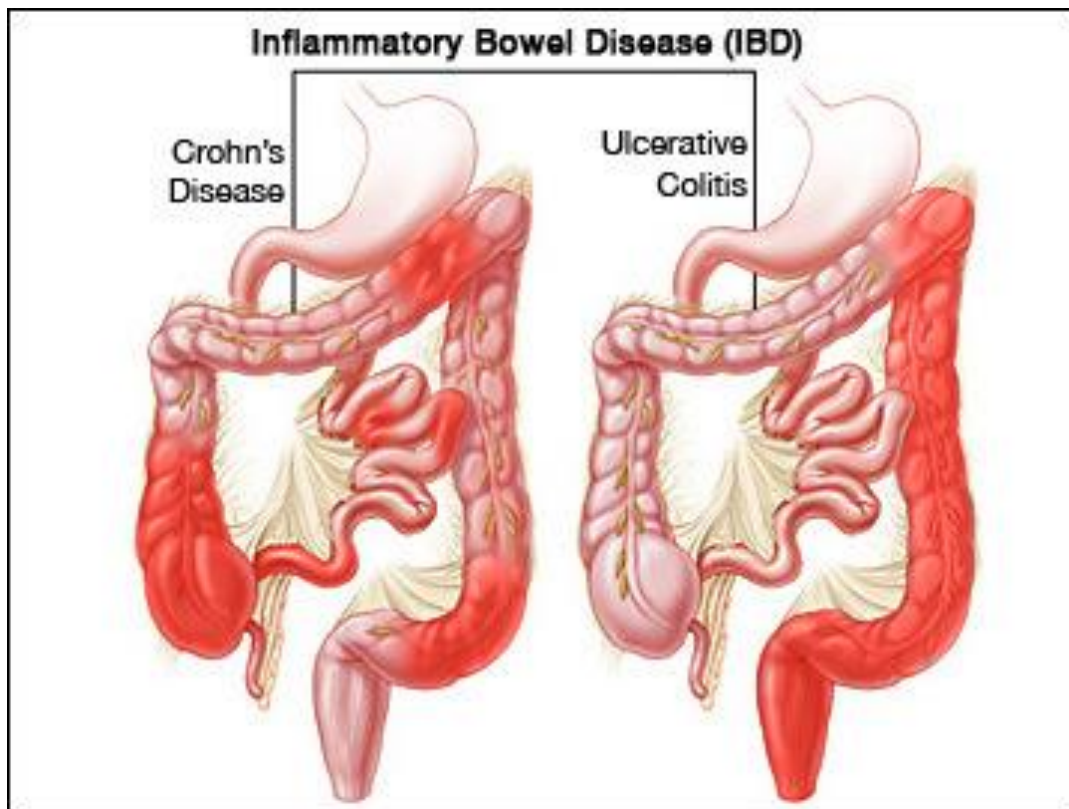


Fig 3. Diagram of the affect areas in IBD<sup>11</sup> (iCons in medicine, 2011). In UC, disease is continuous and affects anywhere in the large colon only. In Crohn's inflammation is not continuous and can affect any area in the gastrointestinal tract.

<sup>11</sup> Diagram found by conducting a google image search for 'Inflammatory Bowel Disease' (Accessed June 2013).



**Health Research Authority**

**NRES Committee East of England - Hertfordshire**

Victoria House  
Capital Park  
Fulbourn  
Cambridge  
CB21 5XB

Telephone: 01223 596906

12 October 2012

Miss Gemma Hardy  
Trainee Clinical Psychologist  
Cambridgeshire and Peterborough NHS Foundation Trust  
Doctorate in Clinical Psychology  
F262 Wright Building, University of Hertfordshire  
College Lane Campus, Hatfield, Hertfordshire  
AL10 9AB

Dear Miss Hardy

**Full title of study:** A qualitative study on the experiences of acceptance and adjustment to Inflammatory Bowel Disease  
**REC reference number:** 12/EE/0409

Thank you for your email dated 10th October 2012. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 26 September 2012.

**Documents received**

The documents received were as follows:

List of revised documents:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter	From Gemma Hardy CI	10 October 2012
Participant Consent Form	Version 1.1	03 October 2012
Participant Information Sheet	Version 1.1	03 October 2012

**Approved documents**

The final list of approved documentation for the study is therefore as follows:

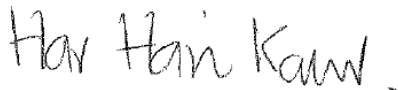
<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter	from Gemma Hardy (undated)	
Evidence of insurance or indemnity	Royal Sun Alliance	06 August 2012
Interview Schedules/Topic Guides	1.0	01 August 2012
Investigator CV	Gemma Hardy (Student and CI)	
Investigator CV	Dr David Wellsted – Academic Supervisor (1)	

Investigator CV	Nicholas Wood (Nov 2011)	
Investigator CV	Dr Gregory Damien Wood	
Letter from Sponsor	Letter from Professor John Senior, University of Hertfordshire	16 August 2012
Other: Resources document - information for participants (Sources of support)	1.0	01 August 2012
Participant Consent Form	1.1	03 October 2012
Participant Information Sheet	1.1	03 October 2012
Protocol	1.0	01 August 2012
REC application	IRAS Parts A&B 112099/354490/1/705	16 August 2012

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

<b>12/EE/0409</b>	<b>Please quote this number on all correspondence</b>
-------------------	---

Yours sincerely



**Ms Har Hari Kaur**  
**Assistant Committee Co-ordinator**

E-mail: [har.hari.kaur@eoe.nhs.uk](mailto:har.hari.kaur@eoe.nhs.uk)

Email to: *Gemma Hardy*  
[g.hardy@herts.ac.uk](mailto:g.hardy@herts.ac.uk)

Copy to: *Professor John Senior*  
[j.m.senior@herts.ac.uk](mailto:j.m.senior@herts.ac.uk)

*Ms Diana Hardy, Luton & Dunstable Hospital NHS Foundation Trust*  
[diana.hardy@ldh.nhs.uk](mailto:diana.hardy@ldh.nhs.uk)



CLINICAL EXCELLENCE, QUALITY & SAFETY

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## Department of Research and Development

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Our ref: CMT/js/LDH0450

4<sup>th</sup> December, 2012

Dr. Matthew Johnson  
Consultant Gastroenterologist  
Luton & Dunstable University Hospital

Dear Dr. Johnson,

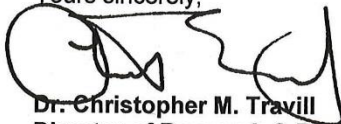
**Re: A qualitative study on the experiences of acceptance and adjustment to Inflammatory Bowel Disease. Protocol version 1**

Thank you for submitting your research application in respect of the above. I am pleased to inform you that this study has been approved by the Research & Development Department to be carried out at the Luton & Dunstable Hospital.

I would like to take this opportunity of informing you that should any amendments be made to the study, e.g. protocol, consent form, patient information sheet, etc. it is your responsibility to inform not only the Research Ethics Committee but also the Research & Development Department of these changes. I would also like to inform you that, as part of the monitoring process, at the end of your study we require documented evidence that the findings from your research are published and made available to those participating in the study. This can take the form of an individual letter, or you could provide an article to be published in our Research & Development Newsletter, which is sent to each participant.

I should be grateful to receive a follow up on the progress of the study in six months and attach a form for this purpose. Thereafter, please update me on progress at six monthly intervals.

Yours sincerely,

  
Dr. Christopher M. Travill  
Director of Research & Development

c.c. Professor John Senior, Dean of the Faculty of Science, University of Hertfordshire, College Lane Campus, Hatfield, Hertfordshire AL10 9AB  
Miss Gemma Hardy, Trainee Clinical Psychologist, Cambridgeshire & Peterborough NHS Foundation Trust, F262 Wright Building, University of Hertfordshire, College Lane Campus, Hatfield, Hertfordshire AL10 9AB  
Dr. Daniel Fishman, Clinical Director – Medicine, Luton & Dunstable University Hospital

Enc:

FILE COPY



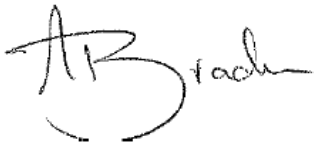
Participant Information Sheet	1.2	07 January 2013
Protocol	1.1	07 January 2013
Notification of a Minor Amendment	Amendment #1 (Minor)	07 January 2013

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

<b>12/EE/0409:</b>	<b>Please quote this number on all correspondence</b>
--------------------	---

Yours sincerely



**Miss Anna Bradnam**  
**Committee Co-ordinator**

E-mail: [nrescommittee.eastofengland-hertfordshire@nhs.net](mailto:nrescommittee.eastofengland-hertfordshire@nhs.net)

*Email to:* Ms Gemma Hardy [g.hardy@herts.ac.uk](mailto:g.hardy@herts.ac.uk);

*Ms Diana Hardy, Luton & Dunstable Hospital NHS Foundation Trust*  
[diana.hardy@ldh.nhs.uk](mailto:diana.hardy@ldh.nhs.uk);

*Professor John Senior* [J.M.Senior@herts.ac.uk](mailto:J.M.Senior@herts.ac.uk);

RE: 12/EE/0409 Ack Amen x

https://netmail.herts.ac.uk/owa/?ae=Item&t=IPM.Note&id=RgAAAAAQH6i%2beoR9TahYwZnFBJ7vBwCuoac41DxpSq%2bsctny%2bZhdAFdu2zIDAACuoac41DxpSq%2bsctny%2bZf

StudyNet Herts Web of Knowledge EndNote Web New Tab Google Scholar

Microsoft Office Outlook Web Access Type here to search This Folder Address Book Options Log Off

Mail Calendar Contacts Deleted Items (214) Drafts [16] Inbox Junk E-Mail Sent Items Click to view all folders Conferences Manage Folders...

Reply Reply to All Forward Move Delete Close

**RE: 12/EE/0409 Ack Amendment #1 (Minor)**  
Hardy Diana (RC9) Luton & Dunstable Hospital TR [Diana.Hardy@ldh.nhs.uk]

**Sent:** 19 February 2013 18:29  
**To:** Hardy, Gemma  
**Cc:** Senior, John M  
**Attachments:** 12 EE 0409 Ack Amendment #~1.pdf (76 KB) [Open as Web Page]

Dear Gemma,

Further to the attached letter I confirm that since this is non-substantial amendment, Amendment #1 (Minor) dated 7<sup>th</sup> January, 2013, can be implemented at this site. Please ensure you use the versions of documents as listed on the attached REC letter.

Many thanks.

Best wishes.

Diana

Diana Hardy  
Research & Development Manager  
Luton & Dunstable University Hospital  
Lewsey Road  
Luton LU4 0DZ  
Tel: 01582 718243  
Fax: 01582 718244  
Email: diana.hardy@ldh.nhs.uk

---

**From:** Hertfordshire NRESCommittee.EastofEngland- (HEALTH RESEARCH AUTHORITY) [mailto:nrescommittee.eastofengland-hertfordshire@nhs.net]  
**Sent:** 18 February 2013 12:30  
**To:** g.hardy@herts.ac.uk

10:45

**RESEARCH STUDY PROTOCOL**

**Experiences of acceptance and adjustment to  
Inflammatory Bowel Disease**

Gemma Hardy: Chief Investigator

Dr David Wellsted: Academic Supervisor

Dr Greg Wood: Field and Clinical Supervisor

Dr Nick Wood: 2<sup>nd</sup> Academic Supervisor



## **1.0 Title**

Experiences of acceptance and adjustment to Inflammatory Bowel Disease

## **2.0 Summary**

It is widely acknowledged that Inflammatory Bowel Disease (IBD) impacts both the physical and emotional well-being of the individual. Some evidence suggests that emotional concerns affect people's ability to cope with their illness and were considered as important as coping with physical symptoms. There is currently a demand for psychotherapy (talking therapy) to be offered to IBD patients who experience difficulties related to their illness. However there is currently little scientific evidence that psychotherapy is beneficial for all IBD patients. More evidence is needed to find out which type of therapy might be useful and where the focus of intervention should be. The aim of this study is to examine IBD patients' experiences of their illness, including identifying themes relating to acceptance and adjustment to their illness, in order to explore whether there are important factors that might impact or influence patients' emotional well-being and ability to cope with the illness.

## **3.0 Background**

Inflammatory Bowel Disease (IBD) is a chronic health condition affecting 240,000 patients and their families in the UK, approximately 400 patients per 100,000 population (IBD Standards Group, 2009). The two main IBDs are Crohn's Disease (CD) and Ulcerative Colitis (UC). These conditions are autoimmune disorders affecting the gastro-intestinal tract. Currently there is no cure and there is no identified underlying cause. It is suggested that that aetiology is likely to be a combination between genetic and environmental factors (IBD Standards Group, 2009).

IBD is associated with periods of remission and recurrent relapses or "flares" of physical symptoms, which may include abdominal pain, weight loss, frequent bowel movements and bloody diarrhoea. These symptoms require long term use of medications which are often associated with complications and side effects. People with these illnesses are also more at risk of complications such as colon cancer and surgery.

In the clinic, medical staff e.g. consultants and nurse specialists are often faced with patients experiencing difficulties related to their illness. Medical staff notice, for example, that patients will often complain of gastrointestinal symptoms, despite being medically well controlled. Research has demonstrated that disease activity is closely related to the psychological states of patients and is associated with increases and decreases in anxiety and depression (Porcelli et al., 1996). Medics subsequently identify patients who are continuing to experience gastrointestinal problems (despite being medically well controlled) as experiencing depression or anxiety.

The physical symptoms can directly impact on the psychosocial well-being of the individual with IBD as it can lead to embarrassment, pain and fatigue, consequently impacting on social and personal relationships and work. A study exploring the experiences of people with IBD identified eight categories of concerns (Casati et al., 2000), including body image, lack of energy, loss of control, isolation and fear, not reaching full potential, feeling dirty and lack of information from the medical community. These concerns are highly influential in terms of affecting people's ability to cope with their illness and were considered as important as coping with physical symptomatology (Guyatt et al., 1989). In particular, the unpredictable and uncertain nature of the illness, including its unknown aetiology presents the sufferer with social and psychological difficulties. It is concluded that it is important to address and integrate psychosocial concerns into the clinical management and treatment of IBD (Casati & Toner, 2000).

The difficulty for clinicians who are involved in the care of IBD, is how best to treat psychological concerns.

### **3.1 Focus for psychotherapy**

There is speculation amongst clinicians that IBD was caused by psychological factors and that they influence the course and severity of the disease. These claims led to the development of psychological research which has mainly been concerned with the relationship between stress and symptom exacerbation, psychological distress and symptomatology and the impact of psychotherapy on IBD (Hall et al., 2005)

### **3.2 Different approaches to psychological intervention**

Given these claims, the aim for psychotherapy is to influence the somatic nature of the disease, to improve the psychological functioning of the patient and health-related quality of life (Timmer et al., 2011).

A systematic review was carried out to examine the efficacy of various psychotherapeutic interventions (von Wietersheim & Kessler, 2006). The main approaches used to intervene with these patients were psychodynamic therapy, behaviour therapy (including Cognitive Behaviour Therapy and stress management programmes), and self-management. The results indicated that there is no evidence that one approach is superior to another (von Wietersheim & Kessler, 2006).

### **3.3 Evidence for the effectiveness of psychotherapy**

A Cochrane systematic review was carried out in 2011 to examine the effect of various psychotherapeutic interventions in patients with IBD on health related quality of life, emotional state and disease activity (Timmer et al., 2011). Twenty-one intervention studies were eligible for inclusion and these studies used multimodal approaches. All studies were of low methodological quality and had high risks of biases.

The Cochrane review, similarly to the 2006 review (von Wietersheim & Kessler, 2006) concluded that there is no evidence for the efficacy of psychotherapies for *all* patients with Inflammatory Bowel Disease. However, the reviews indicate that there may be particular “risk patients” who would benefit from psychotherapy. Characteristics of these people were considered to be those with obvious psychopathology, mental stress and dysfunctional coping techniques (von Wietersheim & Kessler, 2006).

The authors suggest that further evidence is required to identify which subgroups may benefit from a psychological intervention. In addition to this, more evidence is required to establish the efficacy of psychotherapies for these subgroups and to establish what type of therapy is useful.

### **3.4 Demand for psychotherapy**

In 2009 national standards for IBD were developed, identifying six “standards” that should be met in terms of ensuring that patients with IBD consistently receive high quality care. These relate to clinical care, maintaining a patient-centred service and providing education and support for patients and families. Standard A.2. states that essential supporting services should include access to a psychologist or counsellor.

The National Association for Colitis and Crohn’s Disease (NACC) is a charity that aims to improve the lives of people living with IBD and their families. The NACC undertook a counselling project in 2001 which involved training 11 counsellors across 13 hospitals in England. There were some positive

outcomes relating to the provision of counselling services for IBD patients (NACC, 2001). Nine out of ten consultants wanted counselling services to continue in their hospitals and 72% of IBD clients reported positive ratings for the helpfulness of counselling. However, some dilemmas were reported by clinicians, including difficulties in communication between consultants and counsellors and finding suitable clients e.g. *who* might benefit.

There are clear demands regarding the provision of psychological services indicated by a high satisfaction response, however difficulties remain relating to the implementation of these services.

### **3.5 Who may benefit from psychological intervention**

There are several previous studies that have attempted to identify the characteristics of an IBD patient in need of psychotherapy. It was identified that these patients expressed a higher need for psychological intervention than patients with rheumatoid arthritis (Miehsler et al., 2008). Furthermore, this need was characterised by psychological factors which included worry about the disease and anxiety, rather than medical variables.

It is useful to examine the psychotherapy research literature for other chronic health conditions. Chronic pain is comparable to IBD in that patients have to cope with distressing and painful symptoms and psychosocial factors impact both illnesses profoundly.

Acceptance Commitment Therapy (ACT) (Hayes, 2004) is increasingly used in clinical health settings such as for chronic pain. ACT does not seek to cure or control pain symptoms. ACT is particularly interested in the concept of “experiential avoidance”, which is the way that a person tries to avoid or get rid of unwanted thoughts or physical sensations.

The theory suggests that if a person observes their private experiences with openness and willingness, these thoughts and feelings about themselves and sensations of pain can seem less threatening and unbearable. ACT interventions involve changing behaviour by changing the way a person *experiences* their thoughts, feelings and sensations. This intervention was beneficial in chronic pain patients as indicated by fewer sick days and that they used fewer medical treatments (Dahl et al., 2004). However, this was a small feasibility study and more evidence is required to establish the effectiveness of ACT for chronic pain.

In order to establish whether an ACT intervention would be beneficial to patients with IBD, further evidence is required to explore whether there are factors that seem to interfere with acceptance, hence this forms part of the rationale for this current piece of research. It is clear that there are identifiable gaps in our knowledge about IBD, particularly in terms of identifying how to treat patients who are seen as having “problems”. It is clear that more evidence is needed in identifying the characteristics of subgroups of patients who might benefit from psychotherapy.

My own theoretical position is that it seems plausible that patients with IBD might benefit from an intervention focussing on acceptance as described by Hayes (2004) and Dahl et al. (2004). Hall et al. (2005) carried out a piece of qualitative research using grounded theory, exploring the experiences of people with IBD. It suggested that maintaining ‘health-related normality’ as described using combat-like language and ‘appearance of normality’ seemed particularly important to them. From my perspective, this study might also illuminate some of the difficulties that people with IBD face with acceptance, such as a sense of “fighting” to get control, to maintain normality and for appearance of normality. In ACT theoretical terms, these concepts may be related to experiential avoidance and destructive normality (Harris, 2006) thus interfere with acceptance.

This research also has a unique and personal connection to my own experiences. I was diagnosed with Ulcerative Colitis 8 years ago and during this time I experienced a number of flares, although I have been medically well controlled for 5 years. My understanding on the topic of acceptance and adjustment in IBD has developed through my own experiences and, from my perspective, changing the relationship I have with my illness has been key to my psychosocial adjustment. I am aware of my preconceptions about this and that my own experiences, such as what my concerns *were* and *are*, will be different from others.

Insights into my preconceptions will allow myself as a researcher to bracket my personal and theoretical orientations and allow for an openness to immerse myself in others experiences.

#### **4.0 Aims and Research Questions**

The broad research question is to find out what the experiences of acceptance and adjustment are, for people with IBD. This study aims to provide an in-depth analysis of patient's experiences of adjustment such as how they describe their relationship with their IBD and how they make sense of their experiences. Specifically, this study aims to:

- Uncover themes related to adjustment and acceptance
- Establish whether there may be factors that interfere with adjustment and acceptance to IBD

## 5.0 Design

This study will utilise a qualitative method, using Interpretative Phenomenological Analysis (IPA) as described in Smith and Osborn (2008) and Smith, Flowers & Larkin (2009). The aim of IPA is to “explore in detail how participants are making sense of their personal and social world, and the main currency for an IPA study is the meanings particular experiences, events and states holds for participants” (Smith and Osborn, 2008). IPA is recognised as a helpful method in exploring issues in the personal experience of health and illness (Smith et al., 2009). In this study, the focus is on personal meaning and sense-making in the context of difficulties with IBD, so it requires a phenomenological approach.

Following this method, the plan is to recruit 6-8 participants using homogenous purposive sampling. This means that participants will be selected on the basis that they can provide a perspective on a particular experience or phenomena. Participants will be selected using the following criteria:

### 5.1 Inclusion criteria

- Patients with an diagnosis of IBD (Crohn’s Disease, Ulcerative Colitis, Indeterminate Colitis)
- Patients with an established diagnosis, defined by at least 2 years since diagnosis
- ≥18 years old

### 5.2 Exclusion criteria

- Presence of a serious psychiatric illness otherwise not related to IBD
- Previous colorectal or pouch surgery
- Aged under 18 years old
- If medical staff involved in the participant's care feel that the patient is otherwise not suitable to take part in research
- If patient does not speak, read or understand English to an sufficient level to be able to conduct the interview and give informed consent

### 5.3 Recruitment strategy

Participants will be recruited from gastroenterology outpatient clinics in Bedfordshire. The researcher will attend the outpatient clinic and the relevant medical staff on duty (i.e. gastroenterologist or IBD nurse specialist), who are involved in the patients care will screen the medical records of all attending patients for study suitability. During the patient’s outpatient clinic, the consultant or nurse specialist will initially approach the patient with information about the study. Patients will be informed that the researcher is present to provide them with more information and that they will be located in the clinic waiting room. Alternatively, the medical staff will provide the patient with a Patient Information Sheet (PIS). Contact details of the researcher will be provided in the PIS. The researcher will agree a time and date to meet with the participant during which time consent procedures will take place (see *ethical considerations* below)

## **5.4 Interviews**

This study will use individual semi-structured interviews to explore participants' personal meaning and sense making. The interview will be guided by an interview schedule, however, the direction of the interview will follow participants' responses, such as if any interests or concerns are highlighted by the individual. The participants will be interviewed once only and it is estimated that interviews will last between 1-1 ½ hours, however this too, will be guided by participants' responses. Where possible, interviews will take place at the base of recruitment e.g. at the outpatient clinic which will be designated for the purposes of the interviews. Participants will be interviewed alone in a quiet room in order to reduce interruptions and noise. The room is also fully equipped with sofas, so that the setting is as naturalistic and comfortable as possible. Participants will be offered full monetary reimbursement for parking fees incurred during the interviews.

### *5.4.1 Constructing the Interview Schedule*

Questions for the interview schedule will be constructed based on the broad areas or topics of interest. These topics relate to; a description of their illness, their concerns, how they make sense of their difficulties, their experience of adjustment and coping, how they perceive themselves with or without IBD and how they describe their relationship with IBD e.g. using imagery and metaphor. The order of questions will be based on the logical sequence and the level of sensitivity, so that more sensitive areas will be covered towards the end of the interview. Prompt or probe questions will be constructed to facilitate in-depth responses.

In order to incorporate the perspectives of service-users in this research, the plan was to consult with IBD patients to facilitate the development of the interview schedule. A draft schedule was presented to an IBD patient representative, who provided constructive feedback regarding the appropriateness of questions, such as the tone and level of difficulty. A suitable order for these topics was identified in collaboration with the patient representative. Subsequently, questions were amended or added as appropriate.

Prior to conducting the interviews, the plan is to pilot the full interview schedule with a colleague or service user. This will enable any potential difficulties to be identified and managed before interviewing participants.

### *5.4.2 Recording and transcriptions*

Audio recordings will be made of all interviews using a dictaphone. In compliance with the Data Protection Act (1998), recordings will be stored on a password protected and encrypted university or NHS computer. Data will be stored on electronic servers which are securely backed up daily. Informed consent for audio recordings will be received from participants prior to interviewing. Recorded tapes will be transcribed, which will involve typing the interviews verbatim. Transcriptions will be completed by the researcher, or by a paid transcription service. The transcription service will be ethically bound by non-disclosure and confidentiality agreements.

## **6.0 Intended Data Analysis**

Following the idiographic approach to IPA (Smith et al., 2009) analysis will be on a case by case basis, so one transcript will be analysed following the procedure below (step 1-4), before moving on to the next, and so on. As it is inevitable that subsequent analyses will be influenced by what has previously been found, it will be important to "bracket" these ideas in order to allow new themes to emerge. Supervision will be sought to check the plausibility and coherence of the exploratory notes and subsequent emerging themes.

As IPA involves a double-hermeneutic approach, a reflective diary will be kept in order to record personal recollections of the interview e.g. powerful responses, observations or feelings towards each interview or participant.

1. *Reading and re-reading of the transcripts* - this will involve immersing oneself into the data, including listening to the audio transcript and listening to the voice and tone of the participants, reading the transcripts a number of times to become familiar as possible with the account.
2. *Initial note making* - notes regarding emerging themes will be documented, regarding the semantic content and language, in an exploratory way, such as certain use of language and the context they describe. It will also be important to identify abstract concepts that help to make meaning of the account.
3. *Developing emergent themes* - this will include noticing paraphrasing and observing how the exploratory notes (made in previous stage) may be connected or associated with each other. Following this, emerging theme titles and phrases will be documented
4. *Connecting the themes* - the emergent themes will be listed, likely in the order that they emerged in the interview. The next step will be to look for connections between them.
5. *Look for patterns across cases* - once all cases have been analysed separately, it will be possible to look for convergence and divergence across cases. This step will involve looking at the connections across the different cases, e.g. what themes seem prominent and whether there are themes that shed light on themes identified in another case.

Once all transcripts have been analysed in this process, a table of themes and superordinate themes will be identified. These will be presented in a tree diagram format.

## **7.0 Ethical Considerations**

The research proposal will be internally peer reviewed by the University of Hertfordshire prior to obtaining ethical approval. As participants will be recruited within National Health Service (NHS) hospital settings, ethical approval will be acquired from an NHS LREC. Local Research and Development (R&D) departments will also be consulted for peer review prior to this.

There are some ethical issues arising from this study. Due to the nature of the questions asked, some participants may feel distressed or upset during, or following the interviews. In order to minimise the risks of distress, the researcher will emphasise that the participant can stop the interview at any point they feel distressed or uncomfortable. In addition to this, during the interview, the researcher will monitor the participant and adjust questions accordingly, in order to minimise distress. If participants are affected by any issues raised in the interview, they will be provided with time to talk through any difficulties at the end of the interview. All participants will be given information and resources to access relevant services, e.g. the NHS organisation at their outpatient clinic (including the contact details of the IBD Nurse Specialist and Clinical Psychologist) or support from local counsellors through the NACC, the British Association for Counselling and Psychotherapy (BACP) or they can visit their General Practitioner (GP).

The information sheet will include a statement that will clarify that all information provided by the participants will be confidential. However, in very rare cases, if participants disclose information to the researcher that involves risk, such as if there is a concern about their, or others safety, then the

researcher will have to tell somebody about this. However, they will be informed that before information is shared, the researcher will always discuss this with the participant first. The researcher is also a Trainee Clinical Psychologist and therefore routinely carries out risk assessments and delivers psychological therapy. If there are concerns regarding the emotional well-being of participants, they will be signposted to access relevant support via the above.

Secondly, given that transcripts will be reported verbatim within the results, it is important to ensure that anonymity of participants is maintained. Participants will be informed that all information they provide will be kept confidential from the outpatient clinic team. Furthermore, that although transcripts will be included in the results, all names and identifiable information will be changed.

Participants will be given an Information Sheet at least 24 hours prior to the interview, to allow for participants to make an informed decision to take part. The information sheet will outline some of the areas that might be covered in the interview.

Before taking part, participants will be informed of the aims and objectives of the study, what the study involves, the benefits and risks of taking part and that they have the right to withdraw at any time. Participants will provide their consent by signing a consent form before taking part. The researcher will be sensitive to the needs of the participants and, if or when necessary, discuss with the participant the option to suspend or terminate the interview.



## 8.0 Project Management

### 8.1 Investigators

<b>Principal Investigator:</b>  Gemma Hardy, Trainee Clinical Psychologist	Doctorate in Clinical Psychology F262 Wright Building University of Hertfordshire College Lane Campus Hatfield  <a href="mailto:g.hardy@herts.ac.uk">g.hardy@herts.ac.uk</a>
<b>Primary Supervisor:</b>  Dr David Wellsted, Senior Lecturer Head of CLiCIR	Centre for Lifespan and Chronic Illness Research (CLiCIR) University of Hertfordshire College Lane Campus Hatfield  <a href="mailto:d.m.wellsted@herts.ac.uk">d.m.wellsted@herts.ac.uk</a>
<b>Field Supervisor:</b>  Dr Greg Woods, Lead Clinical Psychologist	Disability Resource Centre Poynters Road Dunstable  <a href="mailto:greg.wood@sept.nhs.uk">greg.wood@sept.nhs.uk</a>
<b>Secondary Supervisor:</b>  Dr Nick Wood, Research Tutor	Doctorate in Clinical Psychology F262 Wright Building University of Hertfordshire College Lane Campus Hatfield  <a href="mailto:n.l.wood@herts.ac.uk">n.l.wood@herts.ac.uk</a>

### 8.2 Sponsor

This study will be sponsored by the University of Hertfordshire (UH).

### 8.3 Study time line

February 2012 – Prepare protocol



August 2012 – Apply for Ethics approval



September 2012 to December 2012 – Identify Inflammatory Bowel Disease Patients and collect data



October 2012 to December 2012 – Data Analysis



January 2013 to April 2013 – Write up



April 2013 – Draft Student Report Submission



June 2013 – Final Student Report Submission

## APPENDIX 6: PARTICIPANT INFORMATION SHEET

**Participant Information Sheet**  
**A QUALITATIVE STUDY ON THE EXPERIENCES OF ACCEPTANCE  
AND ADJUSTMENT TO INFLAMMATORY BOWEL DISEASE**

**What is the purpose of the study?**

It is widely acknowledged that Inflammatory Bowel Disease (IBD) impacts both the physical and emotional (or psychological) well-being of people living with IBD. Some evidence suggests that emotional concerns are as important as physical symptoms and can affect people's ability to cope with their illness. Currently the NHS is keen to provide talking therapy (or psychotherapy) to those living with IBD who are experiencing difficulties related to their illness. However, more evidence is needed to find out what might be useful and which aspects of the person's life that the therapy should focus on.

I am interested in experiences of illness of people living with IBD, including experiences of acceptance and adjustment to their illness, in order to explore whether there are important issues that might impact or influence the person's emotional well-being.

**Why have I been invited?**

You have been invited because you have an established diagnosis of IBD and you are currently receiving care in a gastroenterology outpatient clinic. You will have been selected because you will have your own personal experiences of your illness and we are interested to listen to what you have to say about these experiences.

**Do I have to take part?**

No. It is up to you whether or not you wish to take part in the study. If you decide to participate, you may keep this information sheet for future reference and you will be asked to complete a consent form to show that you would like to take part. Participation is voluntary and you will have the right to withdraw at any point in the study. If you decide not to participate, it will not affect any care that you are currently receiving.

**What will happen if I decide to take part?**

If you decide to be involved in the research, you will be asked to take part in an audio recorded interview that will take place in a designated, comfortable room at the outpatient clinic. You will be reimbursed for parking fees, if applicable. The interview is expected to last approximately 1 – 1.5 hours, and will involve asking questions about your experiences of IBD. Similar questions will be asked to every participant, but I am most interested to hear about your own thoughts, feelings and experiences, such as acceptance and adjustment to IBD and your relationship with IBD.

**What are the possible benefits of taking part?**

There are no direct benefits to you for your participation. However, the information gathered from this study will help in understanding and voicing patient's lived experiences of IBD. The hope is that the research might highlight areas that are important to focus on in future clinical practice.

## **What are the possible disadvantages of taking part?**

There are no risks to taking part. However, due to the nature of the questions asked, some participants may feel distressed or upset during, or following the interviews. If you are affected by any issues raised in the interviews, you will be provided with time to talk through any difficulties and you will be provided with information to access relevant services and other resources.

## **What will happen to the data?**

Information you provide will remain anonymous and confidential and will not be made available to the outpatient clinic team. However, in the rare event that you share information about risk, for example if there are concerns about your, or others safety, then we will have to tell somebody. However, before the researcher tells someone, this will be discussed with you first.

The audio recordings obtained from the interviews will be held securely on a password protected computer. Although the information you provide via the recordings will be included in the results, all names and identifiable information will be changed. The lead researcher or a transcription service will transcribe the audio recordings word for word and all people involved are ethically bound by non-disclosure and confidentiality agreements.

## **What will happen to the results of the study?**

The results will be reported and presented in a thesis in order for the researcher to obtain a doctorate qualification in Clinical Psychology. The results may be subsequently presented in academic journals, or for the purposes of teaching or conferences. In all cases the information presented will not allow you to be identified, and you will remain anonymous.

## **Who is organising the research?**

The research is being completed by researchers at the Centre for Lifespan and Chronic Illness Research (CLiCIR) at the University of Hertfordshire, and South Essex Partnership NHS Trust. The lead researcher, Gemma Hardy, is conducting the research as part of a Doctorate in Clinical Psychology and is funded by Cambridgeshire and Peterborough NHS Foundation Trust.

## **If there is a problem**

In the event that you are unhappy with any aspect of the study or conduct of the researcher, and you would like to make a formal complaint, you can contact the Patient Advice and Liaison Service (PALS) at the Luton & Dunstable Hospital on 01582 497990. Alternatively, you can contact Tracey Price, IBD Nurse Specialist, on 01582 718368. There is also a free, Independent Complaints Advocacy Service (ICAS) that can help you to make a complaint. You can contact the Bedfordshire and Hertfordshire ICAS on 0300 456 2370.

## **Further Information**

If you are interested in taking part in the research, please contact me via details below. Alternatively, if you would like to hear more information about the study, please contact me or Dr David Wellsted, primary project supervisor, on the details below.

Gemma Hardy  
Trainee Clinical Psychologist  
Tel: 07732 890004  
Email: [g.hardy@herts.ac.uk](mailto:g.hardy@herts.ac.uk)  
Post: F262 Wright Building, University of Hertfordshire, College Lane, Hatfield, Hertfordshire

Dr David Wellsted  
Head of CLiCIR  
01707 286291  
[d.m.wellsted@herts.ac.uk](mailto:d.m.wellsted@herts.ac.uk)

**APPENDIX 7: CONSENT FORM**

**Consent Form**

**A QUALITATIVE STUDY ON THE EXPERIENCES OF ACCEPTANCE AND ADJUSTMENT TO INFLAMMATORY BOWEL DISEASE**

**Please read the following statements and write your initials in each box to confirm that you understand and agree to each:**

I confirm I have read and understood the Patient Information Sheet v1.2 (07/01/13) and I have had the opportunity to ask questions and have had these answered satisfactorily

I understand that my participation is voluntary and that I may withdraw from the study at any time and that this will not affect my standard treatment of care

I understand that audio recordings will be made of the interviews and that data collected will be used for research purposes

I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from University of Hertfordshire, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

I understand that all information collected from the interviews will be held confidentially and anonymously, in conjunction with the Data Protection Act 1998

I agree to take part in the above study



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\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person  
taking consent.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**APPENDIX 8: PARTICIPANT DEBRIEF SHEET****Thank you very much for taking part in this research.**

You have taken part in an interview that is very important in helping us to make sense of people's experiences of having IBD, particularly about what it means to accept or adjust to the illness. Due to the nature of the questions asked in the interview, you may have felt distressed or upset during or after the interviews.

If this is the case, you will have been offered space to talk through any difficult feelings you might have experienced.

Following our interview, should you experience any distress at any time in the future, and you feel that you require support, I have provided you with some useful resources and organisations that do offer support for people in this situation.

- Tracey Price, IBD Nurse Specialist, Luton and Dunstable Hospitals NHS Foundation Trust (01582 718368)
- National Association for Colitis and Crohn's ([www.nacc.org.uk](http://www.nacc.org.uk))
- British Association for Counselling and Psychotherapy - BACP ([www.bacp.co.uk](http://www.bacp.co.uk))
- Contact your local General Practitioner (GP)

In the event that you are unhappy with any aspect of the study or conduct of the researcher, and you would like to make a formal complaint, you can contact the Patient Advice and Liaison Service (PALS) at the Luton & Dunstable Hospital on 01582 497990.

Thank you again for your help

Gemma Hardy

## APPENDIX 9: INTERVIEW SCHEDULE

1. Can you tell me a little bit about your IBD?  
PROMPT: How did you come to be diagnosed?  
PROMPT: Length of diagnosis, etc  
PROMPT: How would you describe the process of diagnosis?
2. What treatment are you currently having?  
PROMPT: Experiences of this / past experiences
3. How do you feel about what you have to use?
4. What place does IBD have, in your life at the moment?  
PROMPT: How do you relate to IBD?  
PROMPT: And if positive or negative... what do you think would need to change for this to be different? PROMPT: feel/think differently
5. How do you make sense of 'acceptance' of IBD (open question)  
PROMPT: in relation to self/family/work
6. How would you describe 'good' times with IBD?
7. How would you describe 'bad' times with IBD?  
PROMPT: What are the main differences between good and bad times?
8. What would be for you a positive development?  
PROMPT: How can your situation improve?
9. How do you think your life would be, if you did not have IBD
10. How do you think / feel about yourself?
11. Has having IBD changed the way you think or feel about yourself?  
PROMPT: In what way?
12. Has having IBD changed the way others think about or feel towards you?
13. How do you see yourself in the future?
14. If you could use a metaphor or a thing to describe IBD, what would it be?  
PROMPT: visualise what is happening, feelings, experience – solidify into a form or object. PROMPT: What is your relationship like with [this metaphor]  
PROMPT: How has this relationship changed?

Other prompts for depth:

- Can you tell me a little more about that?
- What does [...] mean for you?
- How do you make sense of that?

**APPENDIX 10: AUDIT TRAIL**

**Chronological order of 1<sup>st</sup> iteration of emerging themes for Interview 3 (Linda)**

<b>Initial emerging theme</b>	<b>Location in transcript (page.line)</b>
Waiting	1.20, 2.28
Loss of physical ability	2.24-26, 9.228-234
Disruption of previous roles identity?	2.35-42, 9.235, 35.918
Deterioration with time	2.38
Let down / no help	3.49, 4.88, 6.111, 6.133, 12.323,
Fighting against vs. 'getting on' with it	3.67, 15.396-399
Fighting making it worse	3.72, 15.399
Attempts to retain healthy identity	3.68-72, 20.519-529, 32.847-854
Head/body dichotomy	4.80-85
Isolation vs. support	4.95, 7.164
Awareness of body	5.107
Destroyer of relationships (partner, friends, sex life)	5.118-121, 5.126-130, 6.149
Not understood	5.118, 26.693-697
Separation of self from illness - Externalising colitis from self	6.134, 7.174,
avoidance talking/thinking	6.138-149, 25.654-659
Blaming self you have illness, therefore it's your fault)	6.155
Learning as a process with age	7.171, 16.412,
Reliance on others for support	7.165
Unsaid, difficult to talk about	7.180,8.183, 8.189, 32.859, 10.244-256, 11.270, 33.868

**Continued overleaf**



Isolation / being alone with illness	8.196, 11.268, 14.353, 19.503, 26.695, 28.728, 28.753
Uncertainty vs. knowledge conflict	8.208, 9.119,
Holding back information	8.209
Critical sense of time	9.217
Unknown and uncertain	10.241, 15.377
Coping: humour	10.256, 18.456
Seeking connection, validation – from others with IBD	10.260, 21.544-541, 27.704
Loss of self IBD splits part of self	11.283, 23.600, 25.648,
Refusal to allow IBD to be part of life	11.285, 30.798-803
Loss of self-efficacy	12.316, 13.330,
Invisible disability (I look fine)	14.353, 22.574,
Striving for information	14.356, 14.366, 15.382-389, 25.673, 27.722
Time period - experiences embedded in time	16.409-416
Coping: Practical	17.434, 19.495
Coping: Solution focused	17.440
Attuning to body part of adjustment	17.440-445, 18.465, 28.773-778
Psychological recovery of flare transcends the physical	18.477, 19.486
Fear of incontinence	18.468, 26.686
Struggle with disclosure vs. non-disclosure	22.587
External	24.628
Lost control over self (mood)	24.629
Transforms how you think	25.646
Unpredictable course	25.660
Self-management	27.717
Not an everyday thing	30.789
Attending to body – questioning	31.810
Loss of confidence	31.810-812, 31.821
Identifying with ill self and healthy/social self?	31.830 - 836
Rebuilding self	31.835
Blocking it out	34.887
Process of talking increases awareness	34.893
having it for a long time increases awareness	35.938
Conflict between talking about it and not	36.943

**APPENDIX 10: AUDIT TRAIL**

**Chronological order of final list of emerging themes (2<sup>nd</sup> iteration) for Interview 3 (Linda)**

<b>Initial themes clustered</b>	<b>Renamed emerging theme</b>	<b>Location in transcript (page.line)</b>
Loss of physical ability	Feeling helpless	1.6-8, 2.24-26, 2.38, 3.50-52, 9.228-234, 22.581-583
Waiting	Waiting for help	1.20, 2.28
Uncertainty vs. knowledge conflict, holding back information, Critical sense of time, Unknown and uncertain Striving for information, Unpredictable course	Struggle with uncertainty	1.16, 3.59-66, 4.95-99, 8.208-215, 9.217-225, 9.240-241, 12.312-316, 13.324, 15.377, 25.660, 14.356-366, 15.374-382, 15.383-391, 21.538-544, 25.663,26.673-680, 27.711, 722, 28.734-736
Disruption of previous roles – identity?	Disruption of roles	2.40-42, 9.235-237, 35.918
Deterioration with time	Deterioration over time	2.38
Let down/no help, Self-management	Feeling let down	3.49, 4.88, 5.111, 5.115, 6.133, 6.151-154, 12.323, 13.328, 14.346-352, 27.717-726, 28.740-744
Fighting against vs. getting on with it, fighting makes it worse	Fighting against vs. going with it	3.64-69, 4.77-79, 11.287- 289, 15.396-400
Attempts to retain healthy identity	Struggle to retain healthy identity	3.69-72, 17.447-452, 20.519-529, 31.830- 836, 31.838, 32.852-859
Head/body dichotomy Awareness of body, Refusal to allow IBD to be part of life, Coping: solution focussed, Attuning to body part of adjustment	Learning to listen and attune to body	4.80-85, 5.107, 12.306-311, 17.425-429, 17.440-445, 18.465-474, 28.773-778, 30.796-810

**Continued overleaf**

Isolation vs. support, blaming self – you have illness therefore it's your fault, Isolation/being alone with illness Invisible disability (I look fine)	Feeling isolated and alone	4.94-96, 6.132, 6.154-155, 8.193-8.196, 8.205-208, 10.245, 11.268-273, 13.328, 14.352-356, 19.503-508, 22.571-583, 26.681-685, 693- 698, 28.730-733, 28.751-755, 28.759-763, 34.897
Destroyer of relationships, partner, sex life, friends	Negative impact on relationships	5.118-121, 5.126-130, 6.136, 6.149, 21.550-557
not understood, Uncertainty vs. knowledge conflict	Not understood	5.119, 7.174-177, 8.184, 8.200- 204, 14.368-374, 22.588, 26.693-697, 33.873
Separation of self from illness – externalising colitis from self	Externalising	6.134, 7.174
Avoidance of talking/thinking, blocking it out, process of talking increases awareness	Attempts to block it out	6.138-149, 15.395-400, 25.654-659, 34.889-893
Isolation vs. support Reliance on others for support, Seeking connection, validation from others with IBD	Having support and understanding	5.124-126, 6.131, 7.165, 8.192- 197, 10.257-268, 21.541-544, 21.557-567, 27.704-711
Learning as a process with age Time period – experiences embedded in time, having it for a long time increases awareness	Learning is a process over time	7.171, 35.938, 12.300, 16.411- 416, 16.421, 35.940
Unsaid, difficult to talk about, Struggle with disclosure vs. non-disclosure	Unsaid – you don't talk about it	7.180-191, 8.183-190, 10.244- 256, 11.273, 22.569-576, 22.589-597, 32.855-862, 33.860-874, 33.883, 34.894- 899, 34.900-902
Coping: humour, Coping: practical	Using coping strategies	10.256, 13.338-342, 17.434, 18.456, 19.495, 20.510-516
Loss of self – IBD splits part of self, Refusal to allow IBD to be part of life, External, Lost control over self (mood), Transforms how you think	Loss of control of self	11.281-287, 23.600, 23.608, 24.626-632, 25.646

Continued overleaf

Loss of self-efficacy, loss of confidence, Identifying with ill self and healthy/ social self, rebuilding self	Loss of confidence	12.316, 13.330, 31.818-822, 31.824-838
Not an everyday thing	Minimising impact of IBD	13.320, 16.419-421, 30.788-791
Fear of incontinence	Humiliation of incontinence	18.468, 26.686, 35.913-919, 35.924-929
Psychological recovery of flare transcends the physical	Impact of IBD transcends physical	18.477, 19.486
Attending to body – questioning	Questioning who I am	30.810-817
	Temporal differences over time	34.909, 36.945
Conflict between talking about it and not	Silenced by IBD, yet striving for understanding	35.943, 36.948-952

## APPENDIX 10: AUDIT TRAIL

### Clusters of emerging and superordinate themes for Interview 3

<b>IBD gets hold of your mind and body</b>		
<b>THEME</b>	<b>LOCATION</b>	<b>KEY QUOTE</b>
Loss of control of self	11.281-287, 23.600, 23.608, 24.626-632, 25.646	<i>it starts to get hold of you in your mind and your body</i>
Questioning who I am	30.810-817	<i>It's just like finding which part is the good you, and which parts the bad</i>
Impact of IBD transcends physical	18.477, 19.486	<i>It's not just the physical side, it's the mental side as well</i>
Loss of confidence	12.316, 13.330, 31.818-822, 31.824-838	<i>your confidence goes in a big way</i>
Negative impact on relationships	5.118-121, 5.126-130, 6.136, 6.149, 21.550-557	<i>It wrecks relationships big time</i>
Humiliation of incontinence	18.468, 26.686, 35.913-919, 35.924-929	<i>the first time that happened I was (shudders) oh my goodness... that was so bad</i>
Feeling helpless	1.6-8, 2.24-26, 2.38, 3.50-52, 9.228-234, 22.581-583	<i>I couldn't drive, I couldn't walk I couldn't do anything</i>
Deterioration over time	2.38	<i>As time went on into the months I just got worse and worse</i>

Isolated and silenced by IBD, yet striving for understanding		
THEME	LOCATION	KEY QUOTE
Feeling isolated and alone	4.94-96, 6.132, 6.154-155, 8.193-8.196, 8.205-208, 10.245, 11.268-273, 13.328, 14.352-356, 19.503-508, 22.571-583, 26.681-685, 693-698, 28.730-733, 28.751-755, 28.759-763, 34.897	<i>It is an isolated thing</i>
Unsaid - you don't talk about it	7.180-191, 8.183-190, 10.244-256, 11.273, 22.569-576, 22.589-597, 32.855-862, 33.860-874, 33.883, 34.894-899, 34.900-902	<i>It's something that you don't talk about. And something probably that I don't want to talk to people [about]</i>
Not understood	5.119, 7.174-177, 8.184, 8.200-204, 14.368-374, 22.588, 26.693-697, 33.873	<i>No-one knows how you feel. No one. They can't possibly imagine what it's like either</i>
Having support and understanding	5.124-126, 6.131, 8.192-197, 10.257-268, 21.541-544, 21.557-567, 27.704-711	<i>I think it's important that there are people on board that can talk about it</i>

Struggle with uncertainty		
THEME	LOCATION	KEY QUOTE
Waiting for help	1.20, 2.28,	<i>it took a year before I was actually seen at the hospital</i>
Feeling Let down by others	3.49, 4.88, 5.111, 5.115, 6.133, 6.151-154, 12.323, 13.328, 14.346-352, 27.717-726, 28.740-744	<i>You're diagnosed [...] But then, that's it [no more information]. There's nothing else...</i>
Struggle with uncertainty	1.16, 3.59-66, 4.95-99, 8.208-215, 9.217-225, 9.240-241, 12.312-316, 13.324, 15.377, 25.660, 14.356-366, 15.374-382, 15.383-391, 21.538-544, 25.663, 26.673-680, 27.711, 722, 28.734-736	<i>I know they can't answer questions like that, even now still, they can't tell you why it starts</i>

Managing conflict of mind and body – listening to body while struggling to retain a healthy identity		
THEME	LOCATION	KEY QUOTE
Struggle to retain healthy identity	3.69-72, 17.447-452, 20.519-529, 31.830- 836, 31.838, 32.852-859	<i>I used to make myself get up and, make myself do the cleaning and try and do the normal things that everything does</i>
Attempts to block it out	6.138-149, 15.395-400, 25.654-659, 34.889-893	<i>If you talk about it, it makes you think about things doesn't it?</i>
Minimise impact of IBD	13.320, 16.419-421, 30.788-791	<i>Obviously there's people much much worse than I am...</i>
Externalising	6.134, 7.174	<i>[my children] they're much more sympathetic towards....towards the colitis if you like</i>
Learning to listen and attune to body	4.80-85, 5.107, 12.306-311, 17.425-429, 17.440-445, 18.465-474, 28.773-778, 30.796-810	<i>I've had to learn to listen to what my body is telling me to do</i>
Learning is a process over time	7.171, 35.938, 12.300, 16.411-416, 16.421, 35.940	<i>I think about what's making you feel better, mentally and physically. That's what I've learned really, [...] probably over the last year</i>
Temporal differences - over time	34.909, 36.945	<i>I don't know if you were to ask me last week when I was at the hospital I'd say, well no actually, I'm fine</i>
Using coping strategies	10.256, 13.338-342, 17.434, 18.456, 19.495, 20.510-516	<i>Make sure you've got tissues in your bag</i>

## APPENDIX 10: AUDIT TRAIL

### Superordinate and emerging themes from all interviews

#### Interview 1: David

##### **IBD overlooked in the context of multiple identity adaptations**

Multiple role changes (not attributed to IBD)  
Attributing difficulties to age  
IBD is overlooked as a protection of caring role  
IBD overlooked in context of multiple illness experiences  
Loss of future

##### **IBD is an inconvenience: Pain in the backside**

Another job to do  
Not thought about  
Overwhelmed by medical jargon  
Experience of treatment as intrusive, painful and unpleasant  
Having to get used to IBD

##### **IBD as an emergency**

IBD is uncontrollable and messy  
Fear of fouling self

##### **~~Difficulty giving sequence of events~~ DROPPED**

##### **~~Suffering in time~~ DROPPED**

#### Interview 2: Linda

##### **Living with despair and uncertainty in a body you cannot control**

Feeling let down by medical frame  
Struggle with helplessness and despair  
Struggling with no information  
Living with a body I cannot control  
Relinquishing control to others

##### **Living fine in between: conflict of healthy vs flare self**

Conflict of healthy vs flare self  
IBD takes away life  
Physically restricted from normal activities and roles  
Loss of body confidence

##### **Attempts to manage conflict of selves**

Dwelling on it is not helpful  
Questioning why me  
Coping: Using humour  
Not thought about  
Fighting to live a normal life



**Acceptance, yet hope: A temporal process of learning**

Learning about my body – attuning to changes  
Increasing insight into disease severity  
Taking body for granted  
IBD as a part of self  
Keeping hope and belief in recovery  
Comparison of the early days

**Importance of feeling connected, known and understood: Others living IBD with you**

Feeling isolated from others  
Experiences not understood or validated  
Others not taking it seriously  
Others living it with you  
Knowing me, not just my disease

Interview 3: Pauline**IBD gets hold of your mind and body**

Loss of control of self  
Questioning who I am  
Impact of IBD transcends physical  
Loss of confidence  
Negative impact on relationships

Humiliation of incontinence  
Feeling helpless  
Deterioration over time

**Isolated and silenced by IBD, yet striving for understanding**

Feeling isolated and alone  
Unsaid - you don't talk about it  
Not understood  
Having support and understanding

**Managing conflict of mind and body – listening to body while struggling to retain a healthy identity**

Struggle to retain healthy identity  
Attempts to block it out  
Minimise impact of IBD  
Externalising  
Learning to listen and attune to body  
Learning is a process over time  
Temporal differences - over time  
Using coping strategies

### **Struggle with uncertainty**

Waiting for help  
Feeling Let down  
Struggle with uncertainty

### Interview 4: Arun

#### **Tormented by uncertainty yet having faith**

Struggle with uncertainty  
Lack of trust in medicine  
Not seeing it as serious  
Not been taken seriously  
Let down by medical treatment  
Feeling isolated  
Struggle with no hope

Having a positive attitude, hope and faith  
Seeking medical advice  
Searching for answers to find a resolution

#### **Feeling out of control**

Living with pain and suffering  
Restricted and demoralised by IBD  
Feeling punished/cursed  
Tormented by lack of control

Loss of control of self  
IBD transforming how you think and behave  
Heightened emotions and lacking clarity of thinking  
Living with two selves: Jekyll and Hyde  
Not the person I want to be  
Attribution of unwanted self to CD and steroids  
Fight between mind and body

#### **IBD as a Bhagavad Gita – ultimate test of self-character, determination and faith**

Battling Crohn's Disease  
IBD as a Bhagavad Gita  
Making sense of IBD positively  
Reconnection with God  
Determination to gain

#### **Striving to carry on my duties**

Keeping yourself going, continuing  
Being playful  
Receiving family support  
Fear and responsibility for not being there for family  
Relationships as problematic  
Emotional avoidance as protection

## Interview 5: Iris

### **Struggling to live with the uncertainty of IBD**

Loss of control over bowels

Deterioration in symptoms

Struggle with uncertainty

Importance of receiving consistent and supportive medical care

Hypervigilance about incontinence

Developing practical coping skills

### **IBD is a taboo**

Something being wrong with you

Don't talk about difficulties

Socially unacceptable

IBD as a repellent for intimacy

### **Diagnosis as an alarming and confusing time**

Alarming and distressing onset

Desperate for medical help

Confusion about diagnosis

Living with fatigue

### **Reconciliation: You have to cut your coat according to your cloth**

Accepting help

Learning to listen and attend to your body's needs

Reconciling self with illness (with age, IBD, TIA)

Identity adaptations not attributed to IBD

Maintaining normality

Change in social identity

Learning to say no – gaining control

### **Gaining resilience and perspective through adversity**

Overlooking own needs

Gaining perspective through adversity

Making sense of IBD

Coping: determination and resilience

## Interview 6: Riya

### **Body is burdened with an alien, isolated illness**

Feeling different (from IBD sufferers, family)

Struggle with isolation

Fear of being judged

Burdened – with tablets

Don't want to burden

Living with a body that is 'bad'

Struggle to accept ill self

**Being far away from IBD: managing struggle to accept IBD into the self**

Uncertainty and confusion about symptoms  
 Rejecting diagnosis  
 IBD is invisible  
 Minimising and normalising impact of IBD  
 IBD is ignored  
 Maintaining healthy identity

**Being close to IBD: gaining control over feared consequences**

Gaining knowledge and understanding  
 Being looked after: others as advocate for control  
 Feeling strong, motivated and energised  
 Attempts to gain certainty  
 Fear of consequences of IBD  
 Feeling responsible  
 Having a different relationship with IBD  
 Acknowledging self with IBD

**Final table of superordinate, theme and subthemes**

<b>Themes (*superordinate)</b>	<b>Subthemes</b>
*Positioning self: in relation to self, body and IBD	Isolated with an odd, alien condition Poo taboo Torment of uncertainty and lack of understanding Gaining perspective
Lack of control: IBD grabs mind and body	Losing control of the body Loss of control of self Control in relation to others
Separation vs. integration: Ambivalent relationship with IBD	Separating self from IBD Integrating self with IBD

## APPENDIX 11: EXAMPLE OF TRANSCRIPT

The transcript below is interview number 3 (Linda). The left hand column presents exploratory comments and the right hand column presents emergent themes. The strategy for presenting the comments are from Smith et al. (2009). Descriptive comments are in normal text, linguistic comments are presented in italics and the more interpretative and conceptual comments are underlined.