

# **Investigating how young people learn to live with Inflammatory Bowel Disease**

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by

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## Abstract

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Inflammatory Bowel Disease (IBD) is the medical term for two chronic conditions; ulcerative colitis and Crohn's disease. It affects approximately 180 000 people in the UK, and the incidence of Crohn's disease in children and young people has increased during the last 10 years. Research into IBD mainly concentrates on treatments and causes, with a smaller proportion of studies addressing psychosocial issues. Much of the existing research is disease focussed, and neglects to inform us of how young people live their daily lives with IBD. This research fills this gap, and takes the step of following a group of young people with IBD over an extended period of time.

The first part of data collection was an interview study with adults aged between 20 and 25 years. All had a minimum of five years experience of IBD, and were diagnosed before age 18. The interviews used a life story format, and addressed concerns of the public and private nature of illness experience, perceptions of the body, relationships with family and friends, changing living space, and problems with disclosing illness. These outcomes raised questions about what it means to live "beyond" illness.

The interview study informed the next part of data collection, an audio diary intervention study with a cohort young people. This comprised six participants aged between 11-16 years at the time of recruitment into the study. All were diagnosed with IBD up to a maximum of 18 months prior to being approached to take part. They were each given a digital recorder and encouraged to record aspects of their lives that were of importance to them. These did not have to be disease related. The total period of diary production lasted 48 weeks. Each participant was interviewed first, and then had a follow-up interview every six weeks in between diary sets. This exercise was called an "unclosed diary", to reflect the emergent, flexible nature of documenting information usually disclosed in a private, autobiographical journal. Data were analysed in terms of how much IBD featured in individual lives and how participants positioned themselves in their accounts.

The data from both studies revealed that IBD was not a catalyst for all decisions and events that shaped the lives of the young participants. There are aspects of IBD experience that are aligned to existing literature, in terms of bodily perception and restricted living space through fear of faecal incontinence. However there are other stories of everyday activity that show that IBD is not a prominent force in a young person's life. Methodologically, this is a study that emphasises that living with a chronic illness like IBD involves a significant period of time when illness is absent. Living beyond illness is not limited to doing activities in spite of IBD, but is a concept that is dependent on how young people position themselves and how others position them.

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# Investigating how young people learn to live with Inflammatory Bowel Disease

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## Chapter 1

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### Young people and IBD: introducing the challenge

## 1.1 Introduction

*"IBD is not a death sentence – more like a life sentence."*

This quotation is from an address by Richard Driscoll, director of The National Association for Colitis and Crohn's Disease (NACC) at the members' annual general meeting in 2006. It was used to illustrate how several people with Inflammatory Bowel Disease (IBD) had described the experiences of having this illness.

A week later I began corresponding with a friend who had been recently diagnosed with IBD and was having a difficult time. She had posted her anxieties onto a public Internet forum. I responded, telling her about my research into how young people diagnosed with IBD lived their lives, and enquired how she was getting on. Without having ever heard of NACC, she replied saying that she felt that she had been handed a life sentence too.

I was struck by this way of describing what it is like to be diagnosed, and to live with IBD. The description of a life sentence – something that is "served" – conveys images of incarceration, restriction and tedium. It brings to mind negative connotations concerning the ways in which the disease might limit everyday life. This research project aims to examine the "life sentence" of being diagnosed with IBD, but has a broader focus than the limitations imposed by disease. Clearly such a chronic condition does, and will continue to have, a severe impact on young people's lives. Yet to fully understand that impact we need to examine more than such frameworks of constraint and limitation. We need to enquire into the ways in which these lives, although inextricably linked to a chronic condition, are also lived beyond it.

## 1.2 What is it like to be a young person living with IBD?

This research studies the question of what it is like to be a young person living with the chronic disease of IBD. The aim is to provide evidence about how and in what ways young people interpret their unfolding, or emerging experience of IBD, and to explore the multiple ways in which young people learn to live both within and beyond the disease. This research does not seek to provide normative answers, but this is certainly not to suggest that young people with IBD do not share issues, concerns, and coping strategies.

Evidence of this can easily be found on assorted IBD resources, particularly on web sites and online discussion forums. However, while not ignoring such material, there are other questions that need to be answered in order to build a broader picture of what it is like to live with such an illness. In addition to the main research question, there are practical questions:

- How much does IBD feature in young people's lives? Is it a controlling force or a passive presence?
- How can this be demonstrated over time?

The practical questions also move from the general to the specifics of daily life with IBD:

- How does the public and private nature of the illness impact on young peoples' lives?
- How do young people assess their bodies and the consequences this has for the ways in which they live their lives?
- How are their relationships both in and out of school, with friends and with their families configured, both in terms of the disease and what it is to be young?

There are also conceptual questions that arise from practical ones:

- How do young people position themselves in the stories they tell of their experiences of IBD?
- What exactly does it mean to live beyond the confines of illness?

The thesis aims to answer some of these questions by accessing the lives of young people with IBD. Firstly it is important to gain some information about the disease in question.

### **1.3 What exactly is IBD?**

Inflammatory Bowel Disease (IBD) is frequently confused with Irritable Bowel Syndrome (IBS). In contrast to that non-specific medical condition, IBD has unique symptom qualities and treatments. Equipping readers with information on this will provide the necessary background for dealing with the analysis reported in the later chapters that detail young people's experience of IBD.



Inflammatory Bowel Disease is the medical term for two conditions. These are ulcerative colitis and Crohn's disease. Up to 180,000 people are diagnosed with IBD in the UK. Around 60,000 have Crohn's disease while the remaining 120,000 have ulcerative colitis (National Association for Colitis and Crohn's Disease, 2004). Ulcerations appear on the bowel and digestive organs, which result in urgency to defecate, rectal bleeding, abdominal pain and loss of energy. It is the symptom location that defines the difference between the two conditions. Ulcerative colitis affects only the colon. Crohn's disease can affect any part of the gastrointestinal tract, from the mouth to the anus.

Once IBD has been diagnosed and disease patterns are established, there are known factors that can exacerbate related symptoms. For example, there are studies that have explored the links between smoking and Crohn's disease (Sutherland, Ramcharan, Brynant & Fick, 1990; Lindberg, Järnerot & Huitfeldt, 1992). However, in spite of the abundance of research papers suggesting genetic, dietary or life event/stress influence, there is no evidence identifying any particular cause of IBD. Individuals experiencing IBD symptoms usually cite personal causes, such as change of diet or physical exertion. However, any cause they may personally identify remains officially "unrecognised" in terms of medical evidence on causation.

There are other confounding factors that make it harder to determine what causes IBD. Neither socio-economic status nor demographics such as age, gender and ethnicity provide any normative basis for causation. The variability of symptoms in the presentation of IBD as a disease is also complicated. The areas of bowel affected do not necessarily equate with the severity of the disease. For example, at the point of diagnosis someone may be found to have ulcerations present throughout the whole of the large bowel, yet they may not display as many symptoms and be as physically affected as someone whose colon is only partially ulcerated. As a chronic condition, IBD is characterised by remission and relapse, and there is no discernable pattern to these episodes of being with or without symptoms. There is no cure for IBD. Surgical removal of the large bowel will take away the active disease in ulcerative colitis, which necessitates the application of an ileostomy bag into which faeces are discharged without the control that anal defecation allows.

This can also be performed in cases of Crohn's disease if it is in the large bowel. However, as Crohn's can affect all parts of the gastrointestinal tract, there is no guarantee that the disease will not return elsewhere after surgery. If the disease is not so severe as to warrant ileostomy surgery, the symptoms can be alleviated using immuno-suppressant drugs or steroids. These drugs can affect bodily appearance, causing delayed physical development during adolescence or disproportionate weight gain. There are a whole range of other terms and phrases that apply to IBD. In order to facilitate reading of data extracts and analysis in later chapters, a glossary of these terms is given in Appendix A.

#### **1.4 Why IBD and young people?**

The original initiative to conduct research in the area of young people with IBD came from the National Association for Colitis and Crohn's Disease (NACC). NACC is a registered charity that provides information and support to people with IBD and their carers. It raises awareness of IBD by producing resources for the wider community, and has established a strong network of members who share experiences and offer individual support where necessary. NACC also funds research into IBD, and has issued several grants to healthcare organisations and universities across the UK. As part of a move towards more psychosocial research (alongside the medical research already sponsored by the charity) NACC awarded a PhD studentship to Loughborough University to explore how young people make sense of their experiences of IBD. NACC has also recently developed new initiatives focussing on younger age groups. An example of this is the *IBD and Me* project, which involves an ongoing series of discussion groups aimed at revealing the concerns of young people aged 16-29 and how they can be effectively supported. The increasing prevalence of IBD in young people (Armitage, Drummond, Wilson & Ghosh, 2001) increases the need for a detailed understanding of the sorts of issues that might affect this population. How do they deal with transitions in their lives? What is the impact of IBD on their education and their choice of subjects? Are their career choices affected? How do young people see their identities and image of themselves changing in terms of living with IBD? What is the impact of puberty? This research aims to address these questions in

terms of the ways in which individuals report what it is like to be diagnosed with this chronic condition. Furthermore, how do young people learn to live beyond the confines of IBD? How does IBD affect adolescents' daily activity? What information sources do they use? Does it control their lives? How do their families and friends help? How do they manage IBD in school or college? These are just some examples of the issues that this research explores.

There are also elements of IBD as an illness that give rise to research of this nature. Concentrating specifically on IBD as an illness is not the aim of this project. While it is debilitating, IBD is also an intriguing disease that is confounded by social parameters making it difficult to discuss freely. Some illnesses, such as coronary heart disease or diabetes mellitus, are managed within the NHS under national service frameworks. Therefore they generate much more media attention and are discussed openly in many social contexts. IBD does not benefit from such publicity and therefore is less well known.

### **1.5 What is already known about this research area?**

There are studies examining how people live with IBD, and what their chief concerns are (Casati, Toner, de Rooy, Drossman & Maunder, 2000; Ferry, 1999; Kelly, 1991). A moderate proportion of literature is devoted to adolescents (Brydolf & Segesten, 1996; Decker, 2000; Daniel, 2002). However, this set of literature adopts a different perspective to that taken in this thesis. With the focus on disease related matters, these studies were conducted using a range of rating mechanisms and measurement scales. Furthermore such psychosocial measures often focus on the psychopathological implications of IBD (De Boer, Grootenhuis, Derkx, & Last, 2005; Ellett, 1988; Loonen Grootenhuis, Last, Koopman, & Derkx, 2002c). Disease causation is the main focus in the medical literature (Drossman, 1998; Lichtenstein, Bala, Han, DeWoody, & Schaible, 2002; Murray, 1930). In determining negative affectivity, family dynamics, life events and their relationship to symptom onset, these studies often forget to ask the most basic question. How do young people diagnosed with IBD actually live their lives?

## 1.6 What is the remit of this thesis?

This research aims to extend the existing knowledge of young people and IBD in two ways. Firstly, the aim is to examine accounts of IBD experiences during adolescence. Such accounts are not documented in any detail in the existing literature. The aim is to understand what it is like to be diagnosed with IBD as a young person, and what it is like to live between symptomatic episodes of the disease. Neither of these issues has been documented in any detail in previous studies. The second research aim is to understand how young people were able to use their participation in the research as a means of making sense and accounting for what it is like both to live within, and beyond the confines of a chronic illness.

Overall, the distinctive feature of this research is that it looks at facets of young peoples' lives with IBD that are not primarily concerned with the disease itself. Chapter Two reviews the literature on general aspects of chronic illness, as well as IBD as an illness. The aim is to examine the extent to which this literature reveals how young people live with IBD. The review provides the basis for identifying both the general and particular questions addressed in this research.

Chapter Three describes the methods used to carry out the first part of data collection for this project, with a view to designing a prospective study to follow a cohort of young people diagnosed with IBD over a longer period of time. This first part was a series of interviews with 20 adults, who had all been diagnosed with IBD as teenagers. Participants were aged between 20 and 25, and had a minimum of five years experience of IBD. This included participants who had undergone ileostomy surgery to remove active disease. The interviews were semi-structured, and offered opportunity for participants to talk about many aspects of their lives that were not necessarily disease related. This included recalling what they did before the onset of IBD.

Chapters Four and Five discuss the findings of the interviews. Chapter Four looks at incidents in peoples' lives where IBD has been managed publicly and privately. This includes instances of how individuals have coped with managing IBD in the public environment. There are accounts of how people remembered their bodies changing, and also how they went to extreme lengths to accommodate others' needs and expectations, often at the

expense of their own physical well being. Chapter Four focuses more on the content, but the analysis is developed further in Chapter Five, which looks at what the accounts do, as well as what they contain. By looking at two specific interviews, the analysis looks at how the participants have positioned themselves within their accounts, with relation to their illness and the rest of the world around them.

This is a very good starting point to examine how young people made sense of IBD in everyday life, yet it raised another question: what more could be said about this? The adults recalled some events that happened a long time ago, and occasionally could not remember certain episodes very clearly. While the accounts are extremely useful in establishing issues for further scrutiny, they do not convey any details of life as it was being lived with IBD. The interviews with adults informed the second stage of this data collection, which comprised a longitudinal 'audio diary' study with young people. This 'unclosed diary' intervention of diary recordings and contingent interviews lasted 48 weeks with six children, and produced data which has not been formally documented in previous studies.

Chapter Six describes the methods for this part of the study in more detail. Whilst there are prospective studies of children with IBD (Blondel-Kucharski, Chircop, Marquis, Cortot, Baron, Gendre & Colombel, 2001), they have utilised rating scales to establish how IBD featured in peoples' lives. Outcomes concentrated on disease related material, such as hospitalisation and use of medication. There is little information on how daily situations are managed outside of the clinical setting. The data in this thesis helps to address this, by shifting the focus from disease to address everyday aspects of young people. Chapter Six describes precisely how this unclosed diary method was executed, including the relationships and relevance to questions raised in the adults' interview study. Chapter Seven continues to report the findings of the unclosed diary in terms of the content of the young people's accounts produced over time. More precisely, the chapter looks at links between the data from the adults' interviews to see which issues can be carried forward in the audio diary study. It also identifies how IBD is positioned within participants' accounts, and considers the audio diary as a communicative, as well as an informative tool.

As with the adults' interview data, more can be said about the action within the accounts that the young people produced during the course of the study. Chapter Eight examines this in more detail, looking specifically at how IBD features in individual lives, and questioning if it is a controlling force or a passive presence. This analysis focuses on the diaries of two girls, Emily and Hayley, and charts the presence of IBD and the way the girls place themselves with relation to the rest of the world around them. Chapter Nine expands this analysis to cover how the young people organised their diaries, in terms of recording structure, narrative coherence and emplotment, and what this could potentially reveal about their handling of illness.

Chapter Ten discusses how the findings of both stages of data collection can contribute to understanding the IBD and its effects on young people, and how the methods used in this particular project can themselves assist young people in making sense of IBD. These reflexive accounts reveal how the young participants problem-solved their ways around situations that might otherwise be categorised as a negative outcome of having IBD (e.g., making a decision to leave school or college).

This provides an introductory overview of this thesis, but now it is important to consider the questions that have so far been raised. The first step is to consider what is already known about the concerns and experiences of young people with IBD, and see what existing evidence and research can contribute to understanding how young people live with Crohn's disease and ulcerative colitis in everyday life.

## Chapter Two:

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### **IBD and chronic illness: from disease to daily life**

## 2.1 Introduction

The previous chapter provided an overall introduction to the research and detailed why it is important to study how young people are affected by IBD. It contained general questions and specified the rationale for the whole project, making brief reference to existing research in this area. This chapter provides a more detailed review of previous studies, and examines research into general concerns of IBD, specific issues pertaining to young people with relation to adolescence. As already outlined in Chapter One, this thesis specifically asks how young people live with IBD and manage the complex activities that comprise their daily lives in conjunction with a chronic illness. The aim is to examine the effects that IBD has on key aspects of adolescent life, such as education, relationships with others, and social activities. This review explores whether the literature on IBD and adolescence can help to answer this, and if more can be learnt by studying adult experience of IBD and general research on chronic illness. The chapter also identifies some of the key measurement tools that are used in the medical assessment of IBD, and asks whether these too can help to answer how young people live with the condition.

## 2.2 What concerns are represented in discussions of IBD?

In the context of considering young people's lives it is worth remembering that discussions of IBD are not just the concern of academics and medics, but are also part of the everyday lives of individuals affected by ulcerative colitis and Crohn's disease. Therefore it is initially worth looking at the public presentation of IBD, such as the non-academic "informal" sources of information. Amongst the abundance of patient information from NHS institutions and relevant IBD organisations, there are adolescent specific resources that are not presented in institutional contexts (i.e. they do not originate from hospital departments or specialist IBD organisations, but are managed by people who have IBD). Examples of these are websites that host discussion forums in which contributors can discuss aspects of daily life in conjunction with IBD. The Internet is now widely used by patients and carers across many health related contexts. Two examples of IBD information and discussion forums are *IBD Sucks* (2006) and *Teens with Crohn's Disease*



(Green, 2004). The first is a resource for people of all ages; the other is specifically concerned with teenagers' experiences of Crohn's disease. Despite the negative connotations in the title, the web pages at *IBD Sucks* are an informative resource for people of all ages, and address a wide variety of IBD related issues. The site is moderated and requires user registration to contribute. General indexing directs users both to academic concerns, such as new papers published in gastroenterology journals, and also to comic discussions containing humorous pictures and captions.

*Teens with Crohn's Disease* (Green, 2004) is an adolescent specific resource, and although the title may suggest otherwise, it also provides information and hosts discussions related to ulcerative colitis. One page on the site is dedicated to diagnosis, and invites contributors to post details of the day of their diagnosis. While providing medical information and a social forum, the site also has its own merchandise, from which users can purchase t-shirts bearing slogans such as "Bad Bowel Day", and other branded items like the "Crohn's Zone" box, designed specifically to hold various medicines related to IBD. These electronic sources provide examples of IBD related issues that occur in daily life, yet there is a strong sense of everything being governed by the disease. Most of the indexed discussion points incorporate disease as an integral part of the topic, such as "travelling with Crohn's" or "how to tell people you've got colitis". Aspects of daily life are mentioned in these resources, but they are directly linked to IBD. Therefore it is worth investigating if other resources and studies have taken other directions and looked at IBD as one of many life events, rather than the central one.

A review of emerging themes pertinent to IBD patients includes loss of energy, loss of bowel control, body image, personal hygiene and lack of medical information (Casati *et al*, 2000). The study includes several extracts of patients' accounts of experiencing IBD, but simultaneously demonstrates a lack of analytic investigation into patient responses. The concluding remarks acknowledge the need to further investigate the psychosocial factors of IBD. This is with a view to improving patient care, rather than explicitly encouraging further in-depth investigation into how people live with the illness on a day-to-day basis. The concerns mentioned are not always connected to daily life events. In addition to looking at concerns of patients, some clinicians argued

that patients with IBD were a particular personality type (Robertson, 1989). This claim was made in response to discovering common characteristics in IBD patients that included obsessive-compulsive behaviour, neuroticism, dependency, anxiety, and perfectionism (Murray, 1930). The overall results corresponded with the characteristics mentioned above, but there are no detailed examples to enhance the findings. The discussion acknowledged that providing patients with the opportunity to discuss personal difficulties was beneficial, which is a step towards investigating experiential features in contrast to disease related details of living with IBD. However, general studies such as these do not focus on young people, and it cannot be presumed that the issues contained within them are sufficient to take the enquiry further in terms of addressing points of direct relevance to the research agenda of this thesis. The literature search must be extended in order to see if there are specific concerns of young people with IBD that can further advance the enquiry.

## **2.3 Which concerns of IBD are specific to young people?**

### *2.3.1 Biological and social concerns*

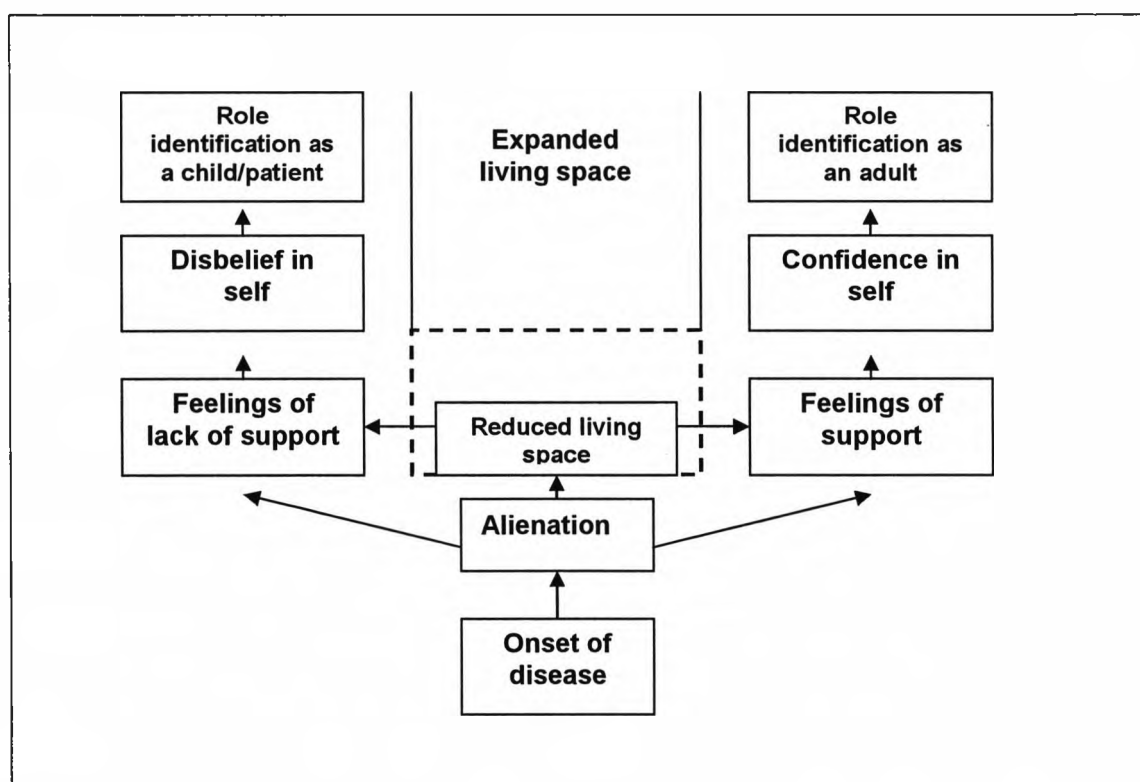
A key work on the effects of IBD on adolescents is provided from a nursing perspective (Decker, 2000). This research identified the changes experienced by young people with IBD through biological development, psychological changes and social transitions. In addition, it addressed family reactions and peer group behaviours. Biological development is a pivotal consideration: most adolescents experience rapid physical growth in height and bone development. Decker acknowledges that such physical changes can be sufficiently distressing, but also draws attention to the ways in which IBD increases such distress. Other studies (Brydolf and Segesten, 1996a: 1996b), also confirmed this from a nursing perspective, noting that adolescence brings an increased awareness of body image and that this occurred more intensely within adolescents with IBD, as the disease confounds standard rates of physical developmental changes.

Social changes are intrinsic to adolescent development, and IBD further complicates these changes. As social skills are developed and peer interactions refined, it is essential to recognise that IBD inhibits such

developments. Decker (2000) identifies the key issue of IBD preventing young people from attending school during remission periods, resulting in feelings of isolation, and also noted that other difficulties can arise through teasing, hospitalisation and teachers' lack of understanding.

### 2.3.2 *Living space*

The issue of living space and how it is reduced or expanded by the onset of IBD emerged as a key topic. Brydolf and Segesten (1996a) define living space as "the sphere one acts within in one's daily life which is subject to change depending on age, development, degree of mobility and health conditions" (p.42). They argued that continual expansion of living space is a natural expectation for adolescents as they mature, yet discovered that IBD considerably reduced living space, as the physical constraints (mainly urgency to defecate and rectal bleeding) limited daily activities, mobility and demanding physical activities (although examples of these were not specified). Other categories that emerged in conjunction with issues of living space were self-confidence, support (or lack thereof), role identification, and more significantly, alienation. Figure 2.1 (overleaf) illustrates how the authors positioned these concepts in relation to personal living space. This diagram is interesting as it covers aspects of living space in a metaphorical sense, yet the authors' definition of living space could also mean a physical space. While the theoretical aspects of living space are important, and as the authors claim, can determine adjustment and dependence levels of young people with IBD, their model does not include how physical space could potentially emerge as an equally significant determinate. If a young person has a relapse and suffers loss of bowel control he/she may literally restrict their physical environment space to such an extent where they are literally confined to a smaller area, due to the fear of experiencing incontinence in a public place. Toilet locations and negotiations of physical space are present in the web pages mentioned earlier, and it is surprising that Brydolf and Segesten (*ibid*) do not seem to factor this into their model of perceived living space in young people with IBD.



**Figure 2.1:** Brydolf and Segesten's model of relationship between disease onset and living space (1996)

### 2.3.3 Information and support

Brydolf and Segesten continued to examine issues of support in more detail (1996b). Using the same methods as before, they concentrated specifically on examples of support that adolescents felt they had received at any time during their illness. Some of their observations reveal striking similarities in patterns of support with other aspects of IBD experience, especially in seeking information sources about the illness, and with reference to seeking advice from family members and health professionals.

A more recent study discusses psychosocial concerns with IBD and adolescence, but does not seem to draw on empirical work (Kim & Ferry, 2004). Instead it is a general overview including clinical and therapeutic concerns, and its overall purpose is to suggest further areas of research. Amongst the psychosocial components, general issues such as social isolation, depression, anxiety and the transition from paediatric to adult care all feature prominently. The authors mention the importance of non-clinical support, such as youth and parent support groups, and IBD specific summer

camps. They conclude that these are of benefit to young people and that they should be encouraged to attend such events. However, there is no data to support this in the article. Others have also noted improvements after young people with IBD have attended holiday camps sponsored by the Crohn's and Colitis Foundation of America (Shepanski, Hurd, Culton, Markowitz, Mamula & Baldassano, 2005). Although Kim and Ferry (*Ibid*) acknowledge differing responses to treatment (from patients and families) the concluding remarks are encouraging as they hail the rising interest in paediatric research into IBD. With reference to the clinical and therapeutic side, several propositions are offered for research, such as quality of life, and it is suggested that further multi-centre trials should develop and validate existing questionnaires. This is an admirable intention, but the scale of such a project would probably be logistically and financially demanding.

In addition to the electronic resources mentioned at the start of this chapter, other information sources for IBD extend to informal levels of consultation, which are verbally managed as opposed to perusing documents or leaflets. Examples include conversations with friends, family members and health professionals, none of which should be overlooked if attempting to establish possible positive influences upon managing IBD. An extensive study into adolescents' use of health information (Ackard & Neumark-Sztainer, 2001) reported that although electronic information is now widely available, adolescents cited their parents and healthcare providers as key sources of information. The study also identified gender differences in information seeking behaviour. The authors noted that girls were more likely to obtain information from parents, doctors, relevant school classes and magazines, whereas boys were more likely to use newspapers, the Internet and telephone help-line numbers. The study also revealed health related topics that adolescents feel uncomfortable discussing, or were too afraid to ask about. Both boys and girls were most uncomfortable with discussing sexuality, body changes and contraception. These are general concerns that are not placed within the context of chronic illness. The focus was on information seeking behaviour, and it did not address seeking information on specific diseases. However, this raises questions about the types of information and support sought by young people with regard to specific diseases. IBD is particularly

interesting, due to the way it is presented (as seen in the online resources) and the embarrassing nature of the disease. As yet there are no studies exclusively dealing with the information seeking behaviour of young people with Crohn's disease or ulcerative colitis.

So far, these studies reveal some issues that are specific to young people in terms of developmental progression, such as developing independence and identity as a result of living space, and noticing bodily changes. Such changes are part of adolescence without the complications of having a chronic illness thrown into the arena. However, there are few perspectives on how young people learn to live with IBD in everyday life. Some scratch the surface, like Decker (*Ibid*), who hints at the difficulties faced by young people with IBD within school through teachers' lack of understanding. However, this is kept at a general level and there are no examples of how individuals managed to overcome this sort of situation. Some literature on IBD and young people has been written by nurses (Ellett & Schibler, 1988; Rayhorn, 2001), usually with the overall aim of establishing models to expand on existing duties of care to facilitate the transitions from health to illness. This could, of course account for the lack of examples of a young person's daily life being documented, as the emphasis is placed on generating a clinical outcome rather conducting exploratory research on which to build further subjective experiences of IBD. However, in developing new measurement tools, many of these articles concerned with Crohn's disease, ulcerative colitis and young people have utilised existing IBD screening tools to collect baseline measures of their participant groups. These include the Crohn's Disease Activity Index and the Rating Form of IBD Patient Concerns. As these rating scales and measurement tools appear so often, it is worth interrogating their content and development to see how IBD rating scales can contribute to knowledge of how the disease fits into everyday life and specifically how young people handle this.

## **2.4 Can IBD rating tools convey what is like to live with IBD?**

### *2.4.1 Crohn's Disease Activity Index (CDAI)*

The literature reveals a close relationship between quality of life, IBD and measurement scales. Whether examining physical or psychological effects of

the condition, many studies of IBD have consistently relied on various measurement/rating scales, which required participants to select appropriate responses. A clear example of this group is the Crohn's Disease Activity Index (CDAI), designed to measure the physical impact of IBD (Best, 1976). The developers of the index identified a need for a single rating form of illness severity in Crohn's disease, and collected data from 112 patients with the condition. This included rating adjustment levels and comparing symptoms from the previous visit to hospital. The CDAI concentrated on physical experiences and symptom presentation of Crohn's disease, and it was 15 years before a form emerged that specifically addressed patient concerns.

#### *2.4.2 Rating form of IBD Patient Concerns (RFIPC)*

The RFIPC (Drossman, Leserman, Li, Mitchell, Zagami & Patrick, 1991) moved further than the CDAI by recognising that a patient's health status could not be explained by symptoms alone. Instead of being completed by physicians, the form is self administered, and contains 25 items of concern (shown in table 2.2 overleaf). The form is valuable in that it encourages clinicians to extend their attentions from symptoms to psychological concerns of IBD. It has made a sizeable contribution to IBD research, heralding an increased interest in psychosocial factors of the disease. Most importantly it deals with the presenting concerns of ulcerative colitis and Crohn's disease, rather than just one condition. However, there are difficulties within the form that confound the understanding of what it can be like to live with IBD. These arise from the mixture of practical concerns (such as worrying about the effects of medicines and having surgery) and more abstract concerns such as "attractiveness". The original study gives little indication of the contexts in which these concerns were established. This raises questions about the participants' circumstances that supported the developmental stages for the RFIPC. Discussing attractiveness as a concern leads to further observations about the variables used in the schedule. While they are ranked within the same tests they are not classified into categories. Concerns range from self-opinion and body image to specific surgical concerns, and most importantly, not all of them can be transposed into daily life settings.

IBD concerns: Numerical Ranking and Comparison of UC and CD Scores

|                                   | All<br>(N = 991)<br>Mean (SD) | UC<br>(N = 320)<br>Mean (Rank) | CD<br>(N = 671)<br>Mean (rank) | <i>p</i> |
|-----------------------------------|-------------------------------|--------------------------------|--------------------------------|----------|
| Uncertain nature of my disease    |                               |                                |                                |          |
| Effects of medicine               |                               |                                |                                |          |
| Energy level                      |                               |                                |                                |          |
| Having surgery                    |                               |                                |                                |          |
| Having an ostomy bag              |                               |                                |                                |          |
| Being a burden on others          |                               |                                |                                |          |
| Loss of bowel control             |                               |                                |                                |          |
| Developing cancer                 |                               |                                |                                |          |
| Ability to achieve full potential |                               |                                |                                |          |
| Producing unpleasant odours       |                               |                                |                                |          |
| Feelings about my body            |                               |                                |                                |          |
| Pain or suffering                 |                               |                                |                                |          |
| Feeling out of control            |                               |                                |                                |          |
| Attractiveness                    |                               |                                |                                |          |
| Access to quality medical care    |                               |                                |                                |          |
| Dying early                       |                               |                                |                                |          |
| Intimacy                          |                               |                                |                                |          |
| Loss of sexual drive              |                               |                                |                                |          |
| Feeling alone                     |                               |                                |                                |          |
| Financial difficulties            |                               |                                |                                |          |
| Ability to perform sexually       |                               |                                |                                |          |
| Passing the disease to others     |                               |                                |                                |          |
| Feeling "dirty " or "smelly"      |                               |                                |                                |          |
| Being treated as different        |                               |                                |                                |          |
| Ability to have children          |                               |                                |                                |          |

Reproduced from Drossman, et al. (1991) The rating form of IBD patient concerns: a new measure of health status. *Psychosomatic Medicine*, 53(6) 701-712 (p.704)

**N.B. the original statistical information on this table has been removed to show the 25 rating concerns more clearly**

**Figure 2.2**

**Key concerns resulting from the RFIPC, reproduced from Drossman (1991).**

### 2.4.3 The McMaster Inflammatory Bowel Disease Questionnaire (IBDQ)

The McMaster IBDQ is another widely used measuring tool for quality of life in IBD (Irvine, 1993). During developmental stages, the researchers noted that little attention was paid to patients' own perception of their disease, in spite of previous attempts in the 1980s (Guyatt, Mitchell, Irvine, Singer, Williams, Goodacre & Tompkins, 1989; Gazzard, 1987), once again signifying a move towards subjective or experiential investigation of the condition. Patients who assisted the development of this scale had a minimum period of 11 years with IBD. However, interpretation of illness and symptoms is still open to question as the example question from the IBDQ illustrated in Figure 3 (overleaf). If someone experiences symptomatic episodes all of the time, 11 years is a considerable time in which to become accustomed to patterns that would not otherwise be clinically "regular".



| How often have you felt unwell as a result<br>Of your bowel problem in the past two weeks? |                        |
|--|------------------------|
| 1  | All of the time        |
| 2  | Most of the time       |
| 3  | A good bit of the time |
| 4  | Some of the time       |
| 5  | A little of the time   |
| 6  | Hardly any of the time |
| 7  | None of the time       |

**Figure 2.3: sample question from the McMaster IBDQ**

The McMaster IBDQ questions are more detailed and do not merely concentrate on more abstract concerns like the RIFPC. However, as an instrument the IBDQ fails to allow for the circumstances in which people are living their lives, which could considerably affect the responses. The above question reproduced in Figure 2.3, is more specific in symptomatic concerns, but is also open to misinterpretation and places a great demand on a person with IBD to identify pain on different levels. IBD causes abdominal pain, but could a young person differentiate between a pain brought in by a Colitis relapse or an acute stomach bug? So far these IBD questionnaires are aimed at adults, but what about ones that are specific to young people?

There are few separate scales for adolescents with IBD and measurement scales were often mixed together, using an adult IBD rating scale in conjunction with general child behaviour scales (Loonen, Grootenhuis, Last, Koopman & Derkx, 2002a). It is not always clear whether these scales have been run in their complete form or if certain parts have been selected for development of a new tool. This not only confuses the aims of a scale, but also deviates further from the issues of IBD and everyday life that this project seeks to expose. However, in 1999 a quality of life index emerged that aimed to reduce the items within the IBDQ (Griffiths et al, 1999). The McMaster IBDQ had been simultaneously revised and refined for adults (Irvine, 1999), but the authors wanted to extend this specifically to paediatric patients. One of the key difficulties they noted (which applies to the development of any scales pertaining to adolescents) was the difference relating to age and IBD type. The latter is surprisingly overlooked in studies of adolescence, with some studies choosing to concentrate only on Crohn's or colitis.

Given the small number of IBD and adolescent related scales, it will be helpful to consider some studies offering broader insights into general experience of illness. Some of these established patterns of healthcare information usage for adolescents. One specifically investigated the behavioural, cognitive and affective nature of peer interaction of adolescents (Meijer, Sinnema, Bijstra, Mellenbergh, & Wolters, 2000) and used subjects with several chronic illnesses. These included asthma and diabetes mellitus but not IBD. Using the Child Behaviour Checklist (CBCL) the authors identified several key points on social interaction. These included the difference of social self-esteem levels between diagnosis groups, stating that adolescents with diabetes mellitus were at the lower end of this scale, while those with cystic fibrosis were highest. This prompted further investigation into group studies that included IBD, with one paper of particular relevance emerging in terms of methodology. This used clinical comparison groups of IBD-affected children alongside children with diabetes, chronic tension headache and a health control group (Engstrom, 1999). It covered issues affecting peer interaction (such as self esteem), and also required participants to respond to various measurement scales, including the CBCL. It also provided results that revealed evidence of IBD pre-disposing adolescents to severe to moderate psychiatric disorder (this was calculated at 60% by using results from the Child Assessment Schedule). The study argued that an in-depth level of discussion on disease-specific issues was hard to obtain, as the young participants showed a tendency to give only short and concrete answers that were found to be "emotionally thin", and that they often denied the significance of the disease in daily life. This supports the need to place emphasis on the subjective experience of IBD.

While providing viewpoints that are valuable in a medical context and informing clinicians and other health professionals about patient concerns relating to IBD, the studies reviewed so far also confirm a distinct lack of research into adolescents' experiences from a young person's own perspective. Individual life stories from other age groups are largely neglected at the expense of developing measurement, disease related scales, and by continuing the necessary research into the aetiology of the disease. Other studies research aspects of life that are affected by IBD, such as sexual

health (Giese, 1996), but lack the personal accounts that would provide an essential resource for other young IBD patients. Attention to the patient perspective seems to be marginalized in preference to clinical issues. To improve knowledge of the young person's perspective of IBD, and gain further insight into person-centred approaches, this review needs to reach a little further into the general arena of chronic illness, and extend beyond naming IBD as the key search term in the literature.

## **2.5 Can concerns of chronic illness experience further the enquiry?**

So far the literature cited in this chapter has focused on generic factors associated with IBD, and how these can be of relevance to adolescence. However, as this has not advanced the enquiry further in terms of how young people live their daily lives, we must ask if other arguments addressing general concerns of chronic illness can provide more information. While the IBD literature is useful for the purpose of setting the scene, it is already becoming clear that this set of literature does not take us much further forward in addressing the main research question. In addition it does not provide much insight into the everyday life of the young person with ulcerative colitis or Crohn's disease. The fact that some work has been done on the subjective experiences of IBD is encouraging, and it is also a welcome shift that interview methods and exploration of individual illness experience have been considered with relation to IBD. While this thesis looks specifically at IBD and young people, there are important considerations relating to chronic illness that are relevant here. This does not suggest that IBD itself should be overlooked in terms of how it has been studied in connection with adolescence and quality of life. However, it is necessary to extend the search from IBD specific literature to obtain a more comprehensive picture of chronic illness. This is with the aim of discovering examples of concerns that can arise in everyday life, which are otherwise absent from previously cited studies.

Extending a literature search from IBD to chronic illness leads to more interesting methodological issues as well as outcomes. An example of this includes experiences of co-creating new understandings of chronic illness (Ironside, Scheckel, Wessels, Bailey, Powers & Seeley, 2003). This study arose from collaborative activity between the authors and participants, and

was derived from aspects of a research course that the authors administered. The research team and the participants simultaneously read the participants' interview data, from which they identified three outcomes:

- functional status does not account for the experience of chronic illness;
- shifting the focus from symptom treatment/management allows for important considerations of sense-making in the context of chronic illness;
- the "objectified" language of healthcare conceals how chronic illness is experienced.

All three of these concerns point to the fact that illness experience is not confined, or characterised within the clinical management of symptoms, and other parameters, such as medical language, hinder rather than enhance our understanding of illness experience. This is crystallised in the following sentence "the space between 'acutely ill' and 'being well' is poorly documented, yet this is where most persons with chronic illness dwell" (*Ibid*, p.173). This suggests a form of imprisonment or restricted activity attached to living with a chronic illness, and argued that previous studies have only focussed on one chronic illness or one dimension of it, rather than seeking the larger picture to learn of common aspects of everyday experience. The authors continued to argue that "compartmentalising" aspects of chronic illness (i.e. by illness and concepts) was too isolated an approach and resulted in ignoring the holistic experiences of living a life with such diseases. What is particularly interesting about their study is that the participants themselves were included in the process of analysis. They joined the authors' research classes as part of the analysis team.

In addition to documenting methodological benefits of approaching chronic illness research from a general perspective, the literature also reveals a number of concepts, which provide insight into living with illnesses. Some of these concepts, such as uncertainty, negotiating the two worlds of health and illness and the causes of illness, can be applied with relation to IBD and young people.

## 2.6 What components of chronic illness are relevant here?

Overall, the evaluation of quality of life in relation to any disease can sometimes be assessed on the quality of life as a whole. However, it has been noted that more *specific* aspects of life are concentrated on in disease studies (Kerr, 1993). So far this chapter has looked at practical concerns of eliciting chronic illness experience, but there are conceptual themes within chronic illness literature that may help to gain a complete picture of how a young person lives their life specifically with IBD.

### 2.6.1 Time and visibility

At this stage it is useful to return to some defining principles of chronic illness. Pia Bülow (2003) provides a useful explanation of chronic illness in a study of living with Chronic Fatigue Syndrome. By explaining that the word “chronos” derives from the Greek word for “time”, Bülow presents a concept that is central to chronic illness. Compared to acute illnesses (which are characterised by the brevity of disruption to a generally healthy existence), chronic illnesses are generally regarded as stable. This perception of stability arises from the illness being protracted over a longer period of time, and also holds implications about the visibility of illness. Conditions that present over longer periods of time can vary in their visibility to that present acutely. Bülow noted the variability of illnesses (e.g., skin conditions may become more obvious when the condition falls into decline). However, less visible conditions such as IBD can present without rendering the patient visibly changed, thus prompting an “outsider’s” response to be “you look well”. This also leads to the concepts of the insider and outsider. An outsider is defined in the literature as an individual viewing an illness experience and ‘minimising or ignoring the subjective reality of the sufferer’ (Conrad, 1990, p.1259). Outsider perspectives have contributed to medical sociology and greater understanding about certain illnesses, but do little to inform how illness is experienced and managed by those who have them.

This argument also supports the shift presented in this chapter, from focussing on IBD to examining generalities of chronic illness. When discussing this distinction, Conrad makes a useful observation that marks

insider and outsider perception in sociological terms. This is the meaning of "disease" as opposed to "illness":

*We can see disease as an undesirable physiological process or state. Illness, by contrast can be depicted as the social and psychological phenomena that accompany these putative physiological problems. Ibid, p. 1259)*

The likelihood of contracting a chronic disease grows with age (Radley 2004). This makes the issue of chronic illness in adolescence all the more removed from the world of health, a world that surrounds everyday living. Overall it strengthens the need for investigation into how young people live their lives under such circumstances. The endorsement of exploring illness in the context of a person's life setting as opposed to their adoption of the "sick role" is very clear in Radley's argument. The emphasis is also on the importance of insider's (patient's) view of chronic illness, as opposed to the outsider's (doctor's) perspective, confirming that the latter perspective cannot explain the variety of experiences that comprise the world of illness. This is not just a difference in words, or about belonging to the category of clinician or patient. The lengths of time that chronic illness occupies in an individual's life, and the visibility levels that illness can display are inevitable parts of the two different worlds that comprise chronic illness experience: the world of health and the worlds of illness

### 2.6.2 *Two worlds in one life.*

While coping with symptoms and altered conditions brought on by chronic illness, individuals continue to participate in everyday life, making intermittent calls on the medical profession for help, thus displaying a marked transition that takes place between two "worlds" (Radley, 2004). Rather than making an "individual" move from health to illness in an acute period of non-serious symptoms and in non-life threatening contexts, the move from health to being chronically ill involves accommodating illness in a "world of health". The illness experience is widened, and includes elements that go beyond symptom causes, management and explanations. Rather than being a patient in a doctor's surgery seeking help for an acute affliction, a person inhabits a world that is ostensibly unaffected in the eyes of the healthy majority. As a result they are affected as they make necessary changes to adapt to their

condition, medically, psychologically and socially. This can bring about other concerns, such as uncertainty, finding the cause of symptoms, and how an individual's life is disrupted.

The transition between worlds is present in the doctor-patient relationship. One interpretation argues that during consultations with general practitioners, the patient must appear to be more than a patient, and that "a display of healthiness, or normality is also required for the patient to appear worthy of receiving [the] entitlements" (Radley & Billig, 1996, p.222). The authors make this statement in the context of a person initially seeking diagnosis and treatment for un-interpreted symptoms. However, this can be extended much further than the point of diagnosis and doctor-patient exchanges to the wider contexts of everyday life. No matter how long it takes to make the journey from the world of health to chronic illness, or how frequently interchangeable these worlds become, the metaphor of two worlds can be applied to many other contexts besides a general sociological, psychological or physiological shift, as illustrated by both Conrad and Radley. It can be ascribed to the shifting forces between body and self; being sure and being uncertain, and between the biographical representation of these opposing points.

### 2.6.3 *Uncertainty*

The transition between health and illness is dependent on several things, but mainly relies on the subjectivity of symptom experience and severity, and how these affect daily activity. However, this transition can take longer for chronic patients due to individuals' initial dismissal of symptoms as being non-serious. This was noted in a study of patients with Multiple Sclerosis (Stewart and Sullivan, 1982), as participants often attributed symptoms to aspects of daily life, such as fatigue and/or hard work, rather than being exceptional and worthy of specific investigation. It was the recurrence and increasing severity of symptoms that necessitated seeking further help. Once a diagnosis is reached, uncertainty can permeate daily activity on all levels. This can be illustrated with a simple analogy of air travel. If health is a departure point, and the experience and eventual diagnosis of chronic illness the arrival terminal, then the issue of uncertainty inevitably

represents the turbulence that hinders and complicates the return journey to health. As well as the problems encountered by patients "normalising" initial symptoms that precede chronic illness, the route to diagnosis is confounded by the *status* of the illness being questioned. This can be reflected in the societal scepticism directed towards such illnesses and therefore exacerbate patients reluctance to seek help for fear of their credibility being questioned. Such conditions include Repetitive Strain Injury (Reid, Ewan & Lowy, 1991) and Chronic Fatigue Syndrome (Bulow, 2003). Uncertainty applies to the meaning of initial symptoms, and is also relevant to lengthy periods of time leading to diagnosis. The limits of medical knowledge have been located as a confounding factor in dealing with uncertainty (Bury, 1982). This may be alleviated by receiving a diagnosis, but can still manifest itself in how people manage their treatment regimes. In terms of how this can assist this particular research, uncertainty about chronic illnesses is a factor that can influence daily activity on several levels, determining whether individuals participate in certain activities or not, and it is useful to consider this with relation to the main research question of how young people manage their daily activities in conjunction with IBD.

#### 2.6.4 Causes (or lack of them)

Uncertainty is further exacerbated when physicians inform patients that the causes for their diseases are unknown, as Bury (*Ibid*) discovered in patients with rheumatoid arthritis. This is certainly applicable to IBD, which has no known cause and provokes uncertainty on many grounds. Genetic research is a major interest with respect to IBD, and Bury also identifies this as a salient concern, as patients frequently held views of their disease being inherited or "in the blood". It has even been suggested that there can be a third type of chronic illness, this being the position of someone who is *likely* to contract a disease (Conrad, 1987). Of course, chronic illnesses are usually characterised by periods of remission and relapse, so the issue of uncertainty extends beyond diagnosis to how the individual manages his/her life within, and outside of symptoms as and when they arise. Whichever stage a patient encounters, uncertainty is a prominent aspect of chronic illness that cannot, and must not be ignored, both generally and in this particular project. Given



the uncertain and often erratic nature of chronic conditions, the consideration of the two different worlds of health and illness extends beyond comparisons to acute illness periods. It also leads to social isolation and re-evaluation of the position of the self in relation to the illness. Bringing this back into the context of the project also provides a valuable consideration as young people are developing independence and identity as they mature. This leads this research to consider what external influences can help young people to adjust to having Crohn's or ulcerative colitis, and questions whether the establishment of the causes of their symptoms can help them to make sense of IBD.

#### 2.6.5 *Biographical disruption*

The two worlds of health and illness are biographically as well as physically represented (Bury, 1982). In addition to considerations of bodily disruption and uncertainty, Bury examined other areas affected by biographical disruption, stressing that there is a lack of understanding and interaction between 'wider social structures and the experiences of ill health' (*Ibid*, p.180). It is unclear whose lack of understanding these observations are directed towards – the medical community or society in general. However, Bury's work is significant as it pays attention to the effects felt by chronic illness sufferers on aspects of their daily life. While observing that chronic patients can make claims on the sick role in relation to acute illness, Bury asserts that chronic illness threatens basic structures of everyday life. More importantly, the knowledge underpinning these structures is disrupted. This includes the re-assessment of relationships with family and friends, acknowledging potentially perilous outcomes in disease progress and, while continuing daily activity, re-evaluating one's own independence. All of these are examples of the shift between the worlds of health and illness, and culminate in the overall claim that a 'fundamental re-thinking of a person's biography and self concept is involved' (*Ibid*, p.169). An example that effectively conveys this is the notion of premature ageing. Bury developed his arguments from a study involving a patient sample of rheumatoid arthritis sufferers, and the significance of age appears in a data extract wherein a participant expressed the belief that arthritis is a disease which affects the

elderly. This was a common belief amongst those who were interviewed, and was therefore a biographical shift from a conventional trajectory of aging to a rapid onset of the process.

The place of "self " relation and re-thinking is also given substantial attention by Charmaz (1983, 1991) who noted how a person "reconfigures" his/her self, comparing the chronic patient to the person that used to exist before disease onset. There is a re-evaluation of physical outcomes, but this is held within re-evaluation of the self as well, resulting in a comparison between the chronic patient and the person who used to exist before the onset of illness. Therefore someone's life story is disrupted by the onset of illness

Staying with this line of argument, Kelly (1986) details personal experiences of ulcerative colitis and adjustment strategies to ileostomy surgery. In a brief communication to a medical journal, Kelly provided a three-part paper detailing the subjectivity of illness experience. Using personal experience, Kelly formed a bridge between autobiography and practical implications for the clinical environment by drawing on theoretical considerations derived primarily from social psychology. The full account of his experience with ulcerative colitis fits very well here, not just in terms of corresponding content with IBD related literature, but also in the questions that it raises. An example of this lies in a description of diarrhoeal symptoms as the key markers from which the author and his family judged how well or ill he was. This prompts examination of what "markers" can be found in young people's accounts that define what is constructed as being healthy and being ill, and where the moment of transition occurs between the two worlds of health and illness.

However, this communication has some omissions. The author remembers soiling clothes in public situations, but says that as these episodes became more frequent he normalised [them] by viewing it as part of the recovery process. It is unclear how old he was at that point, but the text suggests that he was entering his early twenties. However, there is no indication of what the events or strategies were that led up to him "normalising" such an acutely embarrassing event. The paper addresses problems such as collusion within the family on how to communicate aspects

of illness within and beyond the family unit. However, the overall concept that underpins this piece of work is the importance of autobiography in making sense of disruption caused by chronic illness. Ultimately, Kelly sees this as biographical *re-construction* rather than focussing on a singular point of disruption.

#### 2.6.6 *Bodily disruption*

In addition to changes affecting the self, or sense of self, the body undergoes several transitions over the course of a chronic illness. There are also several interpretations of how one experiences bodily disruption through illness. Examples include the biochemical body, exemplified by diabetic patients' organisation of medication regimes, and also that of the body as machine for patients with renal failure undergoing dialysis. Such a process can result in the machine becoming a symbolic extension of the body and the self (Williams, 1996). This also takes the discussion further by examining issues of dualism in the context of chronic illness and the problems of *dys-ease*, *dys-order* and *dys-embodiment*, by documenting the fluctuating states of mind-body dualism during the chronic illness experience. Williams' argument presents the body as a constant source of rebellion against the self, and how in retaliation, sufferers settle for a "trade-off" between managing social activities, and accepting the negative bodily consequences that are brought on as a result of such activity.

The initial phase prior to illness onset sees the body as an "absent presence", a concept that is taken for granted. Our sense of ownership of a healthy body manifests itself as being relatively unaware of the physical mechanics that comprise our daily functions. Other perspectives maintain that the body is the one thing that one can positively claim as one's own, occupying a private state that is to be revealed (or concealed) as a matter of individual discretion (Radley, 2004). Williams argues that more recently, patient's experiences with modern medicine serve to reinforce dualism, as individuals may come to regard their bodies in terms of highly technical vocabulary, or in the context of a rigorously marshalled medication regime. Williams' work is an urgent plea to make the body a central issue in

sociological and psychological enquiry in relation to chronic illness, and proposes a focus on narratives of embodiment in the context of disease.

It is also useful to consider the body *outside* of the realm of chronic illness, especially as there are aspects of certain illnesses, including IBD that have severe implications on bodily and social control. Burkitt (1999) provides an intriguing view of developments of the relationship between the body and society. This view also assists in explaining why some diseases and bodily afflictions struggle to receive open discussion whilst others enjoy general recognition and conversational ease. Burkitt documents the transition from the “grotesque” to the “modern” body, revealing attitudinal changes towards it that have occurred as primary results of environmental and cultural change.

While this is speaking of the body in an historical sense, and is outside the realm of chronic illness, it is a viewpoint that is interesting to consider with respect to how IBD presents symptomatically, and how it is addressed socially. The online resources mentioned earlier on in this chapter contain many references to the embarrassing nature of the disease and the difficulties that it presents in public situations. This ultimately leads to the question of why discussing the nature of such conditions is embarrassing and how this came to be the case.

Burkitt argues that bodily ownership was a commodity that was once always taken for granted, and maintained that the ‘material body of the individual is part of the collective, ancestral body of the people’ (*Ibid*, p.47). The body was perceived to have strong regenerative power, with emphasis placed on the celebration of reproduction. Burkitt continues to assert that the grotesque image of the body paid particular attention to characteristics that are not viewed in the same celebratory context today. Orifices and protuberances were linked to the earth and its reproductive power, as were bodily components that are nowadays associated with privacy like genitals and bowels. This is a fitting argument to include here, as it can help to answer the question of what it is that makes IBD so difficult to discuss and what exactly determines some diseases to be classified as embarrassing.

Burkitt describes an historical shift from the perception of the body in this manner to that of a much more reserved, “closed” entity. He cites the Renaissance period as the time when this great attitudinal shift occurred, and

wherein bodies and objects began to acquire a more private, individual nature. Cultural attention shifted from celebrating the body's orifices and protuberances, to more "closed" components of human anatomy – smooth surfaces, skin, and facial features. Behavioural changes also occurred with regard to bodily functions: sexual activity, urination and defecation were all previously exploited in a carnivalesque kind of way, but were later confined to designated private areas, and not spoken of in polite society. Although this is largely a generalisation of a cultural shift surrounding the body, it sets an ideal scene for the issues of chronic illness raised here. The body had undergone a process from being open to being concealed and rationalised. Burkitt clarifies:

*The person of rationalism and classicism is firmly encased in his/her closed bodily shell, alone with his/her doubt, uncertainly and fear. (Ibid, 1993, p.49)*

While Burkitt personally acknowledges that this is an historical account of sweeping generality and is certainly not an explanation for the basis of human fear, it is worthwhile to consider with relation to chronic illness and also to IBD. Alongside the "unspoken" and uncertain aspects of bodily functions, the nature of explaining and accounting for illness arises, which is a key component in trying to establish how young people live with chronic illness and specifically with IBD today.

## **2.7 Accessing experience**

The literature search has already widened to explore the chronic illness experience, instead of just the IBD experience. The aspects of chronic illness that have emerged so far can certainly advance thinking about IBD and how young people live with it, and can help to consider parts of daily life and how chronic illness is factored into that life. However, we are still no nearer to gaining insight into individual experiences and stories of specific examples of how this has been done. More importantly, there are no examples of individuals simply talking about everyday life without the intrusion of illness because disease is often focused on so intently in the studies reviewed here.

Before trying to access stories of how people have lived with colitis or Crohn's disease in everyday life, it is important to ask what specific aspects of IBD can assist the enquiry further. While the aim of this project is to establish how young people manage their lives with IBD outside of a clinical setting, it is

worth looking inside such a setting to see what aspects of the disease arise in medical discussions. Some of the public discussion forums also contain references to specific procedures and/or medication, as does some of the literature. Therefore as an additional measure to seeking relevant literature, the next step is to gain insight from direct observations in a relevant setting.

## **2.8 Clinic observations**

Observations of outpatient clinics were not a requirement of the project, and were not intended as an independent observational study. At this point they provided an opportunity to become familiar with both medical and administrative clinic practices, and to also become accustomed to the terminology and procedures intrinsic to IBD. The visits occurred twice weekly for a period of six months. These began by observing outpatient consultations alongside medical students attached to the gastroenterology teams within a local teaching hospital. Attendance at these consultations provided the first opportunity to see patients speaking about their illness. In addition to observing consultations with medics, there were also opportunities to sit in on other consultations with IBD nurse specialists. These differed from discussions with the doctors as they generally concentrated on how the patient was getting along in their life outside of the clinical setting, amongst other queries about adherence to medication, and ensuring that regular blood tests were being carried out. Other activities included being present at histology meetings, to see how clinicians arrived at decisions on diagnoses and disease activities.

## **2.9 Outcomes of observations**

Clinicians and nurses explained that people (adults and some children) were used to talking about their condition. This became apparent when seeing a newly diagnosed patient in comparison with someone who had had IBD for a long time. It also became clear how certain words and phrases were used within IBD related discussion, effectively a sub-vocabulary emerging as a result of being affected by this particular illness. Both the adult and paediatric outpatient clinics did not specifically book IBD patients – they dealt with other gastrointestinal disorders that produced varied types of talk. However, specific

turns of phrase emerged within IBD cases. Often consultants would ask how often a person was “going”, which basically enquired how many times a patient would defecate during a 24 hour period. It transpired that this was an informal measure of the severity of the disease, and was always asked when a person fell into relapse. More specifically, waking during the night with the urgency to defecate was considered seriously. Other featured terms were present in the consultations. An acute symptomatic phase was referred to as a “flare-up”, and the frequency of these was as varied as the patients who attended the clinic.

### *2.9.1 Adjustment to IBD*

Another interesting issue that arose from observing clinic practices was that of adjustment to IBD. It is easy to initially assume that this could relate specifically to response to medical treatment, such as adjustment to medication or surgical procedures. However, most consultants and specialist registrars believed that adjustment was determined by social parameters. During informal discussions while introducing the clinic, they explained that an example would be an adult patient who would still rely on a parent to manage medicines, or someone who was seeking constant reassurance from clinical staff that it would be all right to do certain daily activities, like going shopping or meeting friends.

### *2.9.2 Disease status and surgery*

During the visits questions arose about the diagnosis criteria for the project. In discussion with clinicians, a query arose about whether to include patients who had undergone ileostomy or colostomy procedures. This surgery is performed as a curative measure for extreme cases of ulcerative colitis, if the bowel is severely ulcerated, and to alleviate severe symptoms of Crohn's disease. It involves the partial, or complete removal of the colon (large bowel), and results in a stoma and bag appliance to be used. Instead of anal defecation, faeces are discharged into an external bag through a stoma – an aperture in the abdominal wall. Such patients were still registered with the outpatient clinics, but had technically had their active colitis or Crohn's disease removed. However, after observing consultations with clinicians and

IBD nurse specialists, it became increasingly clear that there were several issues that arose through adapting to this new appliance in spite of the absence of actual disease. These included awareness of the bag while eating out in public, its presence during sexual activity and also that of disclosing its presence to others.

There were huge variations within patients who had undergone the surgery. Some were satisfied that they no longer had symptoms and were able to carry on with life without the interruption of medication or loss of bowel control. Others saw the procedure as a loss of control in a negative sense as they could not control the waste being ejected from their bodies. While the disease was no longer present in those who had had the surgery, the procedure itself resulted in dramatic changes to daily life, self-image and physical adjustment. This therefore assisted in the participant sampling process by helping decide on the inclusion criteria, irrespective of the symptomatic presence of IBD.

### *2.9.3 IBD classifications*

Histology meetings revealed more details about a diagnosis of IBD, especially the terms that could be applied either to Crohn's disease or colitis. As stated in Chapter One, the main difference between the two conditions of IBD is that ulcerative colitis affects the large bowel, and Crohn's disease can affect any part of the gastro-intestinal tract. However, the two diseases presented differently, and generated discussions concerning which condition a patient had if s/he was only affected in the large bowel. In other words, ulceration confined to the large bowel cannot immediately be diagnosed as colitis, as Crohn's disease can also inhabit that area. These meetings also provided information about more detailed terms that applied to IBD, especially in cases where the histology images and reports did not convey a clear answer. Terms like "indeterminate colitis"; "Crohn's colitis"; "collagenous" and "microscopic colitis" often appeared as additional descriptors of unclear symptom presentations.



#### 2.9.4 *Investigative procedures*

These included upper endoscopic examination and colonoscopy, but these were only in the adult clinics. The patients were given a sedative, but remained conscious throughout these procedures. Although some of the examinations are booked in advance and individuals are given time to prepare for them, it became very obvious how physically uncomfortable the procedures were for them. Situations also arose when a patient was not prepared for an investigation. If someone reported an increase in symptom severity during routine outpatient consultations, the consultant would often suggest a rectal examination (sigmoidoscopy) there and then, a procedure that examines the rectum and lower colon. Such procedures were extremely useful to see, as it was highly likely that the participants of this study would have experienced them at some point during the course of their illnesses.

The opportunity to see consultations and procedures first hand was invaluable for understanding some terms used in online resources and some of the terms used in medical literature on IBD. This was a great opportunity from which to begin designing methods to access individual stories of IBD.

### **2.10 Conclusion**

While studies investigate the presentation and management of IBD, little has been done to formally document personal experiences of the disease and how it is placed in everyday life. It is already clear that this project must extend beyond IBD related literature to general aspects of chronic illness. Already there are investigative areas that emerge as potentially useful in finding out how a young person lives with IBD. The body, biographical disruption, and issues of living space can all present practical and conceptual lines of enquiry, and can each be explored indefinitely within the framework of IBD and adolescence. They are areas of concern that are undoubtedly important in addressing chronic illness, but at this stage it is doubtful if they would be suitable for seeking out aspects of daily life with IBD, and more importantly, seeking out aspects that lie beyond the confines of illness. It would be unwise to treat them as individual investigative tools at such an early point in this project, as there is a danger that the inquiry will remain centred on disease. The same is true of the concerns that are raised in the development

of IBD measurement scales. They provide information about symptoms and self perceptions but are not located in an everyday context, or to the accounts that lead to the points on rating scales.

This chapter has illustrated the various ways in which IBD has been presented, in the public domain and in medical context. It has broadened knowledge of some of the issues relevant to IBD and chronic illness on a general level. But the specifics of young people, IBD and the “space between” illness and health remain elusive within the context of everyday life. To find this undocumented experience, the next stage is to gain access to individuals with direct experience of IBD, ultimately to fill in areas of subjective experience that the literature largely ignores. The central question posed by this thesis about what it is to live with IBD as a young person has advanced further in terms of scoping what has been done to shed light on this question. However, there are several unanswered questions that have been raised through this review. The first is to ask how young people position themselves in relation to their illness and the rest of the world. The literature does not reveal this as it remains largely within a clinical context. This leads on to a further question as to whether non-clinical aspects of life have more influence than clinical features in terms of assisting adjustment to IBD. Is it more beneficial to focus upon general age-related activities of young people’s daily lives to establish how they live with IBD, rather than concentrating on generic factors associated with the condition? Another omission in the literature is the question of how people live with illness over an extended period of time, and how IBD moves in and out of their lives at different points. The next chapter will consider these emerging questions with relation to designing an interview study to access direct experience of IBD during adolescence.

## Chapter Three

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### Accessing lives:

method description and procedures for  
interview study I

### 3.1 Introduction

The previous two chapters introduced the overall concerns of this research and reviewed relevant literature on IBD and young people. The review then broadened its scope to cover general aspects of chronic illness, to see if these could assist our understanding of what it is like to be a young person living with IBD. While most articles reveal issues that are intrinsic to IBD and young people, these are conveyed at a largely clinical level, and there is little evidence of how people live with IBD on a day-to-day basis. The next step for this research sets about directly accessing individual lives to gather stories that address how young people learn to live with ulcerative colitis or Crohn's disease. This is in response to the questions raised at the end of the last chapter, which asked how young people position themselves in relation to the rest of the world and their illness and how they manage IBD over time. Chapter Two also posed the question of whether it was more beneficial to concentrate on activity that typically lies outside of disease, to try and answer the main research question more comprehensively.

There are several concerns that have been raised that impact directly on the ways in which data were collected for this whole thesis. On the one hand, we needed to gather information about how young people managed IBD in different everyday situations. On the other hand, we also needed to try and answer the question of how young people dealt with IBD in their daily lives over a course of time. This type of intervention has not previously been attempted in the sense of following a cohort of young people over an extended period, and this emerged as a central goal in this research. However, before beginning to consider this, it was essential to find out the types of issues and concerns that arose for people as they experienced growing up with IBD. This was to avoid making assumptions about issues that would directly affect young people currently experiencing IBD, and also to avoid making a sudden jump between the existing literature and following a cohort of adolescent participants over time.

This chapter therefore details the first part of data collection for this project, which was an interview study with adults who were diagnosed with IBD during adolescence. The specific aim was to elicit some of the main

concerns that arose while they were growing up with IBD, which could then be used as a starting block for a second, longitudinal data collection exercise.

### **3.2 The active interview**

In reviewing the way that IBD has been investigated outside of the medical domain, Chapter Two included an approach that involved the patient joining the researcher as part of the analysis team (Ironsides *et al*, 2003). This was an interesting approach when compared to the positivistic descriptors and generalised outcomes of other articles. Nevertheless, there is something very deliberate about the way in which these methods were applied in this particular case. The authors set out to specifically involve their participants in the analytic process, but they did not explicitly mention how they as researchers had contributed to the co-creation of the accounts that they generated. This is an essential consideration, as it holds implications for participants re-assessing events that happened a long time ago, but also touches on an aspect that appears to be specific to IBD experience. Some of the literature discussed in Chapter Two reveals some of the more embarrassing or saddening encounters that Crohn's disease and colitis can bring. A minimalist passive technique in a life story interview could be potentially unnerving for participants who were unused to speaking of their illness outside of a clinical setting. This contrast sharply with a positivist, structured interview, which curtails the richness of data, yet may be more comfortable for participants in the sense of not encouraging discussion of subjects previously ignored for fear of embarrassment. This can be alleviated if the interview is treated as active, by offering the participants the chance to reflect on their experiences and re-positioning themselves in relation to these experiences.

The active interview was championed by Holstein and Gubrium (1997) who acknowledged that the interview is a special form of conversation, rather than just a data gathering exercise. Instead of a passive participant or interviewer, when one party does not contribute to the production of knowledge in the interview, the authors argued that both are active participants in the interview process.

*The active interview is a kind of limited "improvisational" performance. The production is spontaneous yet structured - focussed within loose parameters provided by the interviewer, who is also an active participant.*

(Holstein & Gubrium, 1997, p.123)

This type of interview is very appealing in terms of the flexibility it offers to everyone involved in it. The value assigned to the interviewee within other interview contexts is often as a repository for knowledge, resulting in the interviewee being regarded as an "informational commodity" that could somehow be polluted by suggestibility in an interview. Within the active interview, interviewees are instead active elements that are contributing to the meaning-making process of an interview, which is an appropriate process for trying to make sense of illness. Specifically, it is even more appropriate for a project in which the disease in question is discussed with relation to other everyday life events and activities. As the literature in Chapter Two has demonstrated so far, research rarely extends beyond the facets of life that are disease related. The active interview can infiltrate these undocumented areas of life, and discuss aspects of life that are not always disease related, to get a fuller picture of how IBD is accommodated into a young person's daily life.

### **3.3 Study design**

#### *3.3.1 Interview development and content*

The aim of the project was to establish how young people live with IBD, and the aim of the interviews at this stage was to access experiences of living with IBD that were previously unreported in existing literature, such as managing the disease on holiday and at school. This necessitated designing an interview that would yield a balance between disease related and non-disease related material, so as not to make IBD the central focus of the interview, but instead bring the participants' lives into the foreground. Using the principle of the active interview, the content was not too prescriptive, and was not set out in a series of standard questions. The main purpose was to follow a life story structure and introduce disease related issues as and when appropriate, but not make disease the central part of the exchange. Therefore the interview started as a temporal sequence from pre- to post diagnosis, and then took a more thematic approach.

This part of the data collection used a series of semi-structured interviews with 20 participants (4 pilot study, 16 main study), and followed a life-story design. A life story interview is a useful tool in trying to access aspects of peoples' lives. In the case of chronic illness, it can reach across time spans that capture both everyday and extraordinary activity. It usually involves the interviewer adopting a minimalist passive technique, wherein the interviewer refrains from contributing to answers as much as possible, and the participant does the vast majority of the talking, to maximise his/her own story. However, these interviews were treated as active from both the researcher and interviewee perspectives. This was to encourage the participants to talk freely about their experiences with and without IBD, and to enable them to recall events or feelings that they had not previously discussed. This type of interview also helped to strike a balance between focussing on IBD as a particular illness, and looking at the aspects of life that were not disease related, the "spaces between" that have been previously ignored. It also helped participants to talk about everyday, ordinary activities intrinsic to everyday life that would not otherwise warrant much attention. By probing and prompting to a limited but necessary degree, the participants were able to re-visit and re-assess situations that they had not discussed for a long time, if at all.

The format started with basic aetiological and demographic questions, such as type and length of diagnosis, and if there were any immediate family members who also had IBD. The interview generally established what the participant was currently doing in terms of living arrangements, employment and/or education. The interview then moved back to asking participants to remember what their lives were like prior to diagnosis, what they were interested in, when they first experienced symptoms and what happened in the run-up to eventual diagnosis. In addition to this, it invited participants to discuss their friends, any clubs or social activities they were involved in, who they lived with at the time and what was generally important to them. Some questions related specifically to symptom episodes and changes to bowel regularity, but the interviews also addressed the accompanying social aspects of these changes. They probed the effects of the disease on personal relationships, education, leisure activities and emotional responses to the

disease. The interviews also addressed the level of knowledge participants had of IBD and the information seeking behaviour they implemented in attempting to find out more about their condition. At this point the interview took a thematic turn and invited participants to remember general aspects of their lives following diagnosis, which could follow a roughly hewn timeline to leaving home and developing independence. Such aspects included participants giving examples of:

- education and any effects on school/work attendance, including physical activities in school sports, achievements and disappointments;
- friends, relationships and communication, addressing how others did or did not accommodate or understand IBD;
- family reactions and advice;
- holidays, and school trips;
- sexual relationships, telling new partners about IBD and partners' understanding and any changes to sexual activity;
- body image;
- jobs and careers, including current situations and aspiring career ambitions;
- independence development, moving away from home (if applicable) and settling into new surroundings.

There was no time limit to the interviews, but on average they lasted for 90 minutes. The interviews concluded with some short questions relating to positive and negative experiences of adjustment to IBD, and what participants felt had helped with most in terms of making sense of their illness.

### *3.3.2 Pilot interviews*

Prior to commencing interviews for the main study, four pilot interviews were conducted with two men and two women. The aim of the pilot exercise was for the researcher to become accustomed to asking questions that were of a sensitive nature and the techniques of prompting (e.g. managing loss of bowel control in a public environment). This was an extremely useful exercise and was an excellent way of establishing appropriate interview practice, from



general concerns such as interview location, to specific ones like question clarity. The pilot interviews also tested whether terminology that was specific to IBD was understood by the researcher and in turn used appropriately, so as not to confuse participants or expect them to explain medically related details at the expense of talking about their lives.

### 3.3.3 *Interview setting and practice*

The environment in which the interviews took place was an important consideration. As Chapter Two revealed, the existing IBD literature tended to pathologise the disease, and neglect its relevance to and presence in everyday life. Given the key aim of this project, it was inappropriate to conduct interviews within a healthcare setting. The interviews were removed from the clinical environment, and were instead conducted in participants' own homes most of the time. Sometimes this needed careful negotiation, since even when considering interviewing participants in their own homes there was no way of knowing how IBD was conversationally addressed with other family members/co-habitants, if indeed it was mentioned at all. As several participants were living in shared student houses, they sometimes did not wish to be interviewed in their houses for fear of others overhearing, and instead arranged to come to a more convenient location.

Issues of location and the role of others arose in the pilot interviews. One person indicated a wish to be interviewed with his wife present. This was not a practical difficulty, but it raised doubts about whether the opportunity for adequate self-reflection for the interviewee would be comfortably possible if someone close was also present. However, the participant in question generally found it an ideal opportunity to tell his wife about certain aspects of IBD experience that they had not previously discussed. A specific example was that his wife had previously worked with ileostomy patients while working as an auxiliary nurse. While she was able to practically deal with her husband's stoma appliance as a result of her experience, he actually felt uneasy about her matter-of-fact handling of the situation. Rather than being problematic, or producing conflicting accounts that led to disagreements, the different accounts from the participant and his wife contributed to rendering the interview as active, giving rise to discussion about matters that may not

have been addressed in a standard interview design, or if the participant was interviewed on his own. Furthermore, it did not encourage too much structure in the interview and negate the interviewees' relation of specific events of importance to them. Instead it facilitated accounts of everyday life without placing the onus of the participant to remember every detail.

It also presented an interesting perception of how aspects of everyday life are handled with the added context of IBD. Changing a stoma appliance was a daily routine for this participant, one that he had to become used to, yet his partner's handing of it as a professional daily activity did not seem to fit in with his adjustment to the practice so easily.

Another issue that arose from the pilot interviews concerned more general aspects of interview technique and reflective practice. There were certain points during the interviews that required prompting to move the talk into different aspects of life, which are otherwise not addressed in literature exploring IBD and adolescence. Examples include practical aspects of personal hygiene, which were often dealt with in an abstract rather than a practical manner in IBD related literature (Giese, 1996). Therefore to fully explore how such aspects are managed, it was necessary to prompt the interviewees, whilst taking care not to impose limitations on their answers.

### **3.3 Participants**

#### *3.4.1 Inclusion criteria*

Sixteen participants were interviewed for the main part of the interview study and four were interviewed for pilot work. They were all aged between 20 and 25 years; diagnosed with IBD before age 18; and also had to have had a minimum of 5 years experience of the disease. There were several reasons for this. A five-year period was considered a suitable length of time for adaptation to the disease on practical terms, while not being too distant from the disease onset to prevent remembering key points. It also prevented those who matched the age criteria for diagnosis but who did not have as much experience of the disease being included on the contact list. IBD presents itself in many ways and does not discriminate between age, social groups or race. It was therefore impossible to seek a representative sample of IBD patients. The participants were not all experiencing an acute illness phase –

some were in remission, while others were in relapse. No IBD-specific conditions (e.g., having had surgery or taking medication) were necessary. The inclusion criteria were determined by age and length of illness experience.

#### *3.4.2 Identifying the participant sample*

All of the participants were registered patients of the adult division of gastroenterology at a local outpatient clinic. Following ethical approval (see section 3.5), senior clinicians granted access to patient records that were kept by IBD nurse specialists. The patient lists defined individuals with IBD by ages, but it was not immediately obvious how long they had had the disease. Records commenced from the first contact with the clinic, unless the patient had transferred directly from another hospital. Therefore the listed population sample (N=62) of patients aged between 20 and 25 was further reduced by length of disease experience. All were sent a patient information leaflet with background information about the study (see Appendix B) and asked if they wished to participate in an interview. From the sample, 15 responded positively, 7 declined, and the remaining 31 did not respond. At the agreement of their caring physician, non-respondents were followed up with a telephone call. This added nine more participants to the sample, totalling 24 names. From the 24 who wished to participate, 20 were interviewed (4 pilot interviews; 16 main study) as four people were subsequently unable to continue for personal reasons.

#### *3.4.3 Participant information*

The mean age for participants at diagnosis was 14.8 years, and the mean length of disease experience was for seven years (see Table 3.1). There were eight males and eight females altogether. Eleven participants had a diagnosis of ulcerative colitis and the remaining five had Crohn's disease. From the whole sample, two male participants had undergone IBD related surgery, having had their colons removed. Half of the participants were in higher education, six were in employment and two were unemployed. These varied lifestyles within the participant group indicate how individuals were managing very different circumstances within their lives.

| No. | Name<br>Pseudonym | M/F | Age at<br>interview | Age at<br>diagnosis | IBD<br>diagnosis | Surgery | Status     | Living<br>arrangements |
|-----|-------------------|-----|---------------------|---------------------|------------------|---------|------------|------------------------|
| 1   | Olivia            | F   | 20                  | 12                  | CD               | No      | FE         | With parents           |
| 2   | Joanne            | F   | 24                  | 12                  | UC               | Yes*    | Unemployed | Alone                  |
| 3   | Kate              | F   | 22                  | 14                  | UC               | No      | Employed   | With partner           |
| 4   | Lawrence          | M   | 24                  | 15                  | CD               | No      | Unemployed | Alone                  |
| 5   | Patrick           | M   | 23                  | 17                  | UC               | No      | Employed   | Shared house           |
| 6   | Nadine            | F   | 21                  | 16                  | UC               | no      | HE         | With parents           |
| 7   | Paul              | M   | 22                  | 13                  | CD               | Yes**   | HE         | Shared house           |
| 8   | Jemma             | F   | 23                  | 15                  | UC               | No      | Employed   | Partner & children     |
| 9   | Laura             | F   | 22                  | 17                  | CD               | No      | HE         | Shared house           |
| 10  | Alan              | M   | 22                  | 12                  | UC               | Yes**   | HE         | Shared house           |
| 11  | Rosanne           | F   | 20                  | 15                  | UC               | No      | HE         | Shared house           |
| 12  | Peter             | M   | 24                  | 16                  | UC               | No      | Employed   | With parents           |
| 13  | Terry             | M   | 22                  | 13                  | CD               | No      | HE         | Shared house           |
| 14  | Tracey            | F   | 20                  | 14                  | UC               | No      | HE         | Shared house           |
| 15  | Keith             | M   | 23                  | 16                  | UC               | No      | Employed   | With parents           |
| 16  | Ethan             | M   | 22                  | 12                  | UC               | No      | HE         | With parents           |

\* Bowel Resection

FE= Further education

\*\* Total colectomy

HE = Higher education

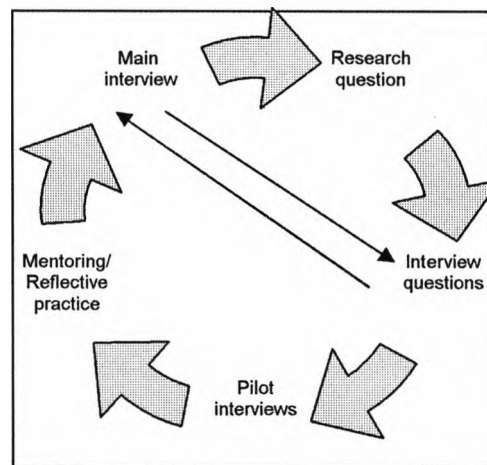
**Table 3.1: Participant demographics****3.5 Ethical submissions**

In addition to submitting a successful ethical application to the Loughborough University Ethical Advisory Sub-Committee, all those involved in the project sought approval from the NHS Trent Research Ethics Committee, and the Research and Development division at the local hospital from which the participant sample was drawn. Rather than making an application directly, Loughborough University personnel arranged to meet with leading clinicians to discuss parts of the application that were highly specific to the NHS. This involved costing analyses and proposing sample numbers that were realistically achievable within the numbers of patients registered at clinics. Both applications were approved on all counts and annual reports were written and sent to the local NHS trust Research and Development unit throughout the duration of the project.

### **3.6 Additional methodological developments: mentoring input**

While the pilot interviews were an effective way to establish practicalities of the design, there were also parts of the interview process that needed extra "fine tuning". External measures were in place to review any queries or issues that arose from the pilot interviews, like those mentioned in the previous section. In addition to its financial support, the National Association for Colitis and Crohn's Disease (NACC) offered an opportunity for reflection on the interviews with a NACC representative, a specialist counsellor. This was suggested at an informal meeting, and was not a condition of sponsorship. During the period of preparation and practice for interviews it was a constructive resource and helped to build confidence in directing dialogue and ensuring that sensitivity was observed at all times. The counsellor and the research student listened to the four pilot interviews jointly. The counsellor had already listened to the interviews in advance and made notes both then, and again in the joint listening session. The reflective practice allowed for further clarification of any unfamiliar terms, and immediately raised some general points, which were useful information for the conduct of the interviews.

After listening to the pilot interviews in the reflective practice sessions there were several issues that emerged as having some influence on interview development for the main study. Some interviews addressed topics of a highly emotional nature, especially consideration of and undergoing colorectal surgery. The reflective practice of listening with a specialist counsellor provided insight on how to deal with this, which meant ensuring that someone was able to continue with an interview if they were upset and offering the opportunity to conduct the interview at another time. While the aim of the project was to remove the central focus away from disease, it also became evident that there was a specific need to address disease related concerns in the interviews, whether this was within the context of the clinical setting or in home environments. Overall, the practice of listening with a mentor encouraged further examination of the interview schedule, particularly the need to make it flexible to the point of allowing the agenda to emerge, rather than be defined at the outset. This stage became part of the design process of the interview, and is included in the diagram below.



**Figure 3.2: Cycle of interview development**

The principle of the active interview was also demonstrated here in another way. The interviews were active in terms of the emergent dialogue between interviewer and researcher, during the course of one interview. However, they were also emergent in the sense that they contributed to future interview questions. From the start of the initial research question and the realisation of the omissions that the literature in the previous chapter presented, the interview development assumed a cyclic development, in which the interview questions at pilot stage were revised after a series of mentoring sessions and reflective practice. This resulted in a cycle of interview discussion points being raised that were expanded upon as interviews progressed. Examples of the issues that emerged from the reflective practice sessions are detailed below.

### 3.6.1 *Bowel control*

Listening to the pilot recordings did not reveal many specific incidents of losing bowel control in a public place, yet the *fear* of this happening was often referred to in various parts of the interview, ranging from accounts of being in school games to routine activities such as shopping.

### 3.6.2 *Names of procedures*

The advantages of clinic observations were realised when listening to accounts of interviewees' experiences with clinic procedures. One example included a female describing having a colonoscopy during an outpatient

appointment, when this would not have been possible as this procedure is performed in theatre. While it was not appropriate to correct the person during an account of what turned out to be an unpleasant experience, it raised awareness of the possibility of such misunderstandings occurring, and implied that patients were not necessarily informed of the procedures that they were to undergo while in outpatient clinics.

### 3.6.3 *Administering medicines rectally*

The difficulties of rectal medicine administration was present as an issue in all of the pilot interviews, with interviewees finding this part of the treatment process very hard to manage between clinical and home environments. While this was expected in the clinics, the difficulties of administering a rectal steroid foam or suppository were not just spoken of in physical terms relating to bodily experience, but also in negotiating how this was managed at home.

Rectal administration and examination also led to a discussion of teenage sexuality with one male, diagnosed with Crohn's Disease at age 12. Following investigative procedures such as a sigmoidoscopy he recalled questioning whether this meant that he was still a virgin, and whether the anal intrusion signified that he was gay. This was an extremely difficult issue for this person at that point of diagnosis, and also indicated that although issues of rectal examination were disease related, these concerns went well beyond the physical into aspects of identity.

### 3.6.4 *Employment issues*

Moving on from school years and into employment experience, fears arose about taking time off work through IBD related symptoms. Although not all of those interviewed had been treated unsympathetically, they recalled some instances of unfair treatment (either that they had directly received, or had heard of) that intensified the reluctance to take time out of work. One interviewee even told how she had emerged from hospital after a bad flare up to discover she no longer had a job. In the discussions about the pilot interviews, the specialist counsellor noted that clients had related this occurrence to her several times.

### 3.6.5 *The outsider perspective*

The phrase “you look well” was mentioned by three of the interviewees when they told of instances when they had not felt well. The ways in which the suffering body could trick outsiders into questioning the presence of IBD were many and varied, and afforded no advantage to the interviewees in terms of how they were externally viewed. An “inside” disease that did not outwardly convey the abdominal pain, energy loss and erratic bowel functions was not met with general understanding. While this may not be different to other chronic conditions, it was a concern that emerged for all of those interviewed.

### 3.6.6 *Relationships with caring physicians*

A fear of “hurting” their caring physician was a concern that arose in two of the interviews and also noted by the NACC counsellor to be a common issue with IBD patients. This meant that the patient had a good relationship with their clinician, but would seek alternatives to the medication or suggestions that were provided by them. These alternative endeavours were often concealed from the clinician to avoid being seen to question professional judgement, and often resulted in lengthy periods of relapse.

### 3.6.7 *Causal factors*

Causal factors of IBD were a rich source of debate in these mentoring sessions. In all interviews, participants would have ideas of the main causes of their illnesses, which would vary in degrees of certainty but were always present. As mentioned at the beginning, IBD is a condition that has no specified aetiology that is recognised in evidence-based medicine. However, all interviewees at this pilot stage identified possible causes, or exacerbations of their symptoms.

All of these factors were considered in light of the interview development for the main part of data collection. Conducting the pilot interviews revealed that some issues emerged after interviews had already been conducted, which raised a new set of questions which may not have been previously asked in a preceding interview. The interviewee who described feeling confused about his sexuality after undergoing rectal examination is one such example that



gave rise to a new set of questions about sex and relationships that had not previously been included.

### **3.7 Handling of data**

After the data had been gathered and interview content had been sufficiently reviewed during the process of conducting all 16 of the main study interviews, the interviews were fully transcribed<sup>1</sup>. They generated a large corpus of data, and rather than initially examining each interview in depth, qualitative analysis software (Nvivo2®) was used to examine the transcripts quickly and elicit further key themes in support of and addition to those raised from the pilot interview outcomes.

Codes were applied to the interview transcripts as within the Nvivo document coding system. A list of codes that were generated can be found in Appendix C. In addition to this, the interviews were also analysed to seek the active components within them, as they were based on the active interview design. Therefore in addition to what they said, the interviews were examined from the perspective of what they did in terms of their active qualities, and what the participants did while engaging in the exchange of dialogue between themselves and the researcher.

### **3.8 Conclusion**

This chapter has outlined how the project began to access individual lives with experience of IBD during adolescence, and how participants as young people began to adjust and deal with IBD on a daily basis while managing the multitude of activities that comprised their daily lives. It has delivered disease related issues that emerged at the pilot interview stage, and explained how mentoring input has also contributed to the methodological process. The question that now remains is if the interviews can give sufficient access to individual lives to the extent where they can begin to fill the space that has been left by existing literature on IBD and young people, and provide specific

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<sup>1</sup> Interviews were transcribed verbatim: punctuation has been included on an assumed basis, rather than indicating inflections, timing of pauses, etc. This was to allow the full nature of the content and action of the documents to emerge.

examples of how young people learn to live with Crohn's disease and ulcerative colitis as they mature.

## Chapter Four

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**Seven years on:  
retrospective accounts of IBD and adolescence**

#### 4.1 Introduction

The general question of this thesis is concerned with what it is like for young people to live with IBD. Chapter Two reviewed arguments and perspectives taken on IBD and adolescence, which revealed few examples of how people lived their daily lives while managing the disease. No one had directly asked any young people what this was like, without making IBD as a disease the central focus. This set of literature sidelined the other everyday issues that co-exist alongside IBD. This clearly raises a set of questions in order to address these.

We know what the general research problem is, but it is important to re-state the specific practical questions that the interviews intended to address with the adult participants. What did they remember about their lives before being diagnosed with IBD? How did individuals manage their disease in public and private circumstances? How did they feel about their physical appearance and changes to their bodies? What did they already know about IBD? What information did they receive, and how did they disclose aspects of their experience to others at that time?

Secondly, the conceptual issues that arise within these questions and in the studies presented in Chapter Two need to be examined. Disease experience involves negotiating living in two worlds, one of health and the other of illness. This chapter addresses this conceptual question of how individuals in this interview exercise achieved this in terms of whether they lived within or beyond the confines of illness, and what levels of inconvenience it may have caused for them.

The previous chapter discussed the best ways of accessing direct experience of young people with IBD, and advocated the use of the active interview to collect data for this part of the research. This resulted in a series of interviews with adults who had been diagnosed with IBD during adolescence. The average length of disease experience was seven years. The outcomes of these interviews are discussed in several ways, firstly in a thematic way, and then secondly by looking at specific isolated accounts from the participant pool. To start with, the chapter presents some initial descriptive outcomes that convey the types of overall issues that emerged for the participants, which also illustrates some of the concerns covered by the

studies that were reviewed in Chapter Two. These initial outcomes are also included here to demonstrate the contrast between the presentation of studies that have previously addressed IBD and its effect in young people, and the richness of individual experience that was displayed in the interviews.

## **4.2 Initial analysis**

When looking across the interview material, it was initially possible to gain a general feel for the types of concerns that were present in the literature. These initial outcomes also provided a basis on which to refine questions and define exactly what needed investigating in more detail. We can identify the following concerns as examples that require further in-depth analysis further on in this chapter.

### *4.2.1 Information on diagnosis*

One of the key points of the interviews in terms of remembering experiences of IBD was how participants received and retrieved information about their condition. Thirteen individuals were dissatisfied with information available to them at the point of diagnosis. This did not necessarily reflect how clinicians communicated information to them. Moreover, it mostly referred to parents' interpretations of information provided in consultations. Of the number interviewed, three participants recalled how, shortly after diagnosis, they were encouraged to speak with other young people with IBD. They found this to be a negative encounter. However, six participants described the value of attending non-clinical support groups for young people, several weeks after diagnosis, as this facilitated discussion of symptom and social management on their own terms. There was also evidence of participants feeling the need to protect family and friends from difficult experiences, with eight people stating that they had withheld information about their experiences for fear of inconveniencing and/or alarming others.

### *4.2.2 Bodily changes*

The bodily changes that IBD brought were also a key aspect of the interviews. All of the participants revealed that they had experienced difficulties in dating and communicating with prospective sexual partners. This was mostly due to

embarrassment about their physical appearance or fear of incontinence. All of them spoke of negative feelings about physical changes in their bodies in other circumstances, such as being on school excursions, out shopping or in within their homes. Catching sight of themselves in a mirror, seeing themselves depicted on a photograph, or video-camera footage fuelled memorable incidents for four of the participants. They had difficulty equating the image they saw with themselves due to the physical changes that they saw.

#### *4.2.3 Medication*

The physical changes in the previous section were mostly caused by medication, which in itself was a concern. All of the participants spoke of steroids and how they had been subjected to teasing due to the weight gain that the drugs had caused. Eight participants were worried about taking medication continuously. Immuno-suppressant drugs for IBD are not just taken during periods of relapse, but continue through to non-symptomatic episodes too. The participants' concerns were related specifically to taking medicines while they felt well, and this sometimes met with avoidance of taking the medicines and then relapsing. Paradoxically some participants reported anxiety about the possibility of a relapse at significant times (e.g. family holidays, public examinations), even if they did not adhere to taking medicines that would prevent this.

#### *4.2.4 IBD in and out of school*

Everyone who was interviewed had spent some time off school during term time for IBD related reasons. Mostly these episodes were a direct result of commencing new medication. Some immuno-suppressant drugs were initially administered in hospital so that participants could be monitored for any adverse reactions. Sometimes the periods of time away from school would be to adjust to a new diet, particularly an "elemental" diet. This was a liquefied mixture that required detailed instruction of how to make it. It contained the basic nutritional elements of a daily recommended diet, and was used for people who had severe ulcerations on the gastrointestinal tract that prevented digestion and absorption of nutrients. Two participants who were diagnosed

with Crohn's disease remembered being fed the mixture through a nasal-gastric tube. Clinicians usually try to introduce the diet with this method over the long school summer holidays, to minimise the potential disruption at school, but this was not always possible. Other participants did not ingest the diet through this method, but had cartons of the mixture to take to school with them. They described lunchtimes as particularly difficult experiences, as friends would be sitting around with packed lunches eating food that was far more appetising.

#### *4.2.5 Qualifications and careers*

The ages at which all of the participants had been diagnosed with IBD ranged between 11 and 17 years. At this time there are several education developments that occur in a young person's life, with GCSEs and A levels being a prime concern for most of the participants. In addition to public examinations there were also other external activities in which the young people participated, and these ranged from music examinations to sporting activities. Throughout all of these endeavours, some participants recalled instances of under-achievement, all attributing these to IBD. These were usually about achievements in school examinations, realising that they had not achieved grades that they knew they were capable of, because they had missed several lessons.

When discussing careers and whether IBD had affected such choices in any way, nine of the interviewees said it had not. From the participant sample, eight individuals were in higher education, and five of them were taking courses in, or related to medicine. They did not explicitly say whether experience of IBD had influenced their career choice, but had engaged in projects that were relevant to IBD. An example of this was a participant who was a pharmacy student who, at the time of her interview, was specialising in new drug treatments for gastrointestinal disorders.

These particular aspects of living with IBD as a young person can be elaborated on in more detail. In order to advance the analysis it is now necessary to seek specific examples of recalled incidents that may help to address the questions posed in the introduction to this chapter. These relate to how individuals managed to handle aspects of disease in public and private

circumstances, the information resources they used, how they felt about their body and physical appearance, and what they did to manage the disclosure of their illness to others.

These were aspects of IBD experience that emerged from the interviews and were also relevant to the literature explored in Chapter Two. It is useful to get a general idea of what was relevant to the participants as they recalled their experience, and quantifying certain experiences is one way in which to ascertain issues that are of more concern than others. However, this does not necessarily indicate relevance when trying to access the subjective experience of IBD. Therefore the following data analysis looks at specific facets of life with IBD and adolescence as it is lived through public and private experiences. In terms of trying to find out how young people position themselves with relation to their illness outside of the clinical setting, it is necessary to deflect focus from illness related concerns and seek experiences that lie within a more general public and private sphere of individual lives.

#### **4.3 IBD: in public and private**

The particular focus of this section is the relationship and presentation of IBD in public and private environments. As the previous sections have illustrated, there is little experiential content in an analysis that tries to quantify occurrences or events related to IBD. To find out more about this, and also how trying to focus on less disease-related incidents in a participant's life, the analysis focuses on private and public experience, to make an initial departure from understanding IBD experience purely within a clinical context.

The first participant to illustrate this is Paul. At the time of the study he had just turned 21 and was in his fourth year at medical school. The course was particularly intensive for him, as he was constantly catching up with work that he had missed due to Crohn's relapses. He had experienced some very unsympathetic attitudes towards his Crohn's disease. From the start of the interview he emphasised how supportive his girlfriend had been and she accompanied him to the interview. Paul lived with her and two other students in a shared house. As the first member of his family to attend university, Paul was very determined to excel in his studies, often to his physical detriment.



This is an aspect of IBD experience that will be expanded upon later in this chapter. When diagnosed with Crohn's disease at 12 years old, he endured a succession of severe symptoms, and was one of the participants to have had a colectomy (aged 15) and subsequent ileostomy bag, which was now a permanent fixture for him. When recalling issues of personal space in relation to the public environment, Paul exemplifies restrictive concerns perfectly:

*I used to dread having to go in open spaces because I thought "oh, I'm going to need to use the toilet", and invariably I did and again it's the same type of situation, thinking "how can I get to the toilet on time"*

*(Paul, interview 7, 2003)*

The physical assessment and appreciation of space is very important in the daily management of IBD. Paul's reflections related specifically to a relapse, but there are other similar considerations that are present on a more general level. Paul refers to this on a specific symptom level, but anxieties that lead to consideration of space in relation to toilet locations are ubiquitous within all the interviews. It is a finding that cannot be ignored as it holds implications for acute periods of illness and also periods of remission. This means that the concern is a practical one in terms of a relapse if someone is experiencing loss of bowel control, but can also be a residual concern if someone has no symptoms and still fears such loss of control in the public environment.

The previous example was a general speculation of toilet locations and where they could be used. The next extract is from another interview and brings this to a more specific level as another participant (Alan) talks about this with reference to staying at other peoples' houses and inviting them to stay over at his own:

*Thinking about it, I'd never go to her [his girlfriend's] house in case her parents got home and I was on the toilet. And the same, staying at a friend's house during school, I hated going to a friend's house, which is something I used to do quite a lot. They would have to come round to my house and even then I'd pick a toilet sort of furthest away so that they wouldn't be able to hear me. Yes, that was quite a big thing.*

*(Alan, interview 9, 2003)*

Like Paul, Alan had also had a total colectomy and ileostomy bag, which was permanent. At the time of the interview he was also at university, living in a

shared house with three other members of his course, and was in his second year of studying engineering. He was diagnosed at age 12, with ulcerative colitis, but was unconcerned about it in the early stages of his diagnosis. He was very popular at school and had a supportive network of friends to talk with. During the interview, Alan did not specify whether his anxieties of being overheard while on the toilet were confined to a symptomatic episode or if they prevailed in times when the disease was not active. Either way, both his and Paul's extracts demonstrate how the physical environment can be geographically self limited and subsequently reduced through the fear of losing bowel control and the fear of others' lack of understanding. The latter part of the extract makes this even more obvious, as he indicates that friends would have to visit him, literally confining him to the smaller living space of his own home rather than venturing to others.

Managing symptoms in the public environment also revealed examples of resilience when individuals described how they pushed themselves to the limits of their physical capacities (either in remission or relapse) at the expense of their physical well-being. Once more, Paul illustrates the point of physical exertion in a similar capacity, when remembering a school expedition:

*I got caught short when I was on Duke of Edinburgh and that was an horrendous day and I basically had to walk twenty miles with shit all over – you know that was all over my legs and that because I ... well I walked twenty miles and didn't tell anybody because I was trying to be a bit cunning about it. What I do is – you know obviously it happened and I couldn't do anything about it and because we were on a field which is wide open and so there's no bushes anywhere [...] it was a right mess and so basically I just like opened my rucksack, put on my longest coat so that nobody would be able to see if there was any stains coming through my trousers and then also got out some deodorant and just sprayed like deodorant and I was (inaudible) to conceal the potential smell  
(Paul, interview 7, 2003)*

Paul recalled the need to conceal this difficulty from a peer group that did not comprise wholly of close friends. His determination to continue without notifying anyone of his distress demonstrates the discrepancies between public presentation and private experience of managing IBD. The extract typifies Williams' (1996) argument of individual determination to maintain agency in events even though this may result in bodily rebellion, effectively a

“trade-off” between dealing with a chronic illness and maintaining a public life. However, when looking at Paul’s account in more detail there are additional factors that are clearly displayed, which are not present in existing research. The detail with which Paul describes the incident is striking, and his description of the physical environment emphasises the lack of control he has in the situation. He has lost control of his bowel, but this is further confounded by the hostility and glaring openness of the countryside where the expedition is taking place. He does not mention anyone else in the extract, and yet it is likely that there were others there. The account is related solely in terms of his own management of the situation and how he portrays himself. There is no speculation of what others may have thought, but he states that he was being “cunning “ in his handling of the situation, thereby implying the covert nature of the operation, and the ability to project an unaffected and undisturbed existence.

Participants also used routine activity to explain symptoms that prevailed before formal diagnosis of either Crohn’s disease or ulcerative colitis. When recalling their experiences, interviewees could clearly remember their environment at the time and how aspects of that environment were often used to account for their decline in health. The next participant to be discussed, Tracey provides an example of this with her story about the onset of initial symptoms:

*I went on scout camp, it was a big international camp [...] it didn't really register at the time but I suppose it must have been a bit out of control, I was just going to the toilet all the time [...] obviously we'd been eating food that was cooked ourselves [...] it's really difficult because we were sleeping in tents and the toilet facilities were sort of a way away. I just remember over the week feeling worse and worse but I didn't let anyone know and I was just so relieved to get home*

*(Tracey, interview 15, 2003)*

At the time of the interview, Tracey was in the middle of a nursing diploma, and was enjoying it very much. She was living in new student accommodation with one other person on the same course. Aged 20 she was diagnosed with ulcerative colitis when she was 15, but unlike Paul or Alan, had not had any surgery connected with it. At the time of the interview she was experiencing a relapse and had been absent from her training placement

for a few days. She had not been eating or sleeping regularly due to the shift patterns she was doing.

The negotiation of space was also a key element of Tracey's ability to get through the time at the camp. As with Paul's account of the school expedition, Tracey also introduced the element of control in relation to her frequent toilet visits. Although she acknowledges that it "didn't really register" at the time, she remembers her surroundings, and recalled assuming that the circumstances specific to the scout camp were in some way responsible for the onset of her symptoms. She was not in her usual home environment and therefore ascribed her experiences to the specific environment that she found herself in, such as the sleeping arrangements and cooking facilities. From the extract, she reveals that her decline in health was rapid, as she begins to feel worse. There are other ways in which this account links to the notions of public and private experience. Tracey creates privacy for herself by not telling everyone. Her account can be seen as one that documents her rapid decline in health as her symptoms worsen, but in addition to this it is also a negotiation of how she moved to a private space from living communally, by refraining from disclosing her discomfort. This highlights another angle from which to view physical space and the environment, as something more than the place in which someone happens to be in terms of the action or event that is being described.

These were some examples of how participants dealt with IBD flare-ups while in public situations or in the privacy of the home. Remembering the physical environment in these accounts emerges as a key factor in recalling specific events of dealing with IBD in the presence of others. However, these accounts do not specifically tell us what it felt like to be physically experiencing these changes. They have answered a question about the practical management of symptoms in public situations, but also lead to the question of what it is like to experience such a change in physical well-being. It is at this point where the analysis turns to accounts of the body, and how participants felt about and viewed their bodies in conjunction with IBD.

## 4.4 The body and IBD

### 4.4.1 Bodily ownership

Discussions of the body, physical changes and aspects of bodily control appeared widely in the data. Interviewees sometimes narrated episodes in which they treated their bodies as separate from their selves, in developing their understanding of the physical changes inherent to IBD. Examples included descriptions of bodies “not belonging” to the individual, and an awareness of the body not being a true reflection of the “self” (especially while taking medicines which altered bodily appearance). In the next example, Joanne used this turn of phrase. She had been diagnosed with ulcerative colitis while in sixth form studying for her ‘A’ levels. In addition to IBD, she had also had to deal with serious illness when she was younger, having been diagnosed with a spinal tumour aged 12. At the time of the interview she was recovering from spinal surgery relating to that complaint, although the tumour was completely clear. She had also suffered from depression for which she had been attending counselling sessions, and had started to keep a personal journal of thoughts and poems.

When discussing the investigative procedures that were performed to aid diagnosis of ulcerative colitis, Joanne, stated:

*My body has been invaded – I don’t feel as though it belongs to me: that’s part of my depression, I think.*

Although attributing this to depression, she reported a disassociation from her body at an early stage in her experience with IBD. Joanne also described how she felt about her body during symptomatic episodes:

*When I’m having a flare up I feel horrible about my body, I go into myself a lot and my depression is quite obvious. I don’t want to talk to anyone, I don’t want people to see me, yet I probably get through more make up than any other time (laughs). In a way it’s a disguise, it’s a bit of a mask. I think something that’s probably come about from the colitis – it’s only talking about it that’s made me think about it really – when I do meet new people I put on a front*

[I] Image wise or personality?

*Both.*

*(Joanne, interview 2, 2003)*

In this extract, Joanne illustrated one of the many diverse ways of coping by using her body as a tool, even though she felt betrayed by it. The make up is a mechanism through which to manage the negative feelings about her body, and it literally is a facial mask for Joanne as it hides her dissatisfaction other physical bodily difficulties. Despite the feelings of betrayal and discomfort brought on by IBD, Joanne still needs to enhance it with make up. Applying the make up does not force her to submit to the control her body could have on her, and instead allowed her to retain a particular image. The extract also links in with the notion of environmental space. As she describes her disinclination to speak to or see anyone, it is possible to imagine her retreating into the reduced living space discussed earlier, and staying within the “comfortable” environmental boundaries that she knows well.

Another element that is especially interesting in Joanne’s account is her realisation that talking about the experiences have made her think about this particular bodily concern in any depth. This is an illustration of the way in which active interviews can produce an account that does something for the participants, as well as saying something. Further examples of this function of the active interview will be discussed in more detail with relation to the data in the next chapter. Joanne’s account suggests that there are elements of control that are being dealt with. Here Joanne wants to maintain a balance between feeling horrible about her body and enhancing its appearance. However, there are other examples of control that are addressed differently, to the extent where they could be seen as defying the body

#### 4.4.2 *Defying the body*

There are several other themes that can also be drawn from this consideration of the body and IBD. Joanne’s brief extracts are a starting point for considering how the body itself is a crucial component to consider how young people learn to live with IBD. Accounts of bodily “defiance “ in spite of illness severity are present too. Here is Graham, speaking about his first holiday abroad with friends:

*I was reckless. When I went to Florida with two mates... my parents wanted me to sit by the pool for two weeks... well, I wasn't going to do that. I remember distinctly, I went water skiing, which*

*probably uses just about every muscle you've got. I felt a great amount of pride that my friend who was fit and muscley was knackered, and I was just high cos I'd just done something so physical. But I knew when I came back from holiday I would be ill. And sure enough I was ill and I lost my job, but at the time I wasn't prepared to go somewhere like that for two weeks and sit by the pool.*

*(Graham, pilot interview 4, 2003)*

Of all the participants in this part of the study, Graham had been the worst affected by Crohn's disease. He had been diagnosed at a very young age (11), and remembered experiencing related symptoms before then. At the time of the interview he was forging a career as a stand-up comedian, and often used Crohn's as a source for his sketch material. He had undergone several episodes of surgery and received essential nutrients through a TPN (total parenteral nutrition) line feed directly into his stomach, as a result of the surgery. Graham makes a comparison with his healthy friend, and as seen in Paul's account of the school expedition in the previous section, he projects an appearance of being unaffected by Crohn's. The difference here is that more attention is paid to his physical experience in the whole episode. This account reveals the extremities to which the body is pushed in this "trade-off" situation. Some individuals were prepared to go to considerable lengths to seize control over aspects of their lives, even if this is at the severe detriment of their physical well-being. Graham was taking as much control as he could; yet there were other instances where the body itself was a controlling force in negotiating daily activity. Paul remembered his initial feelings about his ileostomy operation when he was 14 years old:

*I was devastated, I couldn't even look at it when I first had it, I was so devastated, I was so depressed I just couldn't even speak. I couldn't even speak to explain myself, I couldn't even cry I was just so devastated by it.*

*(Paul, interview 7, 2003)*

What is particularly interesting about Paul's account is that while remembering the time that his physical appearance changed and he had to adjust to a new state of embodiment, as he could no longer defecate normally, he finds that he was unable to explain *himself*. The bodily change had affected him to such an extent that he did not feel in control of emotional parameters that accompanied the change. It is in scenarios like these where

the controlling body is best typified. Without surgery, severe cases of IBD can cause patients to experience sudden loss of bowel control at any time, and can present other complicated symptoms, which interfere with everyday living. A decision to undergo such radical surgery is usually borne from the wish to regain control over such symptoms, and to improve quality of life. This situation presents an interesting dichotomy, as the individual chooses to improve and retain control over daily activities with improved symptom management, yet simultaneously places his/herself in another situation where the body has ultimate control over defecation. Faeces are discharged into an ileostomy bag without the person controlling this action. Faecal discharge can occur at any time – while at home, shopping, even during sexual intercourse. The relationship between the self and the body becomes closer in the aspect of managing daily life, but control is lost in one essential aspect.

#### 4.4.3 “Is that really me?”

The relationship with the self and the body, and the levels of control that are implemented from either side, is a theme that can also be carried forward into another area of considering the body and IBD. Throughout the interviews participants spoke of seeing themselves in various media, and also reported how others had seen them and made comments on their changed physical appearance. As mentioned above, participants spoke of the bodily changes that occurred when they were taking medication. The most common was facial swelling as a result of steroid treatment, and Tracey had a clear recollection of how this change gradually crept up on her:

*The worse one was the big moon face. And you don't really notice it when its coming on so gradually but one time I was just walking out of the bathroom, and I just caught sight of my face in the mirror and even though I had been looking at my face every day I looked and it just didn't look like my profile. It was still my face but massively puffed up. It was strange. It still felt like my face and I said to my mum 'my face looks a bit funny doesn't it?' and she said 'well yes I've noticed that as well you know didn't think I'd say anything'. When I see photos of myself now I look like a hamster. My cheeks were just massive and that was probably the worst one.*

*(Tracey, Interview 15, 2004)*

To give some context to the timeframe in which the changes would be happening, steroids are usually prescribed over a period of several weeks.



They start at a high dosage, usually entailing about 8-10 tablets to be taken all at once in one day, and then reducing the tablet intake on a weekly basis. The way Tracey describes the change to her face in the matter of weeks implies a very gradual change, but she is suddenly alerted to the fact that she has physically changed, to the extent that she seeks confirmation from her mother about it. It is almost as if she does not recognise herself. The emphasis is very much on the physical changes, as she notes that her face still "felt" the same. Her mother is also reluctant to bring the matter to attention, but acknowledges it when she is asked. Retrospectively, when viewing photographs, the change is even more apparent to Tracey, and suggests the importance of viewing an image taken at that time when the physical changes were happening, constructing a sense of identity at that time.

In this instance, Tracey had been quite surprised by a gradual change to her face, and suddenly realised one day the extent to which she looked different. The next extract demonstrates an example of viewing an image through a different medium, but realising something more than just a physical change. This account is from Patrick, who was 22 at the time of the interview and diagnosed with ulcerative colitis when he was 17:

*Last year I was out at a club – a friend of mine plays in a band so we'd gone to see them. I'd been going out before but – not been up dancing, just standing by drinking. The band, they do this multi-media thing on stage, videos and projections and stuff. I remember one night watching them, and I caught sight of myself on the video screen behind the band. I was just sitting there, holding my stomach. It felt weird, like, like I realised that was who I'd become.*

*(Patrick, interview 5, 2003)*

At the time of the interview Patrick was in full time employment, but in the context of the above extract, he had been speaking about his social life in his first year at university. He had been diagnosed with colitis a year before starting his course, but was adamant that his social life would not suffer in the first year of making friends and establishing new interests while embarking on his new university experience. He described several incidents of going out with others, and not feeling physically able to, but was fearful of missing out on new experiences with new friends. The particular incident in the above

extract was just before he had to abandon his course, as IBD symptoms proved to be too disruptive for him and he had missed too many lectures and tutorials to sit his exams. Patrick partly blamed himself for this and acknowledged that had he not exhausted himself by going out so much while feeling ill, he would have been fit enough to continue the course. The extract itself is a recollection of how Patrick realises that his physical capabilities had been reduced through depleted energy levels, but it also sees it as a reflection of “who” he had become. The image on the screen that he catches sight of is unfamiliar to him; in the same way that Tracey was surprised at the reflection of her swollen cheeks. However, rather than confining his assessment to how his body is physically presented, his appraisal of how the image appears on the video screen is concerned with a view of his whole self. It is personally reflective, and while there are other people on the screen, Patrick is not concerned with how others see him, nor does he compare his situation with others.

The accounts in this section have so far focussed on participants' own reflections of their appearance and how this affected them. In contrast to this, Paul describes how others viewed him at a family party:

*Yeah, oh God – I went – I went to a New Years Eve party once with my mum and dad and at this party – we were invited by friends of our family and we went along and at this party were people I did know vaguely but we hadn't seen them for years and years and years. Anyway when my mum and dad and my brother and sister walked in the room and that was fine and then I walked in the room and people just stopped and just stared at me and just like they went quiet and then it started talking again as though – and anyway I heard later that basically people had been saying – were like just shocked about what I looked like and I've got some pictures here just to show you.*

[I] I can see the swelling in your face what age were you at this time?

*This was when I was – I think I was 15 and I mean you can see on my picture that my brother and my dad – I mean this was a couple of years ago now but my brother and my dad are a lot taller than me and my brother's only two years older than me and –*

[Paul's girlfriend]: They're built quite big aren't they?

*Yes I'm quite – I've always been you know reasonably thin and I just look like a completely different person.*

*(Paul, interview 7, 2003)*

The first paragraph from Paul reflects the kind of shock felt by others when they saw him walk into the room. The degree of surprise felt by those who have not seen him for a while is perfectly rendered in the detail that Paul applies to the account. In relation to his size and general physique he makes comparisons to his father and brother. The reason for this is because he was physically smaller than them as a result of continuous steroid treatment, which hinders standard physical developments and can make people appear much younger than they are. Paul's girlfriend interjects with the reminder that his father and brother have a large physique anyway, as if reminding Paul not to be so harsh in the criticism of his own body with respect to IBD, as he was always smaller than them anyway. The particularly important feature of this exchange is the inclusion of the photographs that Paul brought to the interview. Tracey and Patrick had previously described images of themselves and how they acknowledged the changes in their physical appearance, but Paul took the further step of bringing photographs to the interview, indicating the importance of conveying a visual, rather than just a verbal representation of how he looked at that time. In addition to these physical descriptions of bodily change, there is a highly emotive element held within them as the participants struggle to negotiate that they have changed dramatically in terms of how they present themselves, as well as how others see them. This leads to seeking examples of how the body specifically made participants consider the emotional conflicts simultaneously occurring at the time of the physical changes to their bodies.

#### 4.4.4 *The body and emotion*

Some accounts convey issues of bodily and emotional conflict and Graham again provided an example by reflecting on his experiences of medication after his diagnosis of Crohn's disease:

*Emotionally it was a roller coaster because I was very, very upset. Inherent to my personality is to make people laugh... I didn't want to look like I was depressed so I slapped on a happy face for quite a while, which particularly when I was on the steroids, was quite damaging because I was full of fluid from the steroids and my tear buckets were overloading, and yet I was trying to have a giggle and pretend everything was alright.*

*(Graham, pilot interview 4, 2003)*

In his account Graham realises that he needs to utilise personality traits as a way of exercising some control over the changes that his illness brings, but his body also rebels against him. The tearfulness he describes is also related to the course of medication he was taking at that time. The extract contains elements of feeling sufficiently distressed to cause the tears, and also that the tears are superfluous to his current emotional status as they were possibly a result of the steroids. The extract conveys a real and poignant struggle to manage the physical displays of the body going through illness related events, and whilst trying to mask them off with traits “inherent to” Graham’s personality. As Joanne spoke of applying a facial mask of make up to disguise how she was feeling about her body, Graham applies a different kind of mask here.

Re-introducing Joanne brings the analysis to a specific example of the complexity of the relationship between the body and emotions while managing the effects of IBD. As a disease IBD especially complicates this relationship, particularly as it has no known causes. This therefore creates more speculation of symptom aggravation. As no clinical causes are as yet officially attributed to either ulcerative colitis or Crohn’s disease, patients often identify personal causes. Anxiety was a causal factor mentioned in the interview data, and here Joanne recalls a clear example of the relationship she identifies between her body and her feelings:

*I find that when I do have a flare up it’s always related to stress, but it’s a bit of a vicious circle when I’m in remission. If I’m in a stressful situation it’s always like “ I gotta relax otherwise I’ll have a flare up” it’s always at the back of my mind.*

*(Joanne, interview 2, 2003)*

Joanne’s description of the “vicious circle” of stress and its possible impact on how long she remained in remission, illustrates a key point about the discrepancies between physical presence of IBD and the underlying concerns that can beleaguer everyday life in which symptoms may not be present. While IBD flare-ups are intermittent, the effort to try and relax is a constant concern for Joanne.

Indirectly, Joanne also identifies another resource that assists her management of colitis, which is concerned with the handling of information

related to IBD. In spite of the lack of clinical evidence to support a particular cause of IBD, interviewees narrated episodes wherein they cited certain events or emotions as having an impact on their illness. Knowing what causes disease is the most straightforward way of making sense of illness at any age. This is reliant on information sources of all kinds. The previous sections have cast more light on what it feels like to physically experience symptoms of IBD and how this impacts on daily life. However, this is also managed with the information that can be obtained through different sources. Earlier on, this chapter revealed how some participants were dissatisfied with the way information was conveyed to them at the point of diagnosis, but what other aspects of information handling can be found that are of relevance to young people with IBD? Additionally, how can these contribute to a wider understanding of what it is like to live with Crohn's or colitis?

#### **4.5 Information: seeking and conveying**

The discussion now moves from aspects of the body to how information sources are handled in conjunction with growing up with IBD. Information and communication were immensely important in adolescents' management of IBD. Participants produced accounts that revealed the mutual dependency of information and support on more everyday levels. The interview data revealed that there were three contexts within which information seeking was conducted. One originated from the disease as the main starting point, which would usually be at the point of diagnosis. The second was at the point of a disease related investigation/surgery, such as having a sigmoidoscopy in an outpatient clinic. This would usually provoke more information about the procedure in question, rather than seeking an overall view of IBD. The third and final context of seeking information would arise from an occurrence that was not necessarily disease related but something that could be situated in a more everyday context. The next participant, Olivia gave an example of this when describing a visit to her blood donor centre:

*Well I just sort of check about medication. I actually went to give blood the other day but I wasn't allowed to because of the medication I was on, because it could affect me being ill, so I've actually read up on things like that."*

*(Olivia, interview 1, 2003)*

Olivia was the first of the participants to be interviewed and was very excited at the time as she was embarking on a new career as a holiday rep. This meant spending several months' abroad training, and was a big step forward for her in terms of developing independence, as up until the point of the interview she had lived with her parents. She had been diagnosed with Crohn's disease, but had a difficult time, as there was some confusion as to whether she actually had colitis or Crohn's. She had left school at the end of her GCSEs and started 6<sup>th</sup> form college, but found that it was a big jump from one thing to another. After taking some time out, she re-enrolled on a travel and tourism course, which helped her decide on her chosen career route, and she was determined that IBD would not stand in her way. It could be argued that giving blood was not an everyday activity, yet it was certainly something that Olivia might have done routinely. Either way, there is an indication from Olivia's account that she was not expecting to be turned down as a donor, and it therefore prompted her to read more about the circumstances surrounding the centre's refusal to let her donate. The main point is that Olivia did not initially doubt that she could undertake blood donation because of IBD. It was not a consideration for her and only when she was advised that she could not continue was she prompted to seek further information about IBD and those additional circumstances upon which it might impact in her everyday life.

#### 4.5.1 *Concealing information*

Participants recalled how some of their family members tried to withhold information about aspects of the illness prior to, or at the period of diagnosis. While awaiting a confirmation that she had IBD, Tracey was aware that her mother was researching symptoms that she [Tracey] had told her about, but not passing the information on:

*My doctor said to my mum, y'know, sort of querying Crohn's, and my mum sort of knew what that meant but wouldn't really tell me anything [...] I didn't know how potentially serious it could be, so I said to her "Can you get me something off the Internet?" [...] she got this information for me, and I kept sort of asking for it and she kept saying, "ooh, it's at work" or "it's in my bag, I'll get it later".*

*(Tracey, interview 15, 2004)*

As her account continued, Tracey eventually conceded that she thought her mother did the right thing by protecting her from information that she may have found distressing. Equally, Tracey's observations of her mother's reluctance to show her any IBD related information show how interchangeable the terms "information" and "support" can be.

#### 4.5.2 Family members as information sources

Other participants cited family members as information sources in both general and specific levels. This especially occurred if there was an immediate family member who also had IBD. In the following extract, when asked how much she knew about IBD at the point of diagnosis, Olivia remembered the following:

*Yeah cos my nan and my granddad and my auntie have all had it, they've got it as well – my aunt had to have part of the bowel taken away, she's got a colostomy bag, my granddad actually turned into colonic cancer, um, my Nan, she had Crohn's disease and my great Nan had Crohn's disease as well, it's quite funny cos they say it's not hereditary but how – we've all sort of got it. My dad's fine though, he's OK, my brother's fine but it's just –my luck, so I do know quite a bit about it.*

*(Olivia , interview 1, 2003)*

Olivia's account is interesting, not merely because of the members of her family who are also affected, but the knowledge she displays. The information that she has acquired is clearly considerable, and in this particular extract she highlights the worst possible outcomes of ulcerative colitis – that of the disease turning into colorectal cancer – yet the concluding sentence asserts her knowledge of IBD, rather than speculating on the possible turns that her own disease could take. Further on in the interview Olivia remembered looking for other sources of information in printed form, and recalled reading "different things but can't remember what". Through describing the more conventional information sources that she turned to, Olivia reinforces the active role that her parents also had within the information gathering process:

*We were given leaflets and things from the hospital. I wonder if it was because I was quite young, my mum and dad were more on that sort of thing. I was just ill, but I knew what was happening to me. I don't go on the Internet or anything, but if there's something in a magazine I always read it 'cos it's getting a lot more common in there now, but no, I didn't really look at leaflets and things at the time.*

*(Olivia, interview 1 2003)*

This account contains another inference that is crucial to information seeking and dissemination behaviour patterns with IBD. Olivia does not surmise, but plainly asserts that “it’s getting a lot more common” to find IBD related articles in magazines. This raises a question of whether this makes it easier for young people to communicate aspects of their disease to others and how the accounts reveal how a person “becomes” someone with IBD.

## 4.6 Disclosing illness

### 4.6.1 Protecting others from disclosure

Accounts of withholding information from family members for fear of disrupting routine activity appeared in some of the participants’ accounts. Alan was told that he needed to make a decision about having an ileostomy while attending at an outpatient clinic. Aged 17, he saw the consultant alone, but did not reveal to his parents what was actually discussed for 2-3 weeks as they were going on holiday and he didn’t want to cause them anxiety:

*This was just before Christmas, a couple of days before and I went home and my mum was like, “well, how was it at the hospital?” And I was like “yes, fine”. And she went like “is there any new information or stuff”? And I was like “no, no, everything’s fine, they’re just going to stick on with the old stuff”. Because she was – her and my dad were going away on holiday on Boxing Day and if I’d gone to my mum “oh no, I’ve got to have an operation”, she’d be like “oh, I’m not going then”, not going on holiday [...] I was like hmm, I’ve got to – got to keep stum about this one because I knew she’d react and she’d try and cancel the holiday. So then like she (inaudible) “oh, we’re fine to go” and things like that, and things escalate don’t they? So I just thought best keep it under wraps, let Christmas pass.*

(Alan, interview 9, 2003)

Using reported speech and the temporal references to the Christmas season, Alan quite easily talks about the “stuff” of illness management. It is not clear whether the stuff in question means medication, exercise, or anything else which might contribute to Alan’s physical well-being, but he clearly had a big decision to make, not just in terms of his treatment options, but the disclosure of these to those around him. Alan’s narration was event specific, but incidents like these were also related more frequently on everyday levels. Many interviewees spoke of being teased or bullied because of the effect of steroid treatment. Here is Olivia recalling her experiences of



other's reactions to her changed bodily appearance that resulted from steroid treatment:

*"I actually got bullied at school [...] everyone else was sort of like not being nasty – well they were being nasty"*

*(Olivia, Interview 1, 2003)*

Perhaps protection does not befit its exact definition here, but certainly there are instances of excusing the actions of those who were bullies. It is interesting to note Olivia's reassessment of the bullies in that single sentence, initially downgrading the taunting to "not being nasty" to eventually conceding that their behaviour was ultimately not acceptable.

#### 4.6.2 Disclosure of diagnoses

Disclosure of IBD to others was a major concern that emerged within the interviews. In addition to revealing if one had IBD, there were other more detailed aspects that warranted decision-making on more specific levels, from generally speaking of IBD, to disclosing specific symptoms. The beginning of the illness experience was the most difficult period for most people, and the lack of sensitivity shown by others was not always helpful, as Alan demonstrated when he remembered his experiences of returning to school after a relapse:

*And then I actually went back and everyone was quite shocked and sort of like "gee, you're back" really. And asked me loads of questions and stuff. The headmaster or the head of the year or whatever came into one of my lessons and was like "oh, you all know Alan's been really ill recently. He may run off to the toilet at some time and you know, if you could – if this happens you know, accept it" or whatever. I'm just sitting there, like why are you saying this? I was just like –I just sat there, completely embarrassed.*

*(Alan, interview 9, 2003)*

Instances such as these were not uncommon, and usually reported as having occurred within a school environment. Many participants cited teachers' lack of understanding as the most difficult obstacle to maintaining a routine within school that facilitated the disease. Participants also noted this at later stages in their lives, as Paul explained an incident when he was at university:

*One lecturer stopped me and said in front of the entire full lecture theatre said, "where are you going"? I know and I turned*

*round and I said "I've got Crohn's disease and I desperately need the toilet" and I think he was incredibly embarrassed.*

*(Paul, interview 7, 2003)*

Here Paul felt compelled to make the disclosure himself, and his situation was not revealed by anyone else. While this was an embarrassing situation at the time, in the interview he continued to talk about how he later gave talks about IBD to fellow students at university. Others were happy to let knowledge of their condition disperse indirectly and relied on others to tell people. Another participant, Lawrence managed this by instructing his father to tell a close friend, then assuming (correctly) that the friend would pass the news on to other members of the peer group:

*One friend one day when he visited me in hospital... and my father had told him what was wrong with me and he just came to visit me. And he just passed the information on to everybody else, and from then on it was just a case of correcting like mistakes that remained in the understanding about the illness, because they see you all sort of like got a basic grasp of what was wrong with me.*

*(Lawrence, interview 4, 2003)*

In this extract it is particularly noticeable that Lawrence does not actually seem to directly inform anyone himself. His father tells a friend, who then passes the information on. His use of the words "correcting mistakes" implies that there was much speculation and lack of understanding about his situation before, and that the period of hospitalisation proved to be a good chance to set the record straight. Lawrence was fortunate to have such a network in place, as throughout his eight-year history with Crohn's disease he had many relapses and did not enjoy periods of long remission. Diagnosed when he was 16, his medication was also complicated by another diagnosis of epilepsy, and as a result he was unemployed at the time of the interview. He was close to his father, who had shared many of his disease related experiences (throughout his interview he used the pronoun "we" rather than "I" in referring to his actions, and it transpired that he was speaking about his father and himself). He had worked very hard at school and had passed his GCSEs and A levels, enabling him to accept a place at university. However, he abandoned the course a year later due to exhaustion, and was living alone at the time of the interview.

Like Lawrence, Tracey also found a way of disseminating information, this time through an understanding tutor:

*I mean some of them were very supportive and my tutor at the time actually, for all her faults [laughing] she was sort of quite good about it and I handed her you know one of those booklets from NACC and 20 questions on ulcerative colitis. And I'd got like you know loads of leaflets from the hospital and I gave her one and she put it up in the staff room [...] and I think that helped quite a lot and I had sort of a note to get out of lessons when I was feeling poorly.*

*(Tracey, interview 15, 2004)*

The way in which Tracey managed to convey information about her situation was efficient and worked for her. It meant that she was able to provide advice from a specialist IBD organisation and also that she did not have to tell other teachers, therefore minimising any difficulties that disclosing aspects of her illness may have presented. The above account reveals the tutor to be understanding on this matter, but Tracey mentions the person's "faults" and that they were "sort of" quite good about it. There is a slight implication that Tracey may have had previous doubts about her tutor's ability to deal with the onset of IBD. There are also aspects of the account that are unspecific. The mention of the note in the last sentence to excuse Tracey from lessons does not clarify whether this was authorised by the tutor or from another source, and indicates that there are several communication networks in place to manage the knowledge of colitis and its specific impact on Tracey's school life. Ultimately, the method of asking a tutor to place the information in a staff room allowed a quick and easy route to spreading knowledge about this particular issue.

#### 4.6.3 *Indirect disclosure*

Other participants were not so fortunate in having established ways of disclosing their illness, and sometimes found themselves in situations where and information relating to their illnesses was awkwardly prised from them. Such situations would usually arise from everyday activity. Tracey has described how staff at her school came to know of her situation, but now we have an example of how this was managed among a peer group. Alan

describes the difficulties of taking medication at school, and the awkward questions he had to field as a result:

*It probably would have come up somehow in the conversation, like I – I'd have got some pills on the bag or something, to take some pills, any they'd go like "oh, what are they for"? And I guess I'd say "oh, I've got this stomach condition, which I need to take these pills for". And normally that was it. If then – and they might sort of say "okay, what was wrong with you"? And then I had no problem with sort of saying "oh, I have ulcers on my large intestine". I didn't mind explaining that sort of thing, and stuff like that didn't bother me at all. Well, really sort of saying I'd been in hospital a few times and stuff. But I didn't like discussing the symptoms really. That's – like I was – normally people did but if they sort of kept on questioning saying "oh, what sort of symptoms have you got"? Then "were you vomiting", and then you have to go like "oh, not really, no, it was more to do with the other end", sort of try and brush over it a bit, you know, I didn't like to talk about that.*

*(Alan, interview 9, 2003)*

This conveys in detail the expectations of others about noticing something out of the ordinary (i.e. taking the medication), and the minutiae of issues that it raised for Alan. There are definite boundaries being drawn between what is feasible for him to discuss and what feels uncomfortable. More interestingly, there is a marked definition between visible and non-visible symptoms that determine the ease of conversation. Alan is happy to speak of ulcers on the intestine, which cannot be seen and may be difficult to visualise. However, anything that provides external physical evidence of illness, such as diarrhoea and vomiting, is handled less easily, to the extent where Alan actually denies having some symptoms in the last sentence. To a degree, Alan's account can also be considered in the light of the public environment too. The information that he is comfortable talking about is related to the hospital visits. These are easily generalised in the account to describing the visits, and relate specifically to the change in environment rather than the specifics of IBD experience. When pressed about symptoms, Alan is able to once more describe them in a general way without attributing them to a specific illness.

In Alan's case, all of these negotiations arose from a singular activity of removing tablets from a bag in school. However, disclosure within a medically related context or a different environment was not always straightforward and could result in negotiating an awkward chain of communicative difficulties. Olivia again provides an example when seeking emergency contraception:

*Not so long ago I wanted the morning after pill. Now I wasn't allowed to have that as they asked me if I'd had any medical problems – obviously I had to say yeah, and they said "I'm sorry, can't give it to you, got to go to the doctors".*

She continued to say that having visited her GP for this reason, she found that he was

*"... fine about it, he actually gave me a little card saying don't worry about it, just hand that over if you need one again".*

*(Olivia, interview 1, 2003)*

Olivia was referring to a visit to a local pharmacy. To give some background as to why this would have happened, the pharmacist hesitated to provide the emergency contraception pill because gastrointestinal disorders can deplete the contraceptive effects of orally taken hormones. Crohn's disease is actually named as a condition that contra-indicates the desired effects in the accompanying leaflet for the pill in question. This is because the contraceptive hormones need to be absorbed through the gut. During flare-ups of IBD, absorption of this nature is difficult due to excessive diarrhoea, and even in periods of remission there is no guarantee that the bowel will absorb the contraceptive properly. Any pharmacist would be reluctant to dispense such medicines if they were aware of a history of IBD, which is why Olivia was referred to her doctor. Looking specifically at the extracts, it is particularly noticeable how Olivia expected a standard exchange of information with the pharmacist, and the outcome was totally unexpected for her. It was an added complication to what may have already have been an anxious situation in events the led up to the realisation of the need for, and in trying to find out where to access emergency contraception. The combination of Olivia's medical history and the need for certain medicines required an extra level of communication and disclosure to achieve the desired result, which was resolved as the GP provided a type of card detailing all the circumstances, should Olivia have found herself in the same situation again.

#### *4.6.4 Non-verbal disclosure*

Olivia's recollection brings other aspects of information and communication to attention. The use of written material to convey information on a daily basis

was something that seemed integral to IBD patients, particularly if they had subscribed to an IBD support group. When discussing episodes of acute illness and symptom management, some participants mentioned having “the card”. Support groups often provide explanation cards, which can be shown to shop or public service staff, to facilitate access to toilets in situations when this may not otherwise be possible. Some recollections of conveying information in this way are detailed below:

*I remember being given a - I can't remember what it was called now. It was something like a "can't stop" card or something like that. And you just carried it and then whenever you needed to go to the - you'd just give them the card and it just says "sorry I can't explain what's happening but I've got to go to the loo"*

*(Ethan, interview 16, 2004)*

This is a recollection by Ethan, who had a 10-year history of ulcerative colitis, which was diagnosed when he was 12. He was in his final year of studying business administration at university, and lived at home with his parents. Further in the interview it emerged that faecal urgency was never a major symptom that he had to deal with, which in turn meant that he never recalled using the card. While these symptom related circumstances may singularly affect the way this communication mechanism is presented, it is still interesting to note *how* it is presented in this and other extracts. Ethan's account is probably the most detailed one that reveals the explanatory nature of the card. However, others often mentioned this feature without adding any other comments. In response to a question about explaining to others about managing faecal urgency, Lawrence immediately replied:

*Well we've already had the card, but we've never had to use it because I had - sort of an odd time that I haven't had the illness, we always make sure that if we do go out now, you know, sort of like public toilets close by and we have like - I think it's more a case of us never wanting to actually go and sort of like try to explain to somebody why I need to suddenly use a toilet. So it's more a case of like planning ahead to make sure you don't have to have any accidents while we're out and about.*

*(Lawrence, Interview 4, 2003)*

Discussion of presenting such a card brings this analysis full circle to public and private presentation of IBD, as it is a level of communication that indicates being a member of a club. Displaying a card that indicates that

someone must use a toilet urgently if needs be, does not necessarily disclose details of IBD, but it does disclose illness. This may be helpful to some but not others. As earlier sections in this chapter revealed, some people did not find support groups helpful, and felt there was too much emphasis on negative aspects of disease. This could be viewed in two ways. It could be argued that a disinclination to belong to a group was a restriction on activity, without getting support from an organisation that could provide communicative aids like the "can't stop" card. However, this could also be interpreted as living beyond the confines of disease as part of a wish to deflect attention from negative aspects of IBD.

So far the interview data has provided insights in response to the specific questions posed at the start of this chapter. The participants' interviews have revealed aspects of what it is like to deal with IBD at school; on holiday; how they told other people about it; how they felt about their bodies at the time; and other useful recollections that can help to answer the main research question of what it is like to live with IBD. However, they also reveal other aspects of living with Crohn's and colitis that provoke further questions. In most of the sections in which data has been presented so far, there have been examples of participants remembering how they tried to convey that their existence was not blighted by IBD. There were examples of dealing with IBD in relation to other people, and other extracts in which illness aspects were dealt with entirely on individuals' own terms. While the data extracts have so far shed light on various aspects of IBD, they collectively pose further questions. What exactly does living within or beyond the confines of IBD mean? And how do other people and the rest of the environment contribute to interpreting living within or beyond illness?

#### **4.7 Living within and beyond illness**

In the discussion and analysis so far, the accounts are ones of restriction in terms of physical space and bodily limitations, information available and disclosing illness. Equally in the same contexts, there are also accounts of empowerment, especially those that are concerned with defying the body's physical limitations in some way. However, the notions of restriction and liberation/empowerment are interchangeable within these accounts,

depending on the analytical position that is being taken within them. This made it difficult to pin down whether a person was managing to live within or beyond the confines of IBD. Instead of a straightforward definition that living *within* the confines of IBD would involve finding negative experiences in the participants' accounts, and that living *beyond* the confines would be exemplified by positive accounts, the relationship between the two notions was not distinct at all. Instead, the interviewees represented their experiences in a variety of ways, not just singling out negative and positive experience. For example, when describing planning for her first holiday with school friends in her sixth form college, Olivia offers much scope for ascribing definition to living *beyond* the confines of IBD.

*When I'm on holiday as well, most people are excited thinking "have I packed everything?", I'm thinking like "God, I hope I don't get ill".*

*(Olivia, interview 1, 2003)*

Looking at the quote on its own, there is a shift from the general to the particular. To describe her management of the routine occurrence of preparing for a holiday, Olivia compares her thoughts against those of "most people". Throughout the course of narrating her experience, it became evident that Olivia did not abstain from accompanying friends on holiday, or from any other social activities she regularly participated in. However, her account of such experiences indicates that her colitis was a residual concern no matter how much it was concealed from those around her.

Participants revealed circumstances of being socially and bodily restricted by their illness, but continually conveyed a non-disrupted existence to their peers, therefore *appearing* to live *beyond* the confines of illness but actually staying *within* them. The next example shows the within/beyond negotiation in relation to other people as well as the interviewee. Here, Paul tells a story of daily routine, and how he adapted this to facilitate his roommate's typical morning preparation for attending university:

*I didn't really let it affect him at all because basically we had lectures – if we had lectures at 9 o'clock I knew that he'd probably want to get in to the shower around 8 o'clock or just before 8 o'clock, and so I would get up at say 6 o'clock or 7 o'clock because I had to spend a bit longer in the bathroom, and I'd make sure that I ate something as soon as I got up or just had a drink of something that would stimulate to make me go to*



*the toilet, and then I'd got all my shower and my toilet – going to the toilet out of the way before he even got up.*

*(Paul, interview 7, 2003)*

In addition to introducing other people directly into the accounts and describing living in relation to them, Paul's account also introduces time as a resource, which is an integral component in appearing to live beyond illness. To maintain this appearance, Paul had to adjust his own temporal management of preparing for a day at university, to minimise inconvenience for his roommate. In addition to limiting his roommate's exposure to IBD related incidents, Paul also tried to minimise potential inconvenience for himself through these strategies as a way of self-management and self-reassurance. Based on these two examples, it became clear that the characterisation of "within" and "beyond" could be extended much further than looking for aspects of negative and positive experience. Paul's extract adds another perspective on how to explain living beyond the confines of IBD. His story allows for consideration of how restrictive activity (within) or progressive activity (beyond) is situated within the management of IBD on a day-to-day basis.

When asking the question of what it is to live within or beyond illness, the examples that have so far been raised in this section of the chapter have involved participants' consideration of other people. Olivia generalises her account to speculating on what other people are usually thinking about in preparation of a holiday, and Paul is considering a specific routine with relation to a specific person (his room-mate). However, there are other accounts in which participants recall dealing with a situation without reference to anybody else. The way in which participants relate to the world at different levels and across different contexts is not shown in the analysis of the interview data as examined so far. Therefore, to return to the original research question of what it is like to live with IBD as a young person, it is useful to ask how considering the positions that young people take in the world with relation to their illness can extend our knowledge of how they live with IBD.

## 4.8 Conclusion

So far the analysis of the interview data has been conducted in the contexts of public and private experience, the body, information sources and disclosing illness. This followed an initial summary of looking across the data, which demonstrated that it was useful to look at individual accounts in more detail. It has also led to exploring the demands of living within and/or beyond illness. Already there are snippets of everyday activity that are coming into focus and the interview data has revealed a great deal. However, there are questions at this point of the analysis that remain unanswered. How did participants position themselves in relation to the rest of the world and their illness? Already there has been an account in which some events were re-examined by the interviewee, as Olivia remembered incidents of bullying and considered the aggressors' behaviour. To what extent does the IBD feature in individual lives? Although the interviews have already extended knowledge of what it is like to live with IBD as a young person in different contexts, they are all accounts that are closely related to the disease in some way. There is also the problem that some participants remembered excessively negative aspects of their experience of IBD as they recalled peak-end events in their illness. This provokes the question of how the periods of remission are experienced, as well as the periods of relapse, and the need remains to examine this interview data in more detail to answer these questions.

As they were active, the interviews themselves facilitated other considerations that had not been addressed in previous studies, or even by the participants themselves. When thinking about how she felt about her body, Joanne stated how talking about the issue in the interview had only just made her think about it at that time. This raises a question of how such action can be explored as a resource itself, in addition to what the participants said. By looking at how participants have positioned themselves with relation to illness and the rest of the world around them, more can be said about how the interview itself works to extend knowledge of young people's experience of IBD. The next chapter examines these, and the other unanswered questions through a more detailed analysis of a subset of interviews.

## Chapter Five

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**Plots and positions:  
the active interview at work**

## 5.1 Introduction

So far this thesis has made several developments in terms of finding out what it is like to live with IBD as a young person. In Chapter Four the initial outcomes of the interviews with the adult participants revealed some of the circumstances that the participants recalled managing in conjunction with colitis and Crohn's disease. These circumstances included public and private experiences of IBD; recollections of bodily change; how information about IBD was obtained at various points of IBD experience; and how aspects of illness disclosure were managed between friends and family. Participants recalled events within a variety of social contexts, such as in school, on holiday, at home, with friends, colleagues and medical professionals. At this point we begin to gain a greater idea of how IBD was placed within the participants' lives.

There were some other points that were raised from the extracts in the previous chapter that warrant further analysis. The data extracts are extremely enlightening in terms of what they say. Some of the content is closely aligned to the existing concerns in the literature. However, there are other parts of the participants accounts that *do* something as well as say something. The accounts are "active" since they were part of an active interview (Ch. 3, section 3.2), and this current chapter concentrates on the active elements of what the participants were doing when they produced their accounts. How do participants position themselves in relation to the rest of the world and their illness? How much does IBD feature in their lives? In addition to what they say about their experience with IBD, how do they tell it? To try and answer these questions, this chapter moves on to examining participants' accounts in more detail. This was achieved by analysing the interview transcript as a whole document, rather than looking across several transcripts to extract specific incidents (as in the previous chapter).

In conceptual terms, this chapter also emphasises the interviewees' status as active participants on constructing their accounts, rather than simply being patients participating in research and responding to questions. As the principles of the active interviews demonstrate (see Ch. 3), the interviewee is not merely a repository for information that can only be uncovered upon being

asked by an interviewer. Instead of being “people with IBD” who are defined by symptoms and scores on IBD rating scales, the participants were given opportunities to actively advance the issues that were discussed in their interviews. The overall context of the interviews in this study differed from previous protocol-driven qualitative studies in IBD and adolescence (Decker, 2000; Brydolf & Segesten, 1996b), in that the specific wish was to deflect focus from the disease and concentrate on other aspects inherent to everyday life. This encouraged participants to think differently about their illness experience, and re-position it in contexts that they would not usually reflect upon. Instead of selecting isolated accounts from a whole interview to illustrate the themes brought forward from Chapter Four, it is more productive to analyse an individual interview across stages to be able to fully investigate the participatory nature of the interview. This enables the emergent qualities of the interview to be seen more clearly, and can answer questions about adolescent life with IBD on different levels. Therefore the analytic phase in this chapter does not look laterally at all of the interviews in an attempt to find thematically common ground within them. Instead it uses specific interviews to examine resources that have arisen in the literature and that have begun to emerge in analysis within the previous chapter. There are two aspects that this chapter addresses with reference to answering the questions posed at the beginning. These are how participants position themselves and how they tell their story.

## **5.2 Participating by positioning**

The first examples of the active interview “at work” look specifically at how an individual positions his/herself with relation to IBD. To begin, we return to Alan, who featured in the previous chapter. To recap, Alan’s particular circumstances, he was in his second year of higher education at the time of interview. He had a lengthy history of ulcerative colitis, and had a permanent ileostomy appliance following complete colectomy. When asked how he thought his life had changed since he was diagnosed with ulcerative colitis, his immediate response was:

*"I don't know actually, I've never really thought about it, these things. I'll probably think about it after you leave"*

After a brief pause he added:

*Actually I remember I was treated as almost like a – like a hero when I got back to school. They were all like "Oh! Alan's back, oh!" That sort of thing. I don't know, I guess I was sort of – a big change when I got back to school, it was almost like this huge popularity and sort of like oh, and sort of everyone asking questions and sort of how I'd got back to school and stuff like that. Apart from that I remember a big – like a big deal the first night I stayed in hospital. I remember that was quite a big shock to the system. Sort of when my parents went home and I was just sort of sat there in this ward; and yes, that was a very lonely time; just sort of sat there and I had this young lad next to me – I remember; I had this young lad next to me who'd had quite a few sort of scars and stuff. He had like appendix out and all this. He said ah, look at this, look at this. And I was just sort of like hmmm! Didn't like that. And sort of – and I remember I started crying and phoned home and my poor parents kind of had to shoot back out and my mum came back at sort of whatever time of night it was.*

*(Alan, interview 9, 2003)*

Instead of this account being a direct product of a question about hospital experience and one which is limited to disease related concerns, Alan packs several social contexts that occur across differing lengths of time within this account. The first change he remembers is a positive one about his reception on returning to school. His account moves from a general consideration to a particular one about staying in hospital. In this one account, issues of friendship, hospital experiences, peer interaction, body matters, and familial support are all present, ultimately concluding with a brief reflexive sentence of the effects of the experience, for him and his family.

The important part of this extract is the first sentence, in which Alan declares that he had "never really thought about it". It is easy to disregard such comments, yet this case demonstrates how the interview itself has encouraged Alan to consider an aspect of his life in connection with IBD. This does not imply that he had deliberately ignored such considerations before, but exemplifies the essence of this project, which is to access the small aspects of individuals' lives that would not otherwise be articulated. The ways in which Alan positions his self in this account can help to answer how the various types of support play determining roles in adjustment. At the start of this account, Alan is the subject of a big popularity shift. This is a positive

thing for him. But the way Alan mentions others people in his account is especially striking. By describing his hero-like status, he is recalling how his classmates and friends have positioned him, rather than asserting that he himself was a returning hero. Rather than positioning himself, he remembers how his peers had positioned him. It is not until the description of the negative hospital experience that Alan fully and deliberately positions himself within that particular environment. He reverses the situation in terms of being positioned by others, by articulating his own stance in what for him is a strange and upsetting environment. In the extract he is reluctant to identify with the other patient on the ward showing him scars, and IBD does not need to be a major player in this account to enable Alan to assume such a position. He is very aware of his preferences with regard to communicating with others at that point and is reluctant to place himself in the same sphere of infirmity.

While mentioning other people in his account, Alan manages to convey how others have positioned him, and how he had positioned himself with relation to the environment around him. The previous chapter raised the question of how participants positioned themselves in their accounts particularly in the considerations of the public and private environment in conjunction with IBD. For the purpose of highlighting a contrast to Alan's accounts, it is useful to return to the extract from Paul in Chapter 4, in which he described an incident where he had soiled himself while on a Duke of Edinburgh expedition. The absence of anyone else being present in his account was quite conspicuous. He showed awareness of the environment around him, but his account revealed no positioning of, or relation to other people. Paul's position on this particular incident is purely from his own perspective and he does not attempt to speculate on how his actions may have seemed to others.

Other examples follow included aspects of both being aware of others' positioning of the participant, whilst simultaneously containing the private experience of managing a difficult symptomatic episode. The next example is from Rosanne:

*I do remember like sometimes when I was in college like before I was diagnosed towards the end and I was feeling really, really ill and my friends would want to go out to the shop just up the road for a bar of chocolate or something like that, and I*

*wouldn't be able to go with them because I couldn't actually walk that far. When it gets really bad it does get to the point where I find it hard to actually even walk to the post box or something like to walk a hundred metres and its like so painful and it just leaves me feeling really dizzy. Just things like that. Really little things like not actually being able to walk somewhere [laughs] that's only when its really bad though. It's only really got that bad like sort of last year. I was quite ill and like I wanted to go somewhere and I started walking down [name of street] towards the city centre and got into the city centre and I just got there and burst into tears and had to get in a taxi just to bring me back up the hill again. But that is pretty much only when its really, really bad its like that.*

*(Rosanne, interview 1, 2003)*

Rosanne was in her final year of a fine art degree at university, and had been diagnosed with ulcerative colitis aged 17, when in sixth form. Rosanne's account moves from general recollections of her friends taking for granted that she can accompany them to the local shop to a more specific consideration of her own physical abilities. They have positioned her as someone capable of undertaking some the basic activities that comprise their lives. When Rosanne moves from this general recollection to a more specific incident, she only recalls her own actions. Even the taxi is objectified with no mention of a driver in what appears to have been a distressing situation for her, in terms of her physical discomfort and also in terms of her frustration at not being able to complete her journey.

There are theories on positioning within narrative accounts are illuminated here and can support this data. At this point it is appropriate to introduce these theories relevance to the participants' accounts as they begin to reveal some of the ways in which participants position themselves with relation to their experiences of IBD. Harrè and van Langenhove (2002) provide a comprehensive theory on the varieties of positioning, and suggest the need to redress the concept of "role" in identity. The authors define the concept of positioning as a dynamic alternative to a more static concept of role. This goes further than Brydolf and Segesten (1996a) and their model of emerging roles of adolescents with IBD. The analytic stance of positioning allows for role identification to extend beyond a finite interpretation, and allows for greater flexibility in seeking the resources deployed by people in their accounts. The authors repeat the assertion that positioning is something that



is inherent and constant in human life. Not only does this theory support the identification of initial positions within data, but also encourages the reflective possibilities of the active interview.

In addition to the theoretical arguments of Harrè and Van Langenhove, Bamberg (2004) suggests two theoretical possibilities. Describing them as two opposing forces, they are simplified as person-to-world and world-to-person directions in narrative accounts. Bamberg's stance is very flexible, acknowledging that they can be interchangeable, and surmising that they are based on the assumption that they are *co-constructed* on an interactional basis. This perspective is also aligned with the principles of the active interview, and the interchange-ability that Bamberg speaks of is seen in Alan's account of returning to school (world-to-person) and being in hospital (person-to-world). These directions of positioning are useful to apply to the data here and in subsequent analysis, to see how participants recalled their experiences of IBD in their daily lives, and how much it impacted upon non-disease related events.

Returning once more to Alan's interview, his accounts continued to present evidence of other positions that he took, both retrospectively at the time of his experiences and at the time of giving the account. Here he introduces another theme into his reasoning:

*Yes. It's been quite – I think – in a way I think it affected my parents a lot more than I realised at the time and almost a lot more than it affected me. Sort of being young you're sort of quite adaptable. Apart from instances like that when I was quite upset, you sort of take it in your stride a lot more. Whereas now I'm older I kind of realise that if this happened then I'd be, you know, really upset about it.*

*(Alan, interview 9, 2003)*

Some accounts could easily be labelled as negative – or regressive if they were analysed by strictly adhering to the definitions of progressive narratives according to some theories (Kelly, 1991; Gergen & Gergen, 1986). However, these definitions are often displaced in terms of the positioning deployed throughout the interviews. Once again Alan provided several examples. In connection with age, he has already revealed his position of being an "adaptable" young person in terms of adjustment to his disease, and situates this in a general assertion that younger patients are generally more

accomplished at this than adults. Overall, the adaptability that he refers to is positioned in terms of a desire to lead as ordinary a life as possible – to live beyond the confines of the disease:

*I remember there was one school disco yes, there weren't that many social events no, I had sort of friends over the weekend and stuff. I had a couple of girlfriends during secondary school as well, so pretty normal I think really. I was a little bit unhappy at always having a podgy face from the steroids but apart from that I was a fairly normal human – a normal kid.*

*(Alan, interview 9, 2003)*

Accounts of “living a normal life” were used in various contexts, and these were not always in response to direct questions on how such degrees of normality were achieved. In the above extract, while discussing his hobbies and interests outside of school, Alan displays normality in his life despite acknowledging side effects from his medication. The same is also true of his account of change after diagnosis, which not only varies thematically, but differs in the temporal ranges that are recalled. His interpretations of changes in his life differ depending on the various times and places they inhabit. Now that the focus has shifted on to the action of the narrative, it is possible to examine this throughout the duration of the interview. Once again, Alan offers another example, this time while considering the prospect of meeting other adolescents with IBD:

*No, I remember there was a – they set up a thing at the treatment centre where you could – it's – well, I was – I was sort of a child so they used to have a group for kids with IBD with but I never really fancied going to that really. I never really sort of fancied going and talking to other people that had it. The consultant was really pushing to see – talk to this lad. And eventually I gave in and said all right, I will do. And it turned out that he didn't want to do it either*

*(Alan, interview 9, 2003)*

However, further on in the interview, Alan had reached a later stage in his story. He remembered when he was preparing to undergo surgery several years later:

*I got the nurse to phone up this lad who was going in for the surgery in a couple of days and asked him to talk to me, I thought it would be interesting to chat to someone my age, similar sort of position to see how he found it.*

*(Alan, interview 9, 2003)*

Although there was a large time gap between the two points of reasoning (about five years), the interactional nature of the interview allows this to

emerge without seeming like a contradiction. Alan was not comfortable with being introduced to another young person with IBD, but as time progressed and he had become adjusted to having colitis, he was willing to speak to another person about having ileostomy surgery. This emphasises the effect of temporal distance on the variety of positions that are claimed within individual accounts. Not only do individual positions change within accounts, but they also change over reported time. Therefore, it is reasonable to ask if there are any other features of narrative action within the participants' accounts that can assist these changing directions and positions, in terms of how a person tells their story. In other words, how is IBD retrospectively plotted into their lives within their individual accounts?

### 5.3 A participant's plot

As Alan's account demonstrated examples of positioning, Tracey's interview (as with many others) tells a complex story that is not wholly concerned with IBD. Tracey has already featured in the previous chapter. Diagnosed at age 15 with ulcerative colitis, she had had five years experience of the illness at the time of the interview. Beginning with the period prior to symptom onset (not actual diagnosis), Tracey details a great variety of activities and interests that regularly occupied her time. Throughout the interview, she sets the scene of life before IBD as follows:

*I suppose school was you know a big part really. I had just sat exams I was 14, I was in the scouts and my best friend at the time was her dad was really involved with scouts and she was like the first girl to join the Boy Scout movement. And after a while she sort of pulled me into that and that was like sort of quite a big part you know we used on the camping trips with them and stuff and it was quite fun because we were you know sort of tomboys and we'd be the only two girls on a lot of the trips. It was it was good fun [laughing]. Horse riding was a big part of my life then. I mean I've only quite recently stopped that. I used to go as many times a week as I could. It was a lady who had several horses so I used to go and ride and look after them.*

[I] And who did you actually live with? I assume you were at home with your parents?

*Yeah that's right. Yeah my mum and my dad and my brother.*

[I] Okay so there were four of you. And how did you get along with your family?

*Good yes quite well. I mean I'm very close to my mum because my dad can be quite a difficult person to get along with I think. I*

*suppose at that time he probably would have still been at work, he's retired now. So that's mellowed him quite a lot I think. And my brother I mean we get on very well now but in fact probably then we got on pretty well. He is two years older than I am.*

[I] Okay and obviously you've mentioned the horse riding and scout movement was there anything else that you did for entertainment at all?

*I used to play the flute and the baroque recorder in like a little music concert. I think I stopped that when I was about [Laughs] It was like a baroque music group and we used to play like wooden recorders and there was a viol group as well.*

*(Tracey, interview 15, 2004)*

Here is a non-disease related exchange detailing of a series of activities in which Tracey was engaged. She conveys an energetic social life that is unimpaired by symptoms and asserts a pioneering identity by being associated with the first female member to join a traditionally male movement. It is a detailed account, listing various activities of significance to her, which assist her to chart her transition from health to illness. It is evident that Tracey provides a rich tapestry of events and associations. The focus is not directed at the disease, but her account is in response to a question about what she was doing and what life was generally like prior to diagnosis. She revealed that she did horse riding until recently with no indication of why this was stopped. While it could easily be assumed that IBD was in some way responsible for this curtailment, there is no direct assertion in the data to support this. What is clear is the presentation of several events, activities and summary of family relationships, which are all parts of her plot in telling of events leading up to her experience of IBD.

The next stage of the interview asked to describe events that led up to her diagnosis. The following is her account of recognition that things were not right:

*Well I think the first time I can ever remember sort of not being very well and thinking for the first time maybe something wasn't quite right was when I, I was confirmed when I was about 14, we're Roman Catholic and I think it was the morning after that. I mean we'd had sort of like a little party the night before, you know and had loads of family round and things and I had diarrhoea the next morning and I felt, I really didn't feel very well then. So I mean you know you just, you don't think anything of it do you? So I think that went on for probably a few weeks and I can't remember if it was then or after I had been much more poorly in the summer, that was in the February when I was 14. I think I might have been to the doctors then and she said sort of you know it'll take a while before you get back to normal kind of thing and*

*then when I was 14 in the summer, in the summer before I was 15 I went on a scout camp to, it was in, it was called Sherwood '98 it was a big international camp.*

*(Tracey, interview 15, 2004)*

The shift in the account is very obvious. From describing general activities and not ascribing any sequential spacing to them (apart from ceasing the horse riding) in the previous extract, Tracey's focus becomes very specific, and the scene of symptom onset becomes more detailed. A particular event (the confirmation) is identified as a marker, also offering disclosure of religious background. However, there are uncertainties revealed in the narrative, which culminate in a failure to be precise about subsequent events relating to symptom onset. GP visits are not recalled with clarity, there is some doubt on the season, which was cited as a time when Tracey was "much more poorly". However, the distant memories of illness episodes are brought sharply back into focus when she refers again to her scouting activity and finishes by identifying a specific event again.

In the early days of symptomatic episodes, the events are central to Tracey's plot, and become inter-related with subsequent disease and non-disease related discussion. As her account continues, she moves onto ways of learning to live with colitis, and at this stage seeming to live within as opposed to beyond its confines. After discussing the scout camp and other family holidays, Tracey continues to chart the progression of symptomatic episodes:

*We used to go on like massive family holidays with about 16 or 20 of us and I remember sort of having to dash to the toilet and things there but I mean this had been going on for like a few months now so it don't, you know it didn't even kind of register anymore but then, yes I suppose I must have - it really didn't register at the time but even then I suppose it must have been a bit out of control and then when I went on this scout camp I got quite poorly and I mean I was just going to toilet all the time. I mean you didn't, you don't want to tell anyone [...] I just remember over the week just feeling worse and worse and it wasn't just that my stomach felt really bad, I was starting to feel sick and dizzy. By the end of the week I was just, you know so relieved to get home and have a bath and everything and I knew then something really wrong because I'd started bleeding as well.*

[I] Bleeding rectally?

*Yes. When I went to the toilet and I wasn't even able to have a bath without getting up and going to the toilet*

*(Tracey, interview 15, 2004)*

This extract reveals the extent of illness severity, but there is another narrative shift occurring here. From speaking of specific events and hobbies that are not characterised by every day activity, Tracey moves towards speaking of mundane activities that may not otherwise be present in a clinical discussion – the everyday activities that investigation into illness can ignore. As her symptoms escalate and additional ones appear, the extent of disruption to her daily activity results in her not even being able to bathe without needing to defecate. Her organisation of remembering symptom onset moves from extraordinary events to everyday ones. However, what is additionally striking about this extract is her revelation of learning to live with it from a personal adjustment level. She describes the effect of the symptoms as not really “registering at the time”, and concedes that it must have “been a bit out of control”. Her symptomatic episodes had been occurring for “a few months” and they “didn’t even register any more”. This implied acceptance of the symptoms as normal life is remarkable, given the high level of physical disruption to daily activity that Tracey encountered at this stage, but initial symptoms of IBD are often likened to less severe, acute illnesses. Yet at this stage in her narrative, Tracey still had no diagnosis of IBD. The symptoms themselves were enough for her to construct a plot in her account without a named condition.

So far in this study, uncertainty has appeared at various stages. It is also emplotted here in Tracey’s narration and surrounds the diagnosis itself. As mentioned in earlier chapters, determining the differences between Crohn’s disease and ulcerative colitis can be problematic, and occasionally can lead to a diagnosis of indeterminate colitis. Tracey now provides her account of events leading up to this point:

*Then the doctor said, this isn't normal you need to be referred sort of straight away and she did get me an appointment very quickly with the gastroenterologist at the time. It was in the adult department actually because she asked me if I wanted to go to children's or adults. I mean I didn't know that it would be a long*

*term thing at the time because she said to my mum you know sort of querying Crohn's and my mum sort of knew what that meant but wouldn't really tell me anything about it.*

[I] That was my next question actually. Did you know anything about inflammatory bowel disease before you were diagnosed or at the time?

*Absolutely nothing really. I mean its not very common even if people do have it they don't talk about it and I think it, yeah it must have been the doctor who said to my mother that time possibly Crohn's and my mum must have been you know absolutely horrified because a friend of hers, her mother had Crohn's, I mean she's dead now but she'd had it sort of really badly and had had sort of multiple surgery and things and she was being, my mum was being so cagey about it and wouldn't really explain it to me at all.*

*(Tracey, interview 15, 2004)*

At this stage, nothing was conclusive for Tracey, as all she had was a GP and a gastroenterologist's suspicions of the presence of Crohn's disease. Yet again, she provides an informative plot that meshes all the uncertainties together. She was in a transitional period that operates on more than one level. In addition to the transition from health to illness and from the unaccounted-for symptoms to receiving a diagnosis, she is also given the choice between attending an adult or paediatric clinic. The inference in her reasoning is very appealing in terms of identity development and expectations of care. She did not anticipate that the illness would be chronic and therefore selected an adult treatment centre. There is room to question whether the reason behind selecting an adult clinic reflected an assertion of independence in managing those symptoms that had become such a part of her life. However, any notion of this is removed in the next section of the interview when she responds to a question about knowledge of IBD. Her mother assumes the role of information gatherer and is very secretive about her discoveries. Yet despite not receiving information from her mother, Tracey is fully aware of the source of uncertainty and anxiety in relation to Crohn's - a friend of her mother's who had died. While there is no indication that this person actually died as a result of IBD, the woman in question is a crucial character in this plot, which is constructed to make sense of this uncertain period of not knowing the diagnosis. The reference to Crohn's is not as a result of a confirmed diagnosis, as at this stage it was only suspected. Aside

from the obvious relief she felt at finally receiving a diagnosis, Tracey describes the comparison between the two IBD conditions:

*I suppose it felt strange really because you'd sort of reconciled yourself to one thing and you know then someone else says another but I mean I'd read through you know the information, to me at the time it seemed like the same kind of thing anyway but when I said, I said it to a friend or something she was asking and I said oh you know the doctor said I might have Crohn's and she'd asked a nurse who she knew about it and they had said to her 'oh you know it's a really horrible disease' and then when I said actually it's ulcerative colitis she said 'oh you know they know nothing about that'.*

*(Tracey, interview 15, 2004)*

A complex network of communication is at work here, all serving in some way to construct ulcerative colitis as somehow less severe than Crohn's. Tracey's choice of the word "reconciled" is indicative of her acceptance to a very unpleasant illness, yet this is somehow lifted in her own assessment of both conditions, as she thought that they "seemed the same kind of thing". It is others' assertions of Crohn's that imply its severity, and these are intrinsic to Tracey's own assessment of her illness.

IBD flare-ups occurred more frequently for Tracey, and in the time afforded by an interview it would not have been possible for her to chart every one of them. However, what Tracey does not say is very obvious in instances throughout her account. Having moved on from the diagnosis to managing aspects of adolescent life, the interview turned to the issue of dating and forming sexual relationships. In response to being asked whether she had a partner at the time of her diagnosis and shortly thereafter, Tracey replied:

*No. I mean when I was sort of in the scouts as I say that was the time when the whole boy/girl thing starts to take off and you know there was a guy that I really liked but after I'd been ill for sort of a while and there'd been you know sort of quite often I didn't used to go to the meeting on a, I can't remember what evening I think it was a Friday evening you know it was like kind of a social event when I was I don't know 14 or whatever you know and I hadn't been for a while and when I went back I was so kind of, I don't know if it was that I had changed and no-one else had, or that everyone else had changed and I hadn't, but when I went back everyone just seemed so different to how I knew them and it was only like a couple of months later that I hadn't seen them that regularly and I couldn't really feel that I could fit back in again.*

[I] In what way were they different? Can you just explain that a little bit?

*Yes. I suppose peoples relationships change with each other and you know how it is when you're teenagers you know you're going*



*out with someone for two days and then its personal. All that had changed and new people had come in and there was different sort of relationships within like the group as in sort of other people had taken over as leaders. The whole kind of shift that happened really.*  
(Tracey, interview 15, 2004)

The first striking feature is the absence of disease. Although Tracey states that she had been ill for a while, there is no evidence in the extract to suggest that IBD was in some way accountable for the dramatic shift in behaviour she has observed in her peers. Her observations are made at a general level rather than with direct reference to colitis. The way that this account of peer group change emerges from an enquiry about a potential boyfriend is especially conspicuous. A boy is mentioned in the first two lines, but then no information is presented about him, or if the relationship progressed or failed. The larger umbrella of the group's behavioural change is in some way attempting to answer this question, but instead gives a very broad, unspecific phenomenon that Tracey herself finds hard to articulate. The narrative remains unspoken on two levels. Firstly, the absence of further information about the boy in whom she was interested, and secondly, the absence of accounts of how her other friends were behaving. This is in stark contrast to the previous remembering of symptom onset and diagnosis, in which the views and actions of others are recalled in more detail. The only clue appears towards the end, in the deliberate positioning of certain people as having assumed leading roles within this group.

This signifies a shift in the plot, as Tracey notices that the components of her life prior to resuming activities after a period of illness have changed. This was a period in which things had moved on for her and for other people. It is a closure point of that particular episode of Tracey's life, but is not framed as a negative experience. Neither is it indicative of a final acceptance of IBD and the changes it has brought about, yet it may open consideration of episodes in which IBD may be a protagonist in directing events to some sort of positive conclusion in the narrative. More specifically this could relate to how the active interview can assist in reaching such conclusions. For Tracey this was a positive experience: as the interview moved towards educational issues that affected career options, she revealed the following when reflecting on her education and career choices:

*[...]everyone else was doing 3 'A' levels and I was doing 1 'A' level and National Diploma and I had a great time [laughing] and I knew then that nursing was absolutely kind of what I should be doing.*

[I] No. Did having Ulcerative Colitis influence that decision in any way?

*Its funny really because there's lots of (inaudible) saying about Ulcerative Colitis obviously but I always have to remember. I don't think - I am sure I would have become a nurse eventually or something along that lines. I am sure it did influence my decision in some ways. You don't really know what nurses do until you see them working and feel the difference they can actually do. So I am sure I would have become a nurse but I think its good fortune really that I developed Ulcerative Colitis when I did and I was able to decide on a career that I am sure is right for me now.*

*(Tracey, interview 15, 2004)*

Tracey continued with her nursing training, and here the essence of colitis taking on a reparative role in her plot of IBD experience is plainly evident. While this particular account could easily been seen as a reflection of the care Tracey may have received during relapse, it is also a marked shift from the first extracts which detailed the move from remembering specific events to everyday activities which were essentially dictated by the illness, to the illness as a constructive, almost helpful agent in her life. Examining the way in which Tracey told her story as an action within the interview, rather than just examining what she specifically said, has afforded a multi-layered view of living with IBD as a young person. In addition to taking the accounts individually, it elicits a developmental emergent approach, which reveals how participants organised their experiences through telling their stories.

In addition to the theories of positioning that supported Alan's story, there are other theories that can assist in understanding how Tracey has told her experience of growing up with IBD. The concept of therapeutic emplotment (Mattingly, 1994) is based upon giving meaning to particular therapeutic actions by placing them within a larger therapeutic story. Mattingly's work asks why narrative is important in relation to therapeutic positions, or more importantly, how it is important in dealing with illness at all levels and not just within a clinical agenda. Making sense of illness has long been associated with narrative (Radley, 1994; Riessman, 1990; Stainton Rogers, 1991). Mattingly (*ibid*) makes this very obvious when sharing her

research experiences of observing an occupational therapist with elderly infirm patients. Their respective illnesses are unspecified, but Mattingly vividly described how the therapist concentrated on getting the individuals within the therapy group to move their limbs with a clinical aim of improving co-ordination, and ignored their sudden reminiscences of their gardens and associated activities, which had been prompted by the casual mention a window box. In brief, the individuals' stories were cut short and attention quickly returned to the official treatment schedule.

This was with relation to accounts being produced within a clinical setting, but there is also another argument that reverses this principle. Crossley (2002) examined the patient's side when studying therapeutic emplotment stances in relation to the diaries of journalist and broadcaster John Diamond. Diamond wrote the diaries when he had been diagnosed with terminal oral cancer. Referring to Mattingly's concept of therapeutic emplotment (*ibid*), Crossley divided her analysis of the diaries into six stages – pre cancer, learning to live in therapeutic emplotment, in limbo, recurrence, the unspoken narrative and endings. It should be stressed that these stages identified by Crossley are not prescriptive and that this particular framework is not a model upon which the data in this chapter has been analysed. However, there are marked parallels that can be drawn with Tracey's interview data here, in that her story describes life before illness, and that there are aspects of unspoken stories that are embedded in her accounts. Tracey also introduces additional, ancillary plots to describe her illness experience in everyday life. The key component of therapeutic emplotment for both Mattingly and Crossley is that of time, and this also support the benefits of looking across a whole interview document, rather than just looking laterally across all of the interviews to conform themes that are partially addressed in existing medical literature on IBD and young people.

#### **5.4 Conclusion**

The main development in this chapter is that it has made visible the extended role of the participants as actively participating in their interviews, by positioning and plotting their experiences. In the previous chapter, the focus was to reveal key themes based principally on what the participants said, but

it is difficult to ignore the actions that occur in the accounts. These accounts highlight the difference between *narrative* and *narrating*. By studying aspects of participants' lived experiences it becomes possible to investigate how a person learns to organise their life within the context of IBD, rather than simply absorbing what is told and re-telling the story without attending to the action in the interview. The data extracts here illustrate how some participants re-positioned certain aspects of IBD experience within the same interview and allowed for exploration in many contexts by telling other non-disease related stories of their lives.

Seeing how these accounts can relate to analytic perspectives such as positioning and emplotment undoubtedly takes the findings further than a surface level reading of what the accounts say and adds considerable strength to argue the benefits of the active interview. The questions of how people position themselves and tell their stories is beginning to be answered, yet once more, there are questions that remain unanswered. While the analysis delves further into the interview experience and the role of the participant, access to experience of life with IBD is still restricted. This is due to the brevity of an interview in comparison to actual lived experience, and also the participants' ability to remember events that have happened in the distant past. The interviews do not hold the advantage of being conducted over time, and practical limitations prevented repeated interviewing. Positions and plots are partially dependent on time, and time is the commodity that needs to be increased to ensure successful access to how young people manage IBD in their daily lives. While this chapter has demonstrated how an interviewee has become an active participant in the study, and has moved far from the traditional "patient with IBD" paradigm that is present in medical IBD literature, it is important to access how stories and positions change over real time and not just within single interviews. This (and the previous chapter) has yielded many practical and theoretical concepts through which to develop a longitudinal study with a cohort of young people with IBD. The next development moves towards the design an appropriate study to see the changing positions within young people's lives as they live with colitis or Crohn's disease.

## Chapter Six

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**The unclosed diary:  
a new view of young people with IBD**

## 6.1 Introduction

The interview study with adults revealed many examples of how they managed IBD on public and private levels. They included discussing how the participants managed with illness disclosure, bodily changes and acquiring information relevant to IBD. In terms of the project's aim to document the space between remissions and relapse, and to find out about events that involved accommodating IBD in some way, the interview data has partially realised that aim. Yet in finding out more about individual experiences of IBD, another question has been raised, which is how do young people manage and learn to live with IBD over time? The interviews produced rich data, but do not convey how people learnt to live with Crohn's or colitis at the time they were experiencing the situations that they described. As they were looking back, some people quite understandably could not remember exact circumstances that surrounded an event or feeling that they were describing. In some cases this meant that they tried to recall events that happened several years ago. The interviews also did not convey the sense of events unfolding over time. They contain a participant's reflection of events that are packed tightly into one story, but there is no real sense of their changing perspectives and management of IBD over several weeks or months. Chapter Three detailed the methods for the adult interview study, but this was also designed with a view to gaining a sense of the issues that would be relevant to take forward into a longitudinal prospective study. Having gained an insight from the retrospective accounts, this chapter describes the methods and rationale for the next stage of data collection: a unique diary study design. The diary study seeks to address the questions of where IBD features in individual lives, in terms of the extent to which it is present, and how young people position themselves in relation to the rest of the world. Overall, this chapter reveals the design considerations of this study, and ultimately the reasoning behind a data collection exercise that has never before been undertaken with a sample of young people with IBD, with the aim of providing a more comprehensive view of what it is like to live with a chronic illness as a young person.

## 6.2 Study design

With the aim of capturing IBD experiences in more detail, an audio diary study was set up to follow a cohort of young people with IBD over a longer period of time. Diary studies have been conducted with adolescents with IBD but have used measurement scales (as described in Chapter Two). This study was unique in the level of flexibility it offered, in terms of what the young people recorded and how they chose to do it.

Unlike the interviews, this study was a longitudinal design, which covered a 48-week period. Participants were visited every 6 weeks, therefore allowing plenty of recording time. Figure 6.1 below illustrates precisely how this worked:

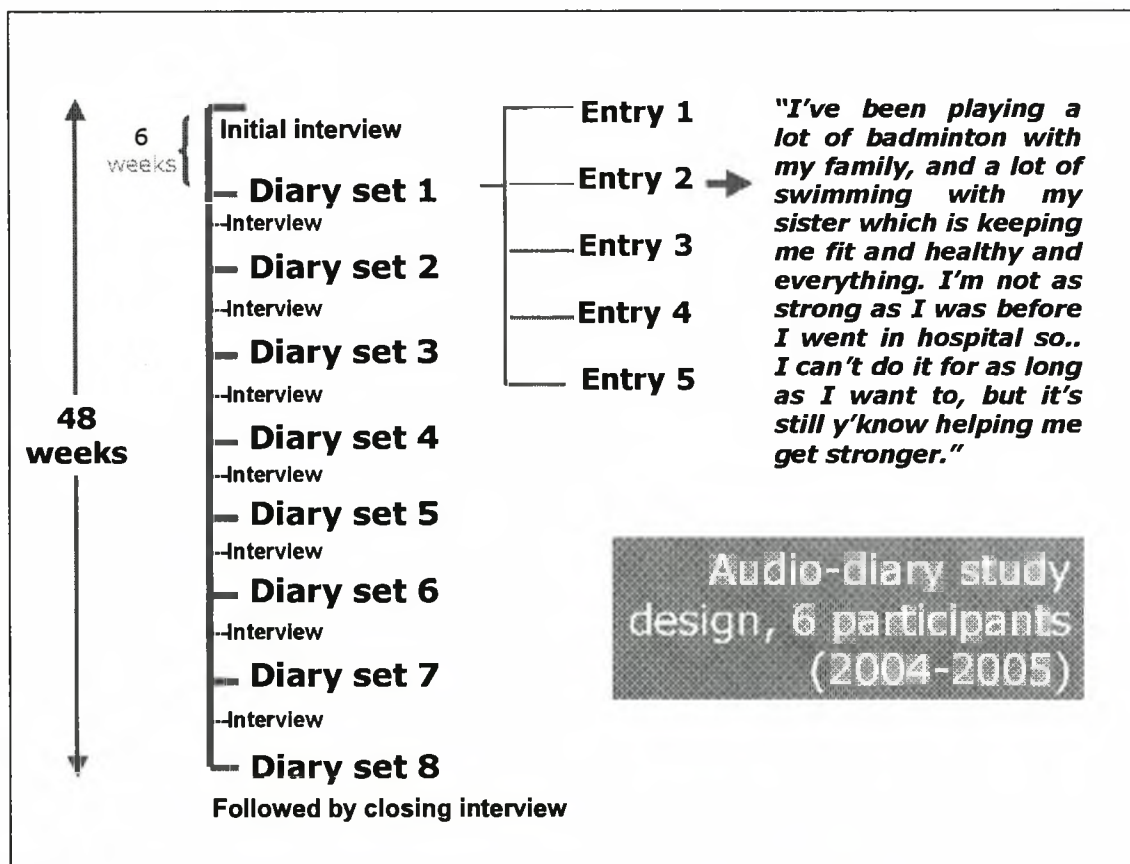


Figure 6.1: Diagram of prospective study organisation

The object of the exercise was to make it an enjoyable procedure, and certainly not to exert pressure on participants to produce data. The proposed six-weekly visiting schedule was flexible as there were inevitable interruptions

such as holidays, hospital appointments and other non-routine activities that interfered with the process. Therefore instead of insisting that each participant recorded the same number of diary sets, they could record a minimum of five and a maximum of eight diary sets over the 48-week period. This enabled the participants to omit recording sessions whenever they felt necessary, especially as some were taking school examinations or experiencing additional pressure. All individuals had full creative licence over the diary productions and could record as many entries in a six-week period as they wished; single entries could also be as long as they wished.

### **6.3 Participants**

The interview study required participants to have a minimum of five years experience of IBD, to ensure that individuals had considerable experiences of the disease in daily life. Like the retrospective participant sample, the inclusion criteria for the prospective diary study were age and diagnosis related, but this time participants were aged between 11 and 16 years at the time of recruitment. As they could have been involved in the study for a maximum of 48 weeks, the age at recruitment was emphasised in patient information material, so that potential participants who were at the older end of the age range would not be deterred if they were due to turn 17 during the data collection schedule. The key criterion was that all of the participants had been diagnosed with IBD within 18 months of the initial approach to participate in the study, therefore having less experience of the disease and ideally still in the process of negotiating facets of the IBD in their everyday lives.

All parties involved with the research generally agreed that numbers should be kept to a realistic level, and that participants' geographical location should be a key factor in selection criteria as well. This therefore excluded everyone who lived outside of the East Midlands region.

Six young people participated in the study, and were identified from a division of paediatric gastroenterology at a local teaching hospital. This was in consultation with caring physicians and relevant IBD nurse specialists from the children's service division. Following discussions with the consultant paediatric gastroenterologist it was also agreed that participants with



additional illnesses should be excluded, to eliminate other influencing factors on everyday life that may have not been applicable to IBD and also to minimise inconvenience for all families concerned. From paediatric clinic records there were 11 possible participants who met the inclusion criteria. They and their parents/guardians were initially contacted in writing by the consultant gastroenterologist, who introduced the study and included a patient information leaflet (see Appendix C) that detailed the aims of the study. Participants themselves, or their parents then directly contacted Loughborough University project personnel if they wished to proceed. The table below gives more information about the six young participants and their circumstances at the time of participating.

| Participant                                  | Gender        | Age       | Condition | Surgery     | Interests               |
|--|---------------|-----------|-----------|-------------|-------------------------|
| <b>Annell</b>                                | <b>Female</b> | <b>14</b> | <b>CD</b> | <b>No</b>   | <b>Arts and crafts</b>  |
| <b>Hayley</b>                                | <b>Female</b> | <b>14</b> | <b>CD</b> | <b>No</b>   | <b>Football, golf</b>   |
| <b>Baljit</b>                                | <b>Male</b>   | <b>11</b> | <b>UC</b> | <b>No</b>   | <b>Cricket</b>          |
| <b>Philip</b>                                | <b>Male</b>   | <b>11</b> | <b>CD</b> | <b>No</b>   | <b>Swimming, violin</b> |
| <b>Emily</b>                                 | <b>Female</b> | <b>16</b> | <b>UC</b> | <b>Yes*</b> | <b>Watching cricket</b> |
| <b>Maxwell</b>                               | <b>Male</b>   | <b>14</b> | <b>UC</b> | <b>No</b>   | <b>Accordion</b>        |
| Indicates participants who piloted the study |               |           |           |             |                         |
| * Total colectomy                            |               |           |           |             |                         |

**Table 6.2: Participant characteristics for prospective audio diary study**

### 6.3.1 Attrition

Of the six participants who began the prospective study, the three girls all completed the maximum of eight diary sets. The three boys did not complete so many. Maxwell completed the minimum of five sets and would have wished to continue beyond this point. However the illness of another family member prevented him doing so, and a decision was reached to halt the recordings, with the understanding that he could resume at any time during the data collection period if he wished. The two other boys were the youngest in the participant cohort. Baljit took part in the pilot stage of the study, but only reached as far as the second diary set of the main study, dropping out thereafter. Philip was not quite old enough at the start of the data collection

process to be included initially, but turned eleven while it was fully operational. In the time left he completed four diary sets, and did not have sufficient time to complete more due to time restriction on the study

### 6.3.2 *Participant profiles*

Given the prolonged contact that the study enabled with these young people, it is necessary to include some more background information to convey a more complete picture of who they are. It is also helpful to include this information here as some of the data analysis in forthcoming chapters reviews sequential extracts, which would be interrupted by more detailed biographical information about the participants.

#### *Hayley*

Hayley was diagnosed with Crohn's disease 18 months prior to beginning the study. She was 14 years old at the time of recruitment and lived with her mother and stepfather. She also had two stepsisters who were both at university and seldom home, but she got on very well with them. At school Hayley excelled in all subjects and was in the top set for all of her streamed lessons, in which she often admitted to feeling considerable pressure. She belonged to an established group of friends in her year group, which included some girls, but felt that she got on better with the boys in the group. Outside of school Hayley played many sports, including football, tennis and golf. She loved playing and watching sport, and often felt frustrated that she could not exert herself as much as she would have liked due to illness-related difficulties. Of all the participants, she took the largest daily amount of tablets a day, this being 22 individual doses of various IBD and related medication. In addition to the bowel problems of Crohn's disease, Hayley also had related arthritic problems, which caused painful joints and occasionally limited her movement.

#### *Anneli*

Like Hayley, Anneli was also 14 years old with Crohn's disease. She was diagnosed one year prior to the start of the study, but said she could remember symptoms as far back as when she was in junior school. She lived

with her mother, father, and two younger brothers. One of her brothers was away at boarding school, and Anneli wrote to him frequently. At the time of the first interview, she had not been attending school for several weeks due to a relapse, and was still experiencing symptomatic episodes. Shortly after commencing the study, she was taken into hospital for investigative procedures to establish whether or not the Crohn's had spread to other areas of the bowel. In addition to being treated for Crohn's, Anneli was also seeing a psychiatrist as she had been exhibiting aggressive behaviour at school and at home. There was nothing to suggest that this occurred as a result of the IBD diagnosis. At the time our first meeting she was very interested in arts and crafts, often making her own greetings cards and gifts. She was also involved with her local church, and at the time of our meeting was choosing her GCSEs with the aim of becoming a teaching assistant when she left school.

### *Emily*

Emily was the eldest of the participant cohort, aged 16 at the time of commencing the study. Her situation differed to the other participants, as she was the only one to have had a colectomy and ileostomy. Her diagnosis was also unlike the other members of the group, who had various lengths of time experiencing symptoms that were managed with medication. A year before the study, Emily complained of a severe abdominal pain that was accompanied by a rectal bleed, and she was admitted to hospital on an emergency basis. An investigation later revealed that she had a severe case of ulcerative colitis, which had previously been undetected and the decision was made to remove her colon at that time. She subsequently awoke with an ileostomy bag, and not only had to adjust to the knowledge of colitis but also to a new state of embodiment. Emily lived with her parents and older sister, Shelly, with whom she was very close. When starting the diaries, she had returned to school midway through year 11, having missed several months, and was working hard to catch up on GCSE coursework. Outside of school she liked to accompany Shelly to watch local team cricket matches. Emily did not take any medication, but was adjusting to a regime of managing her stoma appliance.

*Baljit*

Baljit was 11 years old and had been diagnosed with ulcerative Colitis for 10 months. He lived with his father, mother and younger brother. At the start of the study he was looking forward to attending a new school, making the transition from primary to secondary school, and most of his friends were accompanying him. Baljit was very interested in computers and wanted to be a computer programmer when he was older. He enjoyed science at school and liked to play cricket in his spare time, as well as playing computer games. Since he was diagnosed with colitis, Baljit had been taking immunosuppressant drugs and steroids, but had not had any symptoms since commencing these.

*Maxwell*

Maxwell was 14 years old at the time of recruitment into the study, and was just about to start attending a new school. He had been diagnosed with ulcerative colitis just over a year before taking part, and had just finished a course of steroids at the time of starting the diary. He lived with his mother, father and older brother, and his father also had ulcerative colitis. At his previous school Maxwell had been bullied because of IBD related issues, and had chosen to leave and start year 10 in a new environment, with a new set of friends and a new framework within which to begin his GCSE subjects. He was a member of a youth group affiliated to his local church, and had a keen interest in music. He played the accordion and was often invited to local community meetings to play. His mother had Multiple Sclerosis, and during the course of the diary recording, the family was living in temporary accommodation while waiting for their permanent home to be adapted to her mobility needs, and to those of Maxwell and his father. In terms of medication, Maxwell had just finished a course of steroids at the time of the initial interview, and was hoping that he would not need to take any more.

*Philip*

Philip was 11 years old and the youngest member of the participant group. He was diagnosed with ulcerative colitis 16 months prior to the study, and lived at home with his parents and his older brother. He had just emerged

from a relapse when he recorded his first diary. At that precise time he was in the middle of his school summer holiday, and was making the transition from primary to secondary school. From his peer group in the primary school, only two of his friends were moving up to the secondary school with him. He was slightly apprehensive about this but excited at the same time. At school his favourite subjects were science and maths. He also enjoyed swimming, often taking part in competitions outside of school. His other interests included playing the oboe and violin, but shortly after commencing the study he decided to give up playing the violin as he found it difficult.

#### **6.4 Procedure**

A pilot recording study was conducted with four of the six participants: two boys aged 11, and two girls aged 14. This was a small-scale version of the audio-diary pattern originally proposed, spanning three weeks. As with the interview study, participants were seen in their own homes, and the principal objective was to ascertain whether the recorders would be easy to use, and to get a feel for the type of material that would be recorded. The young people were clear about the nature of the research and produced diary data in between visits, recording a total of three diary sets with as many entries as they wanted to include.

The diary study started with a meeting with the participant and other family members, mainly parents but including siblings if they were available and wished to be present (this included the participants who took part in the pilot study, and those who joined thereafter). This was to explain the nature of the research in more detail and the possible outcomes that would result from it. It provided an opportunity for everyone to ask any questions about the study, and to reiterate that withdrawal from the diary production was possible at any time and without reason. Once all parties were satisfied with the proposed research, an initial benchmark interview was then conducted with the young person on their own.

“Benchmark” in the context of this research has multiple meanings. The term includes comparisons with healthy teenagers, and against the adult retrospective interview data and the themes that were initially raised within that data. Overall, the intention was to establish a flavour of the participant's

life; their educational stage, hobbies and interests, peer groups and personal relationships. These are non-disease related, but some disease specific facts were also established, such as thoughts at initial diagnosis, symptom management and illness disclosure.

The participants were each given a digital voice recorder, and instructed how to use it. This device was a small handheld piece of equipment that was extremely portable and could be easily carried in a pocket or purse. It had various sound recording quality levels. The lowest quality sound allowed for up to 90 minutes continuous recording. There were also options to record material in up to four different digital files, so participants could systematically organise their material if they so wished.

They were then asked to record entries during the first week of the pilot study period. The content of the entries was not important at that stage. Becoming used to the recording technology was the primary issue, and so also was the ease of recording. This meant becoming accustomed to the technicalities of the machine, but also to establish where and when participants felt most comfortable recording their diary entries. Participants were assured that the length or content of their recordings did not matter, only that they needed to become accustomed to using the recorders.

After the participants had recorded the first diary set, the entries were listened to in their presence, without parents (unless a participant preferred otherwise), stopping at intervals to clarify inaudible words, abbreviations, and any other possible misunderstandings. An interview was conducted to see how they had found the experience, which then continued to address what had already recorded. The interviews moved towards asking what events were likely to occur in the young participants' lives within the next few weeks, such as holidays and school trips, and this led into the suggestions for further recording ideas, providing participants with ideas for what they could include in the next set of diary entries. However, participants were continually advised that they had full creative direction in the diary recording process, and that they did not have to stick to the subjects discussed in the interviews for recording material.

All participants were given a new blank recorder and asked to continue producing the diaries as before, but this time to think ahead about the coming

week, and talk about specific events (within or out of school) in their recording. They were not asked to speak about anything disease related. They had contact details of the researcher in case of any query, or if they ran out of recording capacity and needed another machine.

As the participants were involved in the study for a considerable length of time, a debriefing process was also an imperative part of the exercise. This mirrored the initial meeting held with families to discuss their overall feelings about the study, what they thought they all had gained from it, and to address any final questions that were unanswered. Participants were given copies of all their recorded material and were informed that they would receive copies of any outcomes generated by the project. Finally, they were informed that they could maintain informal contact with the research student if they wished.

This was a unique and unusual way of generating diary data, due to the flexibility given to the participants and the wish to detract from disease as a specific central issue and instead to bring other aspects outside of illness to attention. The diaries were the private recordings of the participants, but they were recorded with the knowledge that the data was being used for this project and would be listened to by those involved in it. This study produced very diverse material and opened the door to private experiences that would not usually be documented in IBD literature. However, there were specific circumstances that applied to the production of these accounts, mainly that the study was framed in an IBD context, which the participants were aware of, and they were always aware that people involved with the study would listen to their recordings. Given this unique combination of open recording and the framework in which the diaries were produced it became necessary to give the diaries a technical term. This is where the concept of the "unclosed diary" emerged, and this is further explained in section 6.7.

#### *6.4.1 Pilot study: practical outcomes*

Despite the success of the content of the diaries and interviews, there were practical difficulties that prevailed in the test audio study. On a practical level, the main difficulty that arose was the time took to complete the pilot study period, which was much longer than anticipated. The three weeks originally scheduled took nine weeks, from the initial benchmark interview for the first

participant, to the final diary recording. This was due to several reasons, including participant illness, family holidays, and one incidence of hospitalisation during a relapse for one of the girls. The latter concern has merited particular attention, as uncertainly is a key characteristic of IBD. Therefore the probability of relapse and subsequent implications had to be accounted for.

All four of the young participants liked the appearance of the recorder and enjoyed using it, despite initially feeling self-conscious about speaking into the machine. When asked if they would prefer to use other forms of diary production, such as a written or video diary, three said that they like the audio format. The two boys expressed the preference because of the appearance and capabilities of the recorder, and one girl said that the method allowed her to be more spontaneous with her thoughts, and that she would have found writing too time consuming. Only one girl said she preferred writing, and when asked why, stated that she feared being overheard by other members of her family. However she agreed to continue with the recording for the remainder of the pilot study period. The main study continued as documented in this section, as per the diagram in section 6.2, this time with the six weekly intervals between intervals being the recording time.

### **6.5 Ethical submissions**

As with the adults' interviews, ethical approval was sought from and granted by respective committees at Loughborough University and the local NHS research ethics committee. Informed consent was obtained from both a parent and the participant themselves before any recording commenced. The researcher had enhanced Criminal Records Bureau clearance, and was able to have access to paediatric patients subject to the award of an honorary contract by the NHS Trust, which was granted by the Children's Services Division of the local teaching hospital.

### **6.6 Handling of data**

The determination of general characteristics specific to all participants was not the most important outcome, and unlike the interview data, the diaries did not lend themselves to producing general themes, as there was no structural



framework within which they were operating. The individuality of the diaries and the different trajectories that they followed did not, and could not produce a typical IBD patient. Target issues were addressed in terms of the original research question, which was how a young person learns to live with IBD. These included dealing with school, holidays and personal relationships, similar to the retrospective accounts of the adults in the interview study.

The first stage of analysis looked at isolated diary entries that provided further insights into daily life with IBD at a surface level, similar to the first analysis of the adults' interviews. The next stage involved breaking the recordings into longer chunks of time, to see how participants positioned themselves with relation to their illness, and the extent to which IBD featured in their lives either as a passive presence or a controlling force. The third and final part of the analysis looked at the diaries in their fullest time range, across the 48-week period, depending on how many diaries each participant had recorded. As with the adult interviews, the analysis was twofold: to see what the diaries and interim interviews contained, and also what they as procedures did for the participants in terms of learning to live with IBD. This is explored in the next three chapters. Chapter Seven will give an overview of the data and how it relates to some of the stories told by the adult participants in their interviews. Chapter Eight goes on to specifically look at two diary sets to see how IBD is positioned in the lives of the young participants, while Chapter Nine looks specifically at how the young people organised their recordings and what this reveals about their adjustment to IBD as a whole.

### **6.7 The concept of the "unclosed diary"**

Flexibility was a key attribute for how participants recorded data. Whether written or spoken, diaries are usually private autobiographical undertakings. A diary can be used as a repository for confessions, or to act as a reminder for specific events. Whatever the use, it is essentially regarded as a private activity, but privacy is not operating on a total level here. Participants had the full creative input into their recordings, and they were private in that parents and caring physicians had no access to it. However it was recorded with the knowledge that research personnel would have listening access. This therefore "opened" the diary in two ways. Participants produced the data with

the knowledge that a specific person would be listening to it, sometimes when they would be present. The significance of the diary study was that unlike being asked to record specific events, the participants were invited to disclose personal information and feelings that were (or were not) relevant to their experiences of IBD as they saw fit.

Rather than developing a set of standardised instructions for participants, they were told that they had full creative direction. While they were fully briefed about the background and general nature of the research and understood that it was a sponsored project from the National Association for Colitis and Crohn's Disease, they were encouraged to assume ownership of their diaries while recording, and not to manipulate them into what they thought was appropriate to the study. Whether choosing to record small entries on a daily basis, or speaking at length over fewer days, it was entirely at the girls' and boys' discretion how they arranged their diaries.

The diary production had to be situated within an interview framework, but not to the degree of formality that the retrospective interview commanded. It would be unrealistic to expect participants to record independently without opportunities for reflection, explanation, and identifying material to record for future diaries. This is another way of "opening" the diary. Rather than being an autobiographical vehicle, the diary was being used in a continuous conversational sense. In addition to the diaries, the interviews that were conducted between each recording session were also analysed as they often expanded upon aspects of the diary to get a clearer picture of the issue in the diary recording. The diaries and the interviews are interdependent as they are not seen as two sets of methodological outcomes, but follow a dialogic process which allows the themes of the diaries to emerge, similar to the objectives of the active interviews with adult participants, only over a longer period of time.

However, the term that can be associated with this form of diary data is vexed. While the diaries are theoretically open, it seems inappropriate to simply call them "open diaries". This initially seemed a logical name, but the increasing presence of online web diaries, or "blogs", has captured this term for a digital rendering of diaries. Such online diaries are open in every sense of accessibility, as they are literally uploaded online for the world to see.

However there is a crucial difference with this method of mounting a public, open diary. While the creators of such online diaries usually retain their anonymity, they have the added luxury of reaching an equally anonymous audience, and can choose to reveal their real identity to whomever they wish at any time. The flexibility of this type of diary production is maximised by the vastness of dissemination that the Internet affords, but this cannot be reproduced in the context of data collection for this part of the project, making it difficult to align the term "open diary" to the diaries being produced here. There is also the consideration of the relationship between the participants and audience. Despite having flexibility in how they organised and produced their recordings, the young participants had a more difficult job in maximising openness in the same way as someone writing an online diary might. They had the extra consideration that the study was related to IBD and adolescence, and that their data was going to be listened to by research personnel. While they were not explicitly instructed to record disease related material, they were aware of this as determining the main context and purpose of the research. To refer to the diaries in the same way as online blogs seemed to demean their efforts. Therefore to break this association, the term "unclosed" diary was more appropriate, as they are not open in a universal sense.

## **6.8 Conclusion**

This chapter has outlined the development and implementation of an audio diary intervention study, which aims to examine young peoples' experiences of IBD over a longer period of time. It detailed the unique properties of this particular diary design and introduced the concept of the "unclosed diary", which describes the circumstances of data production in this particular case. The questions that now arise from this diary study development are if the procedure can be successfully sustained, and if there is anything else that can be told about stories of IBD and experience of chronic illness that has not been documented in the previous interview study with adults.

## **Chapter Seven**

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### **Disease and daily life: perspectives in the unclosed diaries**

## 7.1 Introduction

Chapter Six outlined the design and procedure for the prospective “unclosed diary” study. This was designed with the view of seeing how young people lived with IBD over a longer period of time, and to provide an additional perspective to the retrospective accounts seen in the earlier chapters from the adult participants. However, at this stage there is another objective within this aim. This is to see if the issues that were raised from the analysis of the adults’ interview data are visible throughout the process of diary recording and of interviewing the young participants.

This chapter begins by looking at some descriptive outcomes from the commencement of the diary study following the procedure described in the last chapter. It includes examples of entries from the six participants and represents examples of issues from the adults’ data. The issues discussed here specifically include feelings at the point of diagnosis; IBD support groups; and disclosing IBD and its related features to others. Although the data extracts are taken from various points in the diaries, most of the points that relate to the themes from the adult interviews are drawn from the initial benchmark interview that was conducted at the start of the diary process. The chapter goes on to introduce the ways in which participants placed IBD within their accounts, and also how the diary itself was a communicative tool.

## 7.2 Descriptive outcomes – practical issues

The main study commenced with the four participants who took part in the scaled down pilot study, but this time they were aware that the interviews would occur every six weeks instead of every week. The two new participants (Emily and Maxwell) started off in the same way as the pilot study, with an initial benchmark interview. They were aware that they would be visited roughly every six weeks from that point onwards, but were telephoned a week after the initial meeting to check that everything was all right with the recording machines, and if they were happy to continue.

### 7.2.1 Length of entries

Contrary to initial expectations, there was little difference between the participants in the frequency and timing in the first set of entries. The

recordings tended to be short, succinct accounts of what they had done on certain days, ranging from schoolwork to some more detailed accounts of what they had eaten at mealtimes. While the initial entries were brief and often sounded very awkward as participants became acquainted with the technology and recording their daily activity in this way, it soon became clear which issues that were of importance to them, and these issues provided extensions to continue the recordings. An example of this is from Hayley, who revealed in her diary that she was about to take school exams in the period of the first diary, and this was subsequently carried through into her diary.

At this stage of the prospective study, issues emerged that corresponded with those of the adult participants. These were centred on education, medication, support groups and illness disclosure, and were mostly present in the initial benchmark interviews rather than the diaries.

### *7.2.2 Education and future careers*

The adults' interviews had revealed some examples of participants wanting to use their own experiences of IBD in their study and/or work, and indicating that they wished to enhance their own knowledge as part of a reparative exercise, and/or disseminate information about IBD to others. The young participants' diaries and interviews also provided some evidence of this. At the start of the study in the initial interview, Hayley expressed a wish to study medicine with a view to becoming a gastroenterologist. When asked if this was influenced by her experiences of IBD she agreed that it certainly had made her more informed and that she wanted to know more.

*I want to be a gastroenterologist when I'm older*

[I] You want to study medicine – do you think that's been influenced by your experiences of Crohn's?

*Yeah, definitely*

*(Hayley, interview I, 2004)*

At the start of her pilot diary, Hayley was beginning revision for school examinations, which she chose as the focus of her recordings. Naturally whilst wondering about her performance in the examinations, her account is much

more generalised as she framed anxieties of under performing and was anxious not to “let anyone down”. She did not give specific examples of areas where she considered herself to be weak or strong. As Hayley’s diary entries progressed they became less concerned with larger emotive concepts and speculations, and began to record daily activity in more detail including what types of questions were on her exam papers. As her recordings progressed Hayley also began to reveal what she liked and disliked about school subjects.

Despite suffering a slight relapse during the 48-week period, Hayley did not have to spend time in hospital for IBD related concerns. Anneli, however, was not so lucky and had to spend a few days in hospital for various tests to see if Crohn’s disease had spread to other areas on her bowel. She did not record any diary entries during that period, but in the interview that followed after she had arrived home, she discussed the experience of continuing lessons in hospital with a specially appointed teacher. When asked how being taught in regular school classes compared with taking lessons on the hospital ward, Anneli replied:

*I think normal school’s better, you know what you’re going to do and what level you’re in. In hospital there’s loads of different people*

*(Anneli, interview 3, 2004)*

The affirmation of belonging to a certain level is a reassurance, rather than becoming part of a group of mixed developmental ability. Yet she still states that it is good to “meet different people”, and continued to say that she had exchanged email addresses with three other girls on her ward.

In the same way, as some of the adult participants described how they had missed school due to IBD-related symptoms, Anneli also described the consequences of such absence in an interview. Having missed some time at school due to her relapse, Anneli had been told that she could only take five GCSEs. In her initial interview she had expressed a desire to become a teaching assistant when she left school, and had a clear idea of the subjects she wanted to study.

*I can do 8 or 9 now. I had a massive go at the teachers saying look I don’t think this is fair. So now I’m going to do history, RE and more technology.*

*(Anneli, interview 3, 2004)*

While the reduction of the quantity of GSCEs did not necessarily affect her choice of career, Anneli was determined to change this. In terms of the positioning theories that were discussed in the analysis in Chapter Five, Anneli here is positioning her teachers in an obstructive role, saying that the situation is unfair.

### 7.2.3 *Diagnosis*

This was a major issue in the interviews for the adult participants. When asked about initial feelings at the point of diagnosis, responses in this were very varied. Hayley described the diagnosis as not really “sink[ing] in”, and it soon became clear that the main issue for her was connected with the medication that she suddenly found herself having to take. While adult participants cited taking medication as an issue for them, this had arisen from being prompted to talk about medication, rather than having volunteered it as a negative issue. When asked what exactly helped her to come to terms with the diagnosis, Hayley’s said that she felt reassured by

*“Knowing that other people had it, reading stories of long remissions, not it having to get in the way of everything else.”  
(Hayley, interview 1, 2004)*

The gravity of this response lies within the second phrase: hearing stories of long remission periods. This leads to suppositions that these stories are from other IBD patients, but they could as easily arise from clinicians’ secondary accounts of IBD patients in their care. The fact that storied accounts are considered to be of importance to Hayley is very telling, as there is an indication that they address everyday life issues rather than clinical issues specifically associated with IBD.

Telling a story of illness and of diagnosis seemed to be very important in terms of remembering the events and circumstances around that time. The next extract comes from Philip’s interview at the start of the study.

*Had a blood test done because I was getting blood in poos and then, then the doctor, well when I got results back he said I was anaemic, and so he said it would be one night in hospital for observation, but then they started to find out what it was, then sort of I stayed in hospital quite a while, and it came back that it was colitis, that was new years eve, um, so I spent Christmas in hospital, and then came out, I had 11 days in hospital can’t remember what sort of time I came out. I was going fine, and then I went downhill sort of end of January and was re-admitted end of January, and then I spent a*



*week in [hospital name] Children's, then I got moved over to [names hospital], stayed there for about two weeks, and then when I came out before the end of February, I was doing fine, but then my legs got very swollen and that was because I was retaining fluid, spent a night in just at the start of April, and then came back with the results of another blood test and they said I was fine to go and everything was going quite fine since then. A few weeks ago there was a relapse but now it's on the up side so I'm getting better now.*

*(Philip, interview 1, 2004)*

At his initial benchmark interview, Philip conveyed similar elements that were in line with the rest of the participant group, and related his hobbies and interests. In describing events around the time of his diagnosis, his account is very clear. This is an event based rather than emotionally based account. At his initial benchmark interview, Philip related similar elements to the other participants in the diary study, such as his hobbies and interests. However, In describing events around the time of his diagnosis, his account is remarkably detailed. The recollection of events in relation to particular months and times of the year is very definite. At this early stage in the prospective study, Philip wanted to have his mother present in the interview, but at no stage did she prompt him with dates or times. In addition to recalling events around his diagnosis, Philip also brings the story of how IBD has affected him right up to date by mentioning that he had recently had a flare up.

#### 7.2.4 Support groups

From the six participants, three young people revealed that they had joined an IBD support group for children, even if this was initially instigated by a parent. In contrast to some of the adults revealing that they found IBD related support groups negative because such initiatives concentrated on the worst aspects of IBD, the young participants found this to be a useful activity. As some of the adult participants had mentioned, the young people were able to discuss symptom management on their own terms. Once more, Philip provides an example of this:

*Last week, my mum and me went on an activity holiday for people with colitis. It was with Smilie's People<sup>1</sup> and it was great.*

*(Philip, diary set 2, entry 3, 2004)*

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<sup>1</sup> NACC organisation for children and young people with IBD

Philip did not elaborate on the holiday in the diary, but when asked about it in the following interview, he explained that he had enjoyed meeting other children with colitis. He was aware of Crohn's disease as a separate condition, but was not aware if any other children at the camp had it. Like Hayley's description of being reassured by hearing stories of remission and positive experiences of young people with IBD, Philip went on to reveal in a following interview that he also felt reassured in a similar way just by meeting others who had colitis.

By contrast, Anneli had not joined any support groups. In one of her interviews we discussed her thoughts on meeting other people with Crohn's disease in a support group scenario. Rather than being especially bothered by such a situation being dominated by disease and possibly negative aspects that accompany disease experience, Anneli offered a different perspective:

*I don't know how I'd react y'know – I think they'd be harder to get on with. I think you sympathise with other people who are like you but you might really hate them. This might sound horrible but if someone had cancer and you hated that person you wouldn't be horrible to them would you? So I don't think they'd be true friendships really*

*(Anneli, Interview 4, 2004)*

The focus here is not on considering an IBD support group, but on whether or not such friendships within such a group would be genuine. Anneli makes her own position very clear, and this is a position that is not defined by IBD but is her general appraisal of what it is to regard others with illnesses and whether they should be treated exceptionally or not. The account is also not speculating on how others would regard her, but how she would view them.

#### 7.2.5 Hobbies and interests

Discussions moved through school activity to hobbies and interests outside of school, and it is at this point where the definitions of living within and beyond the confines of IBD re-emerged and warrant attention now. During the initial discussion, Hayley revealed that she played tennis and golf, and elaborated on her choice of sports:

*I play tennis on a Saturday and golf too. My friends all laugh at me, I can't persuade them to come along. I have joint problems linked with my Crohn's, it's like an arthritis type thing, it gets*

*better as the illness gets better and worse as it gets worse I had to stop my football and my rugby, stuff like that so I chose golf as it works the joints.*

*(Hayley, interview 1, 2004)*

This is an account of how IBD indirectly affects everyday activity. Choosing to play golf was an extension of Hayley's love for sport, yet she was aware of her own limitations because of related arthritic problems. Golf is not detrimental to the joints, and for Hayley is a way of living beyond the confines of illness, as sporting activity can still be achieved. Yet, as with the adults' accounts, there is an argument for living within confines of illness here, as there is potentially a question over whether Hayley would have taken up golf had she not been diagnosed with IBD, since she has not convinced any friends to play it too.

Other interview questions turned to activities such as music or belonging to certain social groups that were not connected to school. When asked about her favourite music or pop stars, Hayley navigates an association through to IBD:

*I like Anastasia – I sort look up to her, she's got Crohn's she's like my pop idol. On Fame Academy there's a woman on there too, I can't remember her name, but she swears by Perative.<sup>2</sup>*

*(Hayley, interview 1, 2004)*

Like the sport she chooses to play which doesn't complicate the joint problems related to Crohn's disease, a link is also forged between IBD and popular culture, and there is a question whether this artist would have been considered as a favourite of Hayley's were it not for her diagnosis.

### **7.3 Descriptive outcomes: conceptual issues**

#### *7.3.1 The body*

As with the adults' data, there were instances of bodies being "separated" from an individual daily existence. In earlier chapters, the notion of the body as an absent presence (Williams, 1996) was discussed in relation to the heightened awareness of body functions that are otherwise taken for granted.

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<sup>2</sup> Name of medication

As the adult participant cohort recalled, the changing body and the limitations it imposed was a disease related issue from which several accounts were generated. During periods of remission stories of curtailing sporting activity appeared, but were not necessarily negative, as some efforts were made to remain physically active. However, relapses resulted in the body exerting such control that living space was not only reduced physically and metaphorically, but also occasionally static. Maxwell, described this very vividly during his initial diary entries;

*I'm reading loads to take my mind off it. I had to go 25 times one day and it got to the point when we got an extension cable at the top of the stairs cos I was sitting there all the time trying to watch TV*

*(Maxwell, diary set 1, entry 3, 2005)*

In this particular instance, Maxwell's space was so limited, due to severe symptoms, activities had to be brought to him on the toilet. There are clear descriptions communicating differences in pain and demonstrating an awareness of the body, which has developed through experiencing IBD. In his final diary entry of this particular set, Maxwell observed that he has stomach pain but is had difficulty establishing what this means:

*I had bad stomach ache today, but no toilet breaks. It feels like a stitch... but I'm in remission. I can't stop pooing and it reminds me of colitis – I don't want it to be, I missed loads of lessons and coursework before.*

*(Maxwell, diary set 1, entry 6)*

When this issue is further explored in the subsequent interview Maxwell is able to speak about this in more detail, and how he differentiates the types of pain. Maxwell does not think it is an IBD relapse and finds other potential causes for the symptoms. This example also shows how the unclosed diary can be beneficial in practical terms, as it facilitated clarification and elaboration of this entry.

### *7.3.2 Public environments and physical space*

While continuing to analyse Maxwell's interview data, there are interesting parallels with the consideration of the public environment and physical space that were found in the adults' data. In the previous section, Maxwell described how his physical space was literally reduced to sitting at the top of the stairs to

be close to the toilet while he watched television. Physical space is a residual concern for him in other areas too. During the initial interview, he demonstrated an awareness of bowel removal surgery as a possible option to manage colitis.

*People do ask, and I can talk to them. I know I might have to have the surgery and get the bag – my friends dad had one. It'd be a difficult decision. The corridors at school are not very big, and it can be a bit of a squash, so I'd be worried about the bag bursting*

*(Maxwell, interview 2, 2005)*

This concern is particularly interesting, as what is immediately brought to attention is the external practicality of the environment, the size of the school corridors, rather than the considerations of physically adjusting to a new stoma appliance. Maxwell considers this scenario in an environment within which he spends most of his time. This quote also provides a reminder of the adults' initial interview study, which was the utilisation of family members as resources for living with IBD. Adult participants had cited family members or friends, both immediate and distant, as having a positive effect on assisting them to make sense of the condition, symptomatically and socially.

### 7.3.3 Summary of issues

This is a brief overview of how some of the concerns raised in the interview data from the adult participants were mirrored in the young people's diaries and interviews. There are extracts that can also be placed in other categories as well as those that are assigned here, such as Maxwell's considerations of personal space in relation to the frequency of his urges to defecate during a flare-up. However, in addition to mirroring the concerns of the adults, the data also reveals interesting perspectives on the presence of IBD within the young participants' lives. Sometimes IBD is explicitly mentioned in symptom related entries, other times it is not. There are occasions when the disease is present in the data in an indirect way, and suggests the ambiguity of what it is to live beyond the confines of an illness like IBD. The next section will examine this in more detail.

## 7.4 Living within and beyond IBD

Previous chapters have maintained that acknowledging two different worlds of health and illness and making transitions between these two worlds defines the illness experience. The worlds of health and illness are two situations that are different, but are not easily separated in everyday life (Radley, 1994). The adults' interview data also revealed that the concept of living *beyond* the confines of illness did not necessarily equate to accounts of positive experience, or accounts in which IBD was absent. The concepts of living within and beyond the confines of illness are ambiguous and often indistinguishable, and individual accounts offer several ways in which these concepts can be interpreted. In the adults interview data, this was a finding that was discovered in relation to how they remembered conducting themselves in relation to the rest of the world around them. However, in the diaries, this can be exemplified by how the participants factor IBD as a component in their lives, and whether it is a dominant force or a co-existing entity that resides alongside other daily activities.

### 7.4.1 At school

Looking closely at some of the diary extracts, there are entries that could be classed as disease related, and yet simultaneously contain other non-disease related information. Consider the following entry from Hayley:

*Today was best day ever – no English maths or science. Didn't really do much in lessons. We had PE, but it was dance, it wasn't my favourite as I'm not that mad on dance. We had to do a routine and got video recorded which was really embarrassing as one of our group was away and we hadn't got a clue what we were doing. Um, Had IT, that was boring, then French, that was alright, can't remember what else I had...hold on a minute... Hi, I had music, just watched remaining part of West Side Story, which is pretty boring. Then we had textiles, I'm designing a hat and scarf for the design development part, and after that I have to pass my sewing machine test so I can actually get to make the hat. I had all the lesson with my friends which was cool, it makes the time go quicker. We played football, but my legs were really hurting today, my joints are sore. I'll go to bed now as I've got a blood test in the morning and have to be up early for the hospital. G'night.*

*(Hayley, diary set 1, entry 3, 2004)*

Hayley provides an entry that renders Crohn's disease as fairly inconspicuous. Background information from interviews revealed that her legs were painful because of a side affect joint problems brought on by IBD medication, but this diary extract alone does not convey this. A further disclosure of a blood test (which was to monitor Hayley's white blood cell count to establish the efficacy of IBD medication), is described as an event that is factored into Hayley's routine. The blood test does not dominate or direct the account. Instead it is preceded by a detailed description of lessons, likes and dislikes. The blood test is early the next morning, but it is so marginalized in the extract at the side of the other activities that are described that it is barely recognisable as an IBD related feature of the account. It is simply included as a reason for Hayley signing off the diary for the night as she is going to bed.

#### 7.4.2 At home

In the diaries the presence of IBD is sometimes tracked by symptoms, but not directly mentioned as a condition itself. Maxwell's diary entries reveal this in the accounts about the frequency of his defecation and his descriptions of the types of stomach pain he encountered. Like Hayley's positioning of Crohn's disease as an invisible cause of her joint problems, Maxwell similarly follows suit in an interview in which he observed the increased workload he had to deal with at school. He attributed his symptom onset to the workload, rather than directly to colitis.

*In the last 2 mornings I've had really bad belly ache, I haven't been able to get off the toilet., I don't think my disease is coming back, I'm still in remission. It feels like it's a stitch in my stomach, it really hurts. When I go on the toilet I feel funny and I can't stop pooing, - it does remind me of what it was like, and I don't want it to be. I think it might be stress of something as I've got mock exams coming up and coursework .*

*(Maxwell, diary 3, entry 7, 2004)*

Experiences of pain are described which are not deemed to be directly related to IBD. While looking at the placing of illness within the diaries, it is also interesting to note how the body is placed within them. Like Hayley, the presence of IBD in Maxwell's diary sets was minimal. However, given the

nature of the research and because he knew that someone with a working knowledge of IBD listened to the diary, Maxwell did not need to provide any further explanation of how an IBD pain might have differed from another source of pain.

IBD is not a catalyst for account production in Anneli's diaries either. In the same way with Anneli's reaction to initially being told that she could only take a certain number of GCSEs, IBD is once again not the protagonist in these small extracts (section 7.2.2). Rather than positioning Crohn's disease as the restrictive factor in this situation, Anneli directs her frustration at the teachers and cites them in her account. She has assigned parts and characters to people. By narrating this account and using the reported speech in which to convey her displeasure at being unable to fulfil her GCSE potential, she has made available another subject position which would have been adopted by the other speaker in question in naturally occurring talk. Anneli has therefore deliberately positioned the other speaker as obstructive, re-enforcing her part in the account to be one of control and confrontation.

Similarly, when in hospital, Anneli's reasons for preferring to study in regular school classes instead of those within hospital, are not concerned with IBD symptoms or any accompanying feature of the condition. Crohn's disease does not discursively appear as a catalyst that forms these new relationships. By looking at a sample of the diaries in this way, it becomes clear that the notion of living within or beyond IBD is not always due to how much the condition is talked about. This leads to the question of how much IBD is featured in the diaries, and how this can be defined to provide a way of analysing how much the disease impacts on daily life.

### **7.5 Locating IBD**

From the extracts that have so far been presented from across the diaries and interviews, it is evident that IBD is factored into many contexts of everyday life. To analyse how this is done and how much (or little) IBD features in young peoples lives alongside the many activities in which they participate, it is necessary to make sense of how IBD is placed in the diaries and interviews. Therefore it is useful to categorise the extracts in ways that can assist the investigation of how young people move between worlds of health



and illness, and how they may live within and beyond the confines of IBD with relation to the rest of the world around them.

To do this we will look at Emily's diaries. Emily was the oldest of the participant cohort and her diaries are a useful starting point from which to gain a handle on how to classify the presence of IBD in the data. This is largely due to the volume of material she produced and the sequential regularity in which her diaries were managed. After perusing her diaries in conjunction with those of the others, it started to become evident that there were three main types of diary extract that defined the placing of colitis or Crohn's disease (or any related aspects). Locating the presence of IBD in the diaries resulted in assigning three categories to the accounts:

- Disease absent: an account in which IBD and related matters are not mentioned at all.
- Disease embedded: an account that has IBD "embedded" within it begins as a narrative unrelated to IBD, but disease related concerns emerge during the course of the account.
- Disease directive: the final category means that the account is driven by IBD, and is explicitly about the disease.

Examples of these different types of accounts are given in the following sections.

#### 7.5.1 "IBD absent" accounts

This example of an "IBD absent" account comes from Emily's second set of diary recordings:

*Last Saturday I went to see Fifty Cent in concert at Wembley, which was great – I went with my mum, my sister and a friend. I don't think they enjoyed it as much as I did because they don't usually listen to that sort of music whereas I do, so I had a great time. I've been to one of his concerts before but that was in Manchester with a different friend and it was quite different. At Wembley there were a lot more people there than at the arena at Manchester, so it was a lot livelier and louder and everything, so that was good.*

*(Emily, diary set 2, entry 2, 2004)*

This extract reveals issues that were of particular importance to Emily. In addition to its descriptive value, she states what music she prefers, comments on the different environments in which the artist performed and generally regards it as a positive experience. It is a small example of identity development too, asserting a preference for a particular type of music in spite of others not appreciating it quite as much. Most importantly, there is no mention of IBD or related issues.

### 7.5.2 "IBD embedded" accounts

Another extract that occurs just two days after the previous one is also non-disease related in content, the world of illness is discreetly present, making a it disease "embedded" account:

*I've been playing a lot of badminton with my family, and a lot of swimming with my sister which is keeping me fit and healthy and everything. I'm not as strong as I was before I went in hospital so... I can't do it for as long as I want to, but it's still y'know helping me get stronger*

*(Emily, diary set 1, entry 3, 2004)*

This brief account of daily activity indicates how Emily benchmarks her physical abilities. The declaration of diminished strength and stamina is obvious, as she referred to a time when she did not have to contend with any aspects of disease. However, what is particularly interesting is the positive outcome. The realisation of bodily limitation is present, but the entry concluded with an acknowledgement that the gradual exercise is cumulatively a good experience.

### 7.5.3 "IBD Directed" accounts

In other extracts the disease *is* the dominant subject of the narrative (disease directed).

*Two days ago I went to the hospital to find out about having my reversal, I was supposed to have it this summer but being as [the doctor] has been away they said I couldn't have it 'til December. I decided to have it next summer because I don't want it to interfere with school and everything, it's be quite annoying if I had to miss school and had to stop and have a lot of time off again, so yeah, I decided to have it next summer.*

*(Emily, diary set 1, entry 5, 2004)*

Emily's stoma appliance was temporary, and the reversal here means reversal of the ileostomy, which would mean the removal of the external bag and re-construction of an anal pouch which would re-enable anal defecation to occur. It is also important to note that this is a disease directed account in the sense that Emily is aware that she is producing the diary that will be listened to by someone with a knowledge of IBD and the terms/procedures that are applied to it. Returning to the presence of illness in the diaries involves the discussion of such procedures, and also leads us to examine how the IBD is factored into individual lives. From Emily's extract, there is a clear indication that she has taken full charge of the proceedings, and was keen not to let the procedure interfere with her daily life. Overall, she was regaining control over her routine, and is prepared to delay the operation until a suitable time in her academic endeavours.

As discussed in previous chapters, the issue of living within or beyond the confines of illness was not found to be a straightforward definition in analysing the interview data from the adult participants. The same ambiguities are present in the young people's diaries. While it was possible to track where IBD related accounts appeared during the course of recording, there were other positions at work in terms of how individuals positioned themselves in relation to the rest of the world. As with the within/beyond definitions of managing illness, there were shifts when participants maintained a person-to-world or world-to-person direction in their accounts, and these were not necessarily dependent on the presence or absence of IBD.

## **7.6 Positioning**

### *7.6.1 Of illness*

In the same way that positioning theories were apparent in the data generated by the adults, the same was true in the diaries. Many of the examples chosen for extracts have been descriptions of events and activities. Any emotional or attitudinal entries have usually been a secondary exercise, prompted by a previous description in another entry. However, when returning to Anneli's diaries it is clear that she had organised her diary very differently to the rest of the group, as it was a very attitudinally based diary rather than an event-

based one. In other diaries, such as Hayley's, disease related matters were documented as they occurred, but Anneli did not do this so much. In determining how she managed Crohn's disease in everyday situations, it was often through the interim interviews that these circumstances were explained and elaborated upon, instead of through the diaries.

While this was dissimilar in terms of positioning illness, Anneli's claim making with relation to identity and selfhood remained consistent throughout the diaries and the interviews. A week prior to the second interview when her first diary had been completed, Anneli had just returned to school after her period of hospitalisation and convalescence. In response to whether she had found it hard to return to school with relation to her friends perhaps participating in activities that she had missed out on, she responds with an assertion of assumed maturity:

*Well... I don't think so, no not really. I think I'm more mature than they are - I've done more stuff than them. I mean, most of my friends probably haven't seen a boy's arse or anything, none of them wear make-up and stuff.*

*(Anneli, interview 3, 2004)*

Rather than making the association with missing out on daily activity at school, Anneli interestingly posits her answer in terms of a developmental issue of adolescent experience. From her response, her encounter with the Crohn's relapse on this occasion appears not to have induced any feelings of being excluded, but she effectively excludes herself by asserting that there are differences between her and her peers. Once again, IBD does not come into this negotiation.

The fact that disease has not made significant entries into participants' diaries or interviews can be seen to be a positive gain in terms of establishing the importance of support networks in learning to live with IBD. Yet in Anneli's case the absence of disease related content may not necessarily indicate a positive outcome in terms of adjustment. While her diaries were often opinion based and there are few event based entries, the diaries often featured episodes of verbal and physical aggression, which Anneli directed towards her classmates. Of course, there is always the possibility that these incidents may have been exaggerated, but they appeared too frequently in the diaries to be ignored. The need to convey a sense of empowerment and superiority

by relating these actions is partially aligned to theories of selfhood “multiplicities” (Harrè & Davies, 1990). Anneli’s data presents evidence of at least two of the processes described in this argument. She projects herself as having characteristics that frame her as “a member of various sub classes of dichotomous categories and not of others” (p.47). Throughout the diaries there is a development of Anneli’s sense of her self as belonging to the world in a certain way, and therefore seeing it from that perspective. In spite of her declarations of difference in the diaries, the interviews reveal another perspective, this being a preference to remain within a routine, which is exemplified in her preference to stay within school rather than taking lessons in the other context of the hospital.

### 7.6.2 *Of Identity*

Continuing with Anneli’s interview data as the diaries progress, her sense of identity becomes stronger. On two occasions throughout the study, she lost the digital recorders on which she had recorded her diaries, which therefore resulted in greater attention being placed upon the interview data around those times to try and recall issues that had been raised in the diary entries and project them into the interviews. On one such occasion, the interview commenced at week 16 of her diary sets, and there are more examples of deliberate self and other-positioning that occur. Another point made by Harrè and Davies (*ibid*) about the dynamics of positioning, is that the positions created by an individual of themselves and others, are not a linear non-contradictory pattern but the cumulative fragments of a lived autobiography. It is the latter concept that is of particular interest here. Consider how Anneli positions her friends during the interview discussion. In response to a question about what or who has had a positive effect on her dealing with Crohn’s she says:

*Friends – cos you can talk to them. Sometimes you need to if you’re really mad – yeah, school friends*  
(Anneli, interview 3, 2004)

While discussing the positive influences on her management of Crohn’s disease, Anneli, like many of the adult participant interview group immediately notes friends as an important influence for her. However, in the same

interview, the conversation turned to the possibility of a school camping trip. Anneli finds this prospect uninviting to say the least, but this is not disease related:

*God, well we'd have do this walk – about 50 miles, yeah, well crap innit? You're stuck with school friends, no make up, no hair straighteners, no shoes, proper crap.*

*(Anneli, interview 3, 2004)*

Immediately the story is constructed around physical activity, but this is not placed alongside IBD, unlike some of the retrospective participants who sometimes expressed a determination to complete such exercise without disclosing illness and but still factoring IBD as a component of that activity. The placing of friends is now demoted to a negative tone alongside being without other comforts from home. While the diaries are effective in demonstrating differing positions taken on various age related and non-disease related activities, it is enlightening to see that this is possible to elicit from an interview situation too, given its temporal constraints and tendency to perhaps lean towards disease focused content. This brings the analysis round to discussing the diary as a process, as well as a method for revealing how young people live with IBD.

## **7.7 The diary as a process**

In addition to the participants revealing how IBD impacted on their lives, the diaries specifically revealed aspects of the actual process of recording. This was revealed in three ways. The first is the process for the participants themselves and how they managed their diaries individually. The second involves the communicative elements in the diary that are directed at the listener. The third is the continuum of dialogue that is spread across the whole study period, wherein the interviews and diaries were interdependent in that they helped to propel the recording subject matter as an emergent trajectory, rather than reining it in to answer set questions.

### *7.7.1 Participants' diary management*

The participants revealed many differences in how they structured their diaries. All participants generally stuck to recording events, and any emotive content or opinion usually arose from a description of an event. Anneli was

the exception, as her diary entries were mainly opinion, rather than event based. While she described various events in her life, the recording is spontaneous. This was the very first entry recorded by Anneli:

*I'm going to talk about children with Crohn's disease - I think adults treat you differently because they think you're immature, they can't talk about stuff, don't want to upset you. If you have an outside disease it's fine, but if you've got a disease in the intestine, it's really embarrassing. Adults with Crohn's react differently because they find it hard to communicate. I think that children are better at adjusting their lifestyle - when you're a child you adapt to stuff but when you're an adult you don't. If I got it as an adult I think I'd find it much more difficult*

*(Anneli, diary set 1, entry 1, 2004)*

Unlike the other participants, this diary began with a specific need to address a disease related issue of concern, despite not being specifically asked to discuss IBD. If a participant was able to immediately produce a narrative indicating a position without being instructed to, this held positive implications for the audio diary as a tool for making positions visible and seeing how these would, or could change during the course of data collection. Given the enormous variety in the diaries, an examination of the process of recording it self also highlights the benefits of the diaries being produced over time.

### *7.7.2 The communicative diary*

As the previous chapter highlighted, these diaries are quite exceptional in many ways. Such a method has not been used to previously investigate any aspect of IBD and daily life. As a research tool, the diaries are also exceptional in that they are unclosed, and not an exclusive confidential repository for reflection that a private journal would otherwise involve. They access aspects of young people's lives that are not otherwise documented in existing literature on IBD and adolescence, yet they are aimed at a particular audience. The young people were given the task of recording aspects of their daily lives, whether they included IBD related issues or not. Yet simultaneously they were aware of the nature of the research, and who would be listening to their diaries. Specifically, they knew that someone who had knowledge of IBD would be listening and in the same way as the interviews with the adults, the young people were able to use IBD-specific terms in their

recordings without the need for further explanation. Baljit was so used to this that he mentioned his medication regularly, an example being:

*We read the papers this morning with Daddy while Mummy was making breakfast and she made me a lovely milkshake, which I had with Pentaza.*

*(Baljit, diary set 1, entry 8, 2003)*

The individual diary entries that Baljit produced are brief, and are more group orientated, describing what activities he had been doing with his family, rather than what he himself had been doing. However, any IBD features were not the leading subject in any of his recordings, and were mentioned as casually as any other non-IBD related feature of his daily activity. In the case of the example above, the “lovely” milkshake is the main subject, and IBD medication (Pentaza) just happened to be there at the same time. Emily also displayed this communicative element. Not only did she disclose what happened during her day, but is speaking with the specific knowledge that someone who is aware of IBD will be listening to the diary. She therefore knew that she did not have to explain all terms and references pertaining specifically to IBD as there is an assumption that this will be understood. She often referred to “the bag”, and mentioned it in the context of it interfering with her sporting activities. The background to these terms was located in previous interviews. This paralleled the emergent qualities of the interviews with the adults and enabled the diary method to support the ethos of the project in terms of shifting the focus away from the disease and onto daily life.

There are other communicative elements in the data, as the diaries gradually adopt a conversational tone. Phrases like “I’ll see you next week”; “I’d better go now as you’ll be coming round in a minute”: “did you know I’m in a band?” all contribute to the dialogical components of the method, and will be discussed further in later chapters.

### *7.7.3 Emerging subjects*

In addition to the participants’ individual organisation and conversational elements in their diaries, the diary process also highlighted the ways in which recording subject matter emerged. This occurred as a result of the interviews addressing some issues that the diaries contained when they had been



listened to in the presence of the participants, and also suggesting ways in which these issues might be further explored in the next set of diaries for the participant. This pattern occurred within the diaries without the interviews too, as there were instances of participants describing a recent event, or looking forward to something forthcoming, and being reminded of a past one, which they documented in their next entry. Examples of such developments involve more lengthy data extracts, and will be examined in later chapters.

## 7.8 Conclusion

So far the analysis has explored some aspects of IBD that were raised in the adults' interview data, and looked at the differing levels of the presence of IBD in the diaries, and examined the diary as an active process. This helps to get an initial handle on this large corpus of data, and to think about the ways in which it can be managed.

Rather than seeking the extraordinary aspects of life with IBD – the hospitalisation, discomfort and exceptional circumstances it brings that are outside of daily life - the diaries revealed and achieved a level of "ordinariness" that is otherwise difficult to ascertain in the context of chronic illness research. The diaries and interviews made the transitions between the two worlds of health and illness more visible. Sometimes the oscillations between these two worlds were gradual shifts, while others were more frequent and occurred within much shorter spaces of time. This chapter shows is that even within the diary entries that are directed by disease, there are also references to general activities in everyday life, revealing how individuals negotiate chronic illness alongside other contexts. There are also instances of diary extracts that are completely without disease related features, while others indirectly refer to it. Additionally, other diary extracts are led entirely by IBD related concerns, and are dominated by symptoms, medicines and procedures.

The definitions of living within or beyond illness can, and must be investigated further here, as the diaries allowed a view of how the disease fitted into individual lives. Whether these were occasional mentions of medication being taken at school alongside a packed lunch, or recording the date of a medical appointment, they presented an initial portrait of how the

presence of the disease varied in these young people. The elements of the diary as an ongoing, emergent process in terms of content and communication with the researcher also demand further attention. Analysis should now focus on what is being done in the diaries in addition to what is said in them, and should question the strategies that the young people use to produce their accounts. The next two chapters will respectively look at how IBD is positioned within the participants' lives, and how they have organised them throughout the data collection process.

## Chapter Eight

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**Two worlds, one diary:  
positions between health and illness**

## 8.1 Introduction

From initially questioning what it is like for a young person to live with IBD, this research has discovered several issues that are useful, both in terms of the development of this study, and for the wider community of clinicians, carers and others involved with colitis or Crohn's disease in some way. The previous chapter began to look at the interview and diary data produced by the young participants in the prospective study, and began to see how some aspects in the data corresponded with the adults' interviews in earlier chapters. Two main points emerged. The first was that the presence of IBD was extremely varied in the accounts; this led to classifying the diary entries as being disease absent, embedded or directive. It also led to considering how participants positioned themselves in relation to the rest of the world around them. The second point to emerge was the evidence that keeping diary worked as a communicative process for the participants. This began by showing the different varieties of how such communication appeared and what it revealed about the action of recording the diary for the young people.

This chapter expands on the presence of IBD and how participants positioned themselves in more detail. By looking closely at two participants' diaries over a sequential recording period, (as opposed to excerpts from across the diaries) this chapter will demonstrate the varied patterns of the presence of IBD in the accounts, and how participants manage to combine IBD related matters alongside their day-to-day activities. To do this, the analysis depended on more lengthy accounts and regular recordings. This made the transitions between health and illness more visible and easier to track. Hayley and Emily, the participants who feature in this chapter produced larger amounts of data and recorded regularly.

## 8.2 Hayley's diary

We begin with Hayley's diary and look at a continuous period of recording to see how IBD featured in her life over this particular period of time. At the time of recording Hayley was in her first year of GCSEs. The diary extracts that are used in this section range from a half term holiday, until the Easter holiday at the end of the school term. These are the last set of diaries in her total recordings, and by this time, she had adopted a regular routine of recording

weekly entries, detailing what had taken place in the last week. The series of entries contain many examples of the illness being embedded further into her accounts. The first entry in this set begins with a varied account of activities at the start of half term:

*Just about start of holidays – it's Tuesday. On Saturday I didn't really do a lot cos my step sisters came round, er I went to tennis, oh, I went into town for a bit then we went to tennis, on Sunday I didn't do a lot - then one of my friends came round. We decided to have a sleepover at their house and that was pretty cool we stayed up till about 6 in the morning so I'm a bit worn out. We were sleeping on the floor and my hips were an absolute nightmare, I just didn't sleep at all, my hips just kept going really stiff, really painful so, but it wasn't too bad.*

*On Monday we had a party round at a friend's house, they've got a big trampoline that's got big nets round the edge. There was like ten of us on this trampoline. Hmmm, can't say I'll do it again, but yeah it was good. And then today I've got my friend Sam coming round, then we're going round to see another friend, he's re-decorating his bedroom. We said we'd go over and - not help him, rather like unhelp him. He says we can doodle on the walls before he paints them so that'll be cool.*

*That's about it really. I'm home alone for the rest of the week, I'm sorting my room out at the moment, so - Mum said I'd better sort my room out before my friend comes round. Anyway, got to go cos I think she's here now. 'Bye*

*(Hayley, diary set 8, entry 1, 2004)*

This account is a clear description of Hayley's activity during the week and records her activities right up to the point of someone arriving at her house. There are some events recalled from a few days ago, and the account concludes with an event that was happening in real time. Amongst this wide range of events, a symptom is raised that is not directly attributed to IBD. However, in the previous interviews which were conducted between diary recordings, Hayley had explained that some of her medication prescribed as part of the treatment for Crohn's disease caused her to have joint stiffness. There is a slight reference to this in the above extract, as Hayley notes how stiff her hips were when sleeping on the floor during her friend's sleepover. As with the interviews with the adults, care was needed not to confuse illness related behaviour with other actions described in the diaries. In this context it is analytically interesting to note the ambiguity of Hayley's observation. Sleeping on the floor could easily cause stiffness in her limbs on waking. At this stage of the set of diary entries, it is not completely clear if she is deliberately positioning herself as someone who has IBD in this context, or if it

is a general observation. The diary continues with recordings of school activities, and then reaches a holiday when a family skiing trip takes place. In the following extract Hayley records the week's activities in detail:

*Sorry I've not spoken into this the whole time I've been on holiday but it's been so hectic and busy. Got there on Monday and we were completely exhausted, went straight to the hotel, got our passes so had to sort our skis and boots out and everything. We got all our ski gear on and because me and my mum had never skied before, so we were on the school slope. And that was fun but also hard work neither of us knew what to expect. It's a lot easier on snow, a lot easier to turn and stuff, but it's a lot faster because there's less friction and everything.*

*On Tuesday we did the same so we could get used to it a bit more. Then on Wednesday dad took us to the top of the mountain and we had to ski down. And cos me and my mum aren't good skiers at all. We ended up a bit panicking Mum ended up taking her skis off and just walking from the top of the mountain. I thought I'm never going to do that, my legs will just give way. It's quite hard on my legs cos you're constantly bending and you're at a really funny angle. I just sat down, put the skis across me and slid down the mountain on my bum. I had to watch out for people coming from all different direction cos I wasn't quite sure where to go.*

*On Thursday and Friday we had ski school and we learnt quite a lot cos by Saturday we could parallel turn and I could go down the whole mountain skiing, but on Friday night we went tobogganing - that was so dangerous. We paired up, and cos it was quite late at night the run was really icy so we just could not stop, and I was with Sally, my Mum's friends who we went on holiday with we went round this corner and fell off, and then Jeff and Diane who we were with as well came round the corner and drove the sled into the back of - into my back so I've got a big bump in my back, so I could hardly walk but I'm starting to recover.*

*Um, generally we just skied in the day, Got back to the hotel and went for a rest, then came back down to the restaurant for tea and stayed up till about 1 on clock most nights - or mornings. And that's about it really*

*(Hayley, diary set 8, entry 2, 2004)*

This is a more detailed account in which Hayley describes lots of new experiences to do with her holiday. The sense of achievement in the extract emerges very effectively, with regard to both general and specific concerns. Generally, Hayley is embarking on an activity that she has not done previously, and she makes very clear the hard work that is incorporated into learning the skills of skiing. This extract is also illuminating in that it exemplifies the novelty and effectiveness of the audio diary method here and

the further insight it can bring into how young people live with IBD. Compared to existing studies, and indeed to the adults' data in earlier chapters, this is an account that is a recollection of a holiday without being framed in an IBD context. In Chapter Four, Graham and Paul described their holiday experiences, but these were often framed in the context of asking how they explicitly managed IBD while on holiday. Hayley, on the other hand, documents her holiday activities without framing them in the context of Crohn's disease.

With this in mind, it is a more challenging task to look for the manifestations of illness in her account. The previous chapter categorised IBD as being absent, embedded or directive in the data. Not only are illness related issues even more embedded in Hayley's holiday extract, but there are also changes in directions determining how Hayley positions herself in relation to the rest of the world around her. The person-to-world direction can be seen here as Hayley reveals how she positions herself in relation to everything and everyone else around her. She soon establishes the best surfaces on which to ski and generally becomes more confident in her abilities. However, as the extract progresses, illness related features concerning her hips become more apparent. These symptoms are an IBD related concern, and Hayley continues to explain how she deals with their reappearance. Her main concern in the account seems to be the trepidation resulting from feeling unable to ski down the slope. Hayley notes her mother's solution of removing the skis and walking, but also notes that this is "not an option" for her due to her painful legs and the steepness of the slope. However, the account does not display a peak-end low point as the symptoms enter into the proceedings. Instead Hayley continues to work out the best way of getting down the slope with her physical limitations. In terms of how she positions herself to the rest of the world around her, the tenor of the account remains constant. The diary entry conveys no sense of doing this activity in spite of illness, but rather is concerned with the current physical situation. Hayley assesses her own situation with direct reference to an engagement with her environment; she does not describe being controlled by it, nor does she describe being dependent on others. The time when the person-to-world direction is reversed is when an accident occurs that has nothing to do with IBD and a toboggan

injures her back. She is hardly able to walk, but concludes the entry on a positive note of being able to stay up later at night than usual.

This returns the discussion to living beyond or within the confines of chronic illness. There are fluctuations between the two concepts which are present in this diary, and they do not necessarily involve aspects of disease severity. Looking more closely at the diary reveals the presence of IBD more sharply. On returning from the holiday, Hayley realises that she needs to catch up with her schoolwork and notes the increase in her stress levels. Her demanding schedule is detailed in the following entry:

*Schools really hectic because I'm catching up with all my work. Generally really stressful, actually thinking about it we've got so much work, I'm not having any time in the evening, I start homework around half three and don't finish till ten or eleven at night, it's just absolute mayhem. I've started to get a slight Crohn's attack I think cos of stress at school cos I find stress does - I start to get really bad cramps and the usual symptoms of Crohn's. So that's not very good as I'm trying to concentrate on my work but my stomach's not letting me so it's yeah, it's been quite a bad week. But it's the weekend now, so I'm OK, I've got tennis, I'll go in town to the cinema. Although I've only been gone a week I really missed my friends a lot. I've got to spend time with them and I've really enjoyed seeing them again, just generally messing around and getting back into it all. But school's been a nightmare. Played golf a couple of times this week, yeah, that's about it really. Oh, it's my friend's birthday this week so I bought her a present, so she'll probably have a party sometime - but we don't know when, even if she's going to have one, and that's about it really*

*(Hayley, diary set 8, entry 3, 2004)*

There are several positions being taken in this extract, more so than in previous ones. This time there is a more marked indication that Hayley is positioning herself as someone with Crohn's disease. The relapse is described as "slight" and Hayley makes a connection between the symptom episodes and the stress brought on by the increase in workload, as indeed some of the adult participants also identified. Rather than the arthritic secondary symptoms that prevailed on the ski holiday, the primary IBD symptoms emerge, and there is a distinct separation of mind and body, which was seen in the adults' data. This is seen in Hayley's description of trying to concentrate but conceding that her "stomach is not letting" her. As the retrospective interviews facilitated certain re-positioning activity within individual narratives, so too can the diaries. This is discernible in the initial



assessment of the relapse being slight, through to Hayley declaring that she has experienced “quite a bad week”, which could indicate that the symptoms were much worse than initially implied. The extract then changes focus away from the world-to-person direction in which studying is curtailed, and presents a short account of some of Hayley's other activities.

The weekly recording pattern continued, and the diaries assumed an almost rhythmic temporal regularity:

*Sorry I'm only doing this weekly but school so mad and I haven't got much time at the moment. I prefer it on a weekly basis – um, what was I going to say about this week? Pretty much the same as last week really. Homework starting to settle down now I'm getting back into a rhythm, it's good in that respect – it's a calm week. My Crohn's is still playing up a bit, and um been having the cramps and stuff, been having to go to matron in lessons cos I just can't stand it anymore and I have to have a hot water bottle. The medications – putting me back on, they're taking me off Diclofenac, then they put me back on, then there are different tablets, very confusing. In a few weeks when it's settled down I'll put a medication entry in explaining all that, but it's just too complicated at the moment. Mum tells me what tablets to take, and I take them, I think that's the easiest way, otherwise I'd end up having too many or too little – it's really confusing me.*

*Oh, did you know, I'm in a band? That's what I was going to tell you. Some of my friends are in a boy band, so we decided to do ours I think I've already mentioned Blank page, but that sounds really cheesy. We decided not to do that cos that was just a bit – that was just to annoy the boys. But anyway, my friend called Kate is having guitar lessons. They've put me on drums cos I've got a drum set up in my room, such a laugh as none of us know quite what we're doing really. On the practices – if you can call them practices really it's just gossiping, just a bit weird really.*

*(Hayley, diary set 8, entry 4, 2004)*

By this time, the relapse and symptomatic episodes begin to invade the accounts on a more detailed level. The sense of control in the person-to-world direction that Hayley displayed in the earlier extracts is considerably depleted, as her daily life is being frequently disrupted by symptoms and visits to the school matron. In addition to her lack of symptom control, medication becomes a prevalent concern, especially as this regime has also been disrupted. A noteworthy part of this extract is Hayley's assertion that she will later make a “medication entry” into her diary set. This was not a requirement of the recording exercise, as the whole idea was to enable the young participants to record aspects of their lives and to see how they managed

everyday activities in addition to, rather than in spite of having IBD. However, Hayley specifically states her desire to record an entry dedicated to her medication regime. This immediately raises questions about the purpose of recording such an entry. She mentions that it is “too complicated” and is reliant on her mother to tell her which tablets to take. Therefore charting them logically in the audio diary could be a way of ordering the medication regime for future reference. Hayley also asserts that she will make this entry “when it [Crohn’s] has settled down”. In dealing with the pain and change of medication, it is fair to deduce that she cannot or does not want to draw attention to her medication while she is experiencing symptoms, and is looking for a more suitable time to record this information. She is prepared to document this when the symptoms have subsided. The direction of the entry changes back to the person-to-world direction, and disease related aspects of the account disappear, but only when Hayley is disclosing some news – being in a band - something that is otherwise not part of her routine until now.

Two extracts later this medication entry is clearly announced after some introductory accounts of the holidays and noting that the Crohn’s flare-up is subsiding:

*Well about half way thru Easter holidays now, and so far its been quite relaxing. My Crohn’s has settled down. Anyway, this is my medication entry. I saw my new doctor, and he decided that the Diclofenac was no good to be on as well as the ibuprofen because it can destroy the stomach lining. So he suggested they put me on Paracetamol - as well as everything else and try and wean me off the Diclofenac which is OK as I’m not too happy about being on Diclofenac because of the side effects.*

*So I’m on Paracetamol, although I’m still on 21 tablets a day which is quite depressing, but I’ve not really felt much different which is good, I’m only on one Diclofenac a day from two, along with 8 Paracetamol and the rest. I’m feeling quite good about it. The new consultant was really nice – I don’t know, there was just something about him that made me feel at ease as if he really cared about how I feel and how I thought about it all and talked directly to me and not mum, which was really good. He wanted a reply from me and not my mum, my mum’s really pleased about that as well*

*Going back to the holiday - I’ve been to town and seen my friends, been to the cinema, done a bit of catch up work but not very much. Seem Mitch and Matt and Jo - they’re not all boys by the way – well, most are. I’ve been on a girly day with Mum, which was really nice. Been relaxing and taking it easy. Um, I don’t really know what’s*

*planned for next week I'll just play it by ear a bit – just go with the flow*

*(Hayley, diary set 8, entry 5, 2004)*

Over this particular period of recording, we see here the fluctuating positions of the presence of IBD in the accounts and also how Hayley switches positions between world-to-person and person-to-world directions. In the approach to the “medication entry”, Hayley’s position in the account gradually changed from the person-to-world direction and the aspects of control that she held, to a more symptomatic based existence, which she has to comprehend in terms of her bodily capabilities and social networks. The particular extract above conveys a clear picture of Hayley’s medication regime such as the quantities she has to remember, and also contains mention of a paradox which is often observed in the management of IBD. This is due to non-steroidal anti-inflammatory drugs (NSAIDs) being prescribed to treat related arthritic complaints of Crohn’s disease. However, NSAIDs themselves can cause further gastro-intestinal complications and Hayley makes this clear in her description of pain relief as she notes the potential harm that certain drugs could cause to her stomach lining. However, in spite of these factors, and overtly stating that she finds taking so much medicine depressing, the person-to-world direction re-emerges very strongly: the medication entry assists Hayley to assess how she is responding to the change in medication, and she concludes that she feels positive about it. In contrast to some of the other participants, she also displays a striking awareness of her medication, naming drugs and the effects that they have on her and also the side effects associated with them. Overall, she does not position herself as a Crohn’s patient, but maintains control throughout the extract in opposition rather than submission to the adverse circumstances created by IBD.

A point worth noting about this extract is that it does not immediately begin with a declaration that it is a medication entry. Using the distinctions identified in the previous chapter, the trajectory of the diary continues with the recording of holiday activity, even though a medication entry was explicitly planned, therefore rendering the disease related features of the extract embedded rather than directive. While the medication entry was important for

Hayley, she includes it within a context that initially seems to be structured around her holiday. When she has finished giving details of the medicines, the extract quickly returns to discussing other aspects of the school holiday, implying that a point of resolution has been achieved within this series of accounts. Leaving the specifics of the medication behind, Hayley is happy to return to a state where she is not sure what is happening in her immediate future. This is not, however, the disturbing uncertainty which often accompanies the experience of living with chronic illness. Instead it is documented in a systematic way, verbalised and contained within one extract, then packaged amidst aspects of everyday life. This could suggest that her adjustment to, and accommodation of IBD in her daily life is positive. The final account in this diary set is disease absent:

*It's the second week of the holidays and it's been quite hectic, as I've been trying to do all my catch up work. It's been quite relaxing too though. I've seen my friends, been to the cinema – just normal really, and I'm now back in remission. Been to see my Gran cos its lambing season and we've got sheep, and we have to, so someone has to be there in case a lamb's born and stuff, so mum had to – well, let me explain from the start. We were at my Grans house – there was a sheep in one of the stables that was going to give birth soon. So I went to look at the mum and I saw a lamb's head where it shouldn't really be. So I told my mum and she had to go and get a bucket. My mum cleaned her hands and arms, and she had to try and pull this lamb out. It wasn't very nice all slimy and disgusting – I wasn't very pleased cos I had to hold the sheep which was screaming. So mum has now delivered a lamb, which she's quite proud of and I'm proud of as well.*

*On Saturday I went looking for some school shoes and we ended up in Nottingham. We started in Derby but couldn't find any cos I'm dead fussy. So we went to Nottingham and got them so that was a girly day , stopped over at a friends house, Mitch and Matt came over and rest of week was pretty much the same as last week, just getting ready for school, I should see you sometime next week hopefully. 'Bye*

*(Hayley, diary set 8, entry 6, 2004)*

This final entry completely dissociated from illness and has emerged into as Hayley lists another series of activities and some new experiences. There is a fleeting acknowledgment that this entry is a return to recording non-disease related activities as Hayley adds that these activities are “just normal really”. Examining a course of diary entries over an extended period of time allows for this type of comment to be taken within the contexts of other diary entries, and

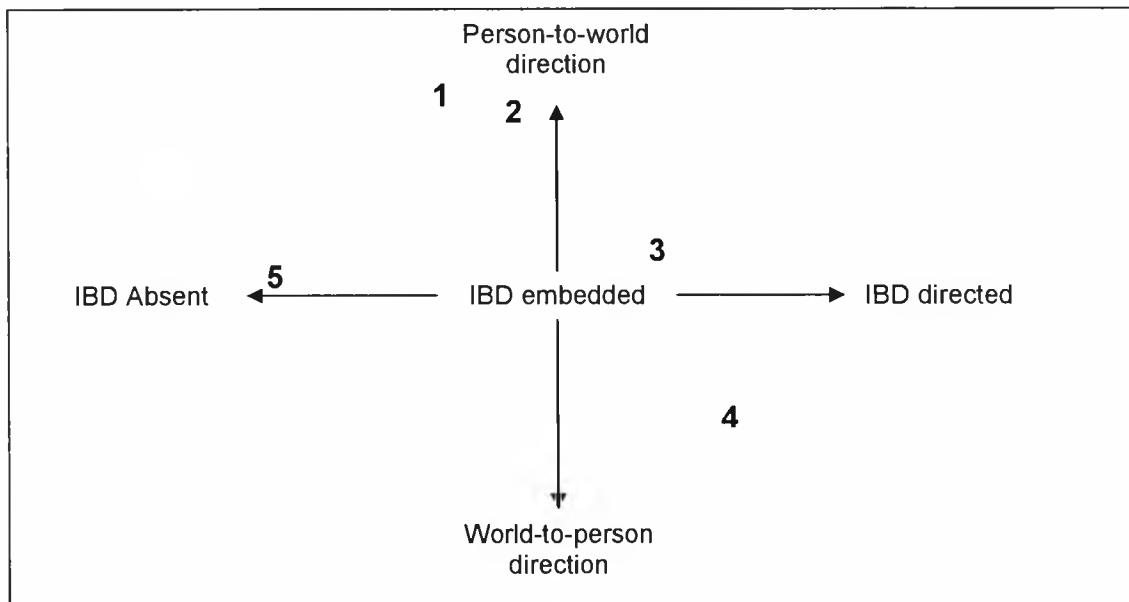
highlights the stark contrast in the inclusion of disease related issues in the medication entry.

In addition to the sense of achievement that is conveyed so effectively in the description of the lambing activities, the extract demonstrates that the contexts in which Hayley lives her life are constantly changing, and when viewed over time cannot be classified in terms of the singular roles that IBD literature has described. The diary entry shows a clear example of “self” and “other” positioning. Hayley demonstrates it in this account quite explicitly, proclaiming her and her mother’s pride at the outcome of their involvement with farming duties. While this is not disease related, it certainly reflects the positive outcomes that emerge through non-disease related activity, and how encouraging recording of such activity can provide a resource for personal adjustment to a chronic condition

### *8.2.1 Hayley’s diary: summary*

This analysis of Hayley’s set of diary entries has systematically run through the recording sequence, and examined the presence of IBD and positioning in more detail as the diary entries were presented. In order to summarise this with a view to describing the presence of IBD in Hayley’s life over an extended period of time, it is helpful to display this in diagrammatic form (see next page). The diagram contains the diary properties, and also the direction of person-to-world and world-to-person positioning. The points where Hayley’s diary entries occur are roughly plotted on the diagram, in terms of the analytic viewpoints expressed in this chapter.

The diagram acts as a visual marker on which to place the accounts in terms of where IBD has featured in them, and the direction which Hayley has deployed in the account in terms of positioning herself in relation to the rest of the world. When trying to assign places to the extracts in terms of where they belong, it is easier to determine the presence of IBD in the whole extract.



**Figure 8.1 – representation of Hayley's positioning in her diary.**

The numbers on the diagram represent the extracts in the analysis of Hayley's diary as they appear in this chapter.

However, determining the positioning direction that Hayley takes in the entries is slightly more complicated. This is because these directions can change within the individual accounts, while the presence of IBD can remain the same. This is certainly not a definitive guide to analysing data of this nature, but informs us that the positions that Hayley has taken in this set of diary entries can and do change quickly, irrespective of where IBD is placed in the accounts. The accounts are also open to several interpretations, as one view of an IBD embedded account may vary from one reader to another. Whatever the interpretation, it can be a helpful tool in examining how young people manage a chronic illness on a daily basis.

### 8.3 Emily's diary

In the set of entries examined so far in this chapter, Hayley's recordings clearly revealed the transitions between health and illness. While it could be argued that IBD is to some extent embedded in all of the accounts, the diary entries start out as mainly disease absent, gradually work towards a Crohn's disease flare-up and then conclude with another disease absent entry. The presence of IBD could be tracked from entry to entry and contained different levels of disease absent, embedded and directive experience. By contrast, the

presence of IBD and the positioning dynamics were sometimes present in single entries, and at this point we return to Emily's diary to look at this in more detail.

This section of diary entries spans a time period of roughly thirteen weeks. There are fewer entries, as Emily tended to record lengthy single accounts, rather than a series of shorter ones. At the time of the study, Emily had begun to prepare for sixth form college to commence studying for her A levels. These accounts range from the end of the long summer holiday though to New Year's Eve. Some of Emily's earlier diary entries have been seen in the previous chapter (section 7.5), so we begin our analysis at the fourth entry in her second set of recordings. Having previously documented experiences of driving lessons, Emily recorded an activity with her sister, Shelly:

*My sisters boyfriend plays cricket for [name of village] so me and Shelly have been going to watch quite a few of their games, so it's getting me out of the house more. Cos when I first came out of hospital I was too embarrassed to go out even though not many people knew about what had happened I still y'know, felt too scared to go out. I was too scared to answer the door and I was too scared to answer the phone. So I'm happy now to be just getting out more, cos you know schools different to just going out with different people*

*(Emily, diary set 2, entry 4, 2004)*

The three entries prior to this one were disease absent, and recorded what Emily had done that day. Initially this one appears to be disease absent. However, IBD related concerns are introduced very early on in this extract. The feelings that Emily recalls from the third line refer to when she had returned from hospital following an emergency colectomy. She had no active disease of IBD once this surgery had taken place, but was clearly very bewildered and frightened by what had happened to her. Disease is embedded into this account, but unlike Hayley's diaries it is a recollection of past events and feelings triggered by a description of everyday activity. Emily describes how the ileostomy procedure and subsequent convalescence are not part of current activity, and there is no indication that she wants to take this aspect of her life further in future recordings. While this is a recollection of past events, it cannot be discounted as IBD related features are embedded in this account. While they are not present in relation to the activities that were

happening at the time, (just as Hayley described her painful joints on the skiing holiday and the abdominal pain caused by a flare up during that period of recording), they can still be monitored in the same way with relation to the position of illness in the accounts and the positioning in relation to the rest of the world. In Emily's case, disease related elements are embedded, but there is also a contrasting element when analysing this extract with relation to the positioning dynamics of person-to-world and world-to-person directions. In her diary entries, Hayley positioned herself in relation to the world when IBD was not embedded in or directing her accounts, an example being how she problem-solved her way down the ski slope when her legs were troubling her. There was no speculation about how others saw her. In Hayley's set of extracts, the world to person position came into play when IBD related aspects began to feature prominently in the recordings. This might lead to an assumption that illness related accounts adopt a world-to-person direction, while accounts in which disease is not present adopt the opposite direction.

Emily's account, however, does not do this. While she remembers an acute period of disease related fears following her discharge from hospital, she is still positioning herself in the person-to-world situation, with no mention of others and how they have affected her. Her account is also relevant to positioning in a physical sense, and this particular entry indicates how the issue of personal space has affected Emily. Not only does she relate how her living space was altered during an acute period of illness, but the action of producing the diary also enables her to consider how she positions herself as a young person with a chronic illness amongst others. Emily realised that her world has literally "shrunk" and illness related issues require her to live in a reduced space, physically and socially. Chapter 2 showed a figure of Brydolf and Segesten's (1996) model of changing living space of adolescents with IBD. They suggested how reduced, normal and expanded living space is dependent on other factors such as support levels and self-belief. However, that particular model treats the different states of living and personal space as independent entities and does not imply that these are interchangeable in any way. The diary data makes this changing concept more visible and Emily's example shows the different interpretations of positioning. She was living in an area of reduced living space, but although IBD related concerns are still



present in her accounts, she has negotiated the issue of living space and it is no longer an issue for her.

As the diary continued, the next entry (number 5, not reproduced here) detailed her and her sister (Shelly) meeting up with Shelly's boyfriend, Frank, and his friend, Ahmed. The entry that followed the recording of this meeting, is another reflective account, and can be considered illness related in many ways. However, consider Emily's observations about making friends:

*It's quite, erm, strange being friends with Ahmed because, for a start he's ten years older than me, but erm, Frank told him about my illness before I'd even met him, cos they like, y'know, share all their secrets and stuff, so - but I haven't got a problem with Shelly telling him at all, because Ahmed's got people in his family who have different illnesses and stuff like that so I knew he wouldn't be cruel about it. But it's just so strange cos all my other friends, like who I made friends with after my illness, I became friends with them and then told them about my illness, cos I thought if I tell them about my illness then they might not want to be friends with me, cos they might think I'm - like a freak, that's what I thought when I came out of hospital, like all the time I was just thinking, Oh my god, no-ones gonna want to know me now, cos I'm - abnormal. But Ahmed wasn't like that. So yesterday when we were in the Cherry Tree and having a laugh and all that, I got - I didn't actually show it but I did get quite emotional inside because I thought - I never thought that someone would make friends with me even after my illness because, whether it was through pity or not I was just so happy t to have - someone like that - you know, just as a mate who I like, don't really see much, but when I do I have a laugh and ... stuff. And its like with the cricket team, they're sort of the same, even though they don't know about my illness they're not - it's so - I dunno - it's just like I never thought people would want to know me afterwards, and - cos you just feel so, with the stoma, you just feel so... ugly with it and you just can't... sometimes you just can't cope with it, and when I first came out of hospital I couldn't cope with it, and I was like really depressed and all that, so I think personally I've come a long way since then as I've learnt to deal with it.*

*I haven't really had the choice of whether I want to or not, but I never ever thought that people would wanna be mates with me afterwards because I just thought - cos especially with me losing my hair as well, I thought people are gonna think I've got y' know, God knows what wrong with me. So to have people who would still talk to me and I can still make new friends - it means a lot.*

*(Emily, diary set 2, entry 6. 2004)*

Although this entry centres on aspects of colitis, Emily does not provide an illness related summary here. Instead this is an opportunity for Emily to re-evaluate her friendships and what they mean to her. This particular piece best emphasises the action within the diaries that assist in creating positions. In the diary entry immediately prior to this, Emily had been recording the

previous night's activity. This prompted her to evaluate her friendships in relation to her experiences of colitis and surgery. This diary entry begins to reveal what types of support networks are most helpful in learning to live with IBD. Once again, Emily breaks the routine of recording recent events or looking forward to forthcoming ones, and gives a detailed reflective account of her assessments and reassessments of friendships within and beyond her illness. Like the adult participants in the retrospective study, her sister, who has told people closer to the family about her condition, has set up a communication network for Emily. Emily takes a deliberate position here as someone with illness, as she notes that her friend has family members who have experienced different afflictions and immediately feels sure that he won't "be cruel about it". There is also a tacit acknowledgment of her insecurity here in her note that vindictive behaviours could be exhibited from others. There is a distinct separation of "before" and "after" illness onset, with Emily deliberating as to how her health status would subsequently affect her ability developing new friendships. What follows is a noticeable re-positioning of others, as the realisation occurs that she can make friends with people after illness onset.

The rest of the cricket circle is unaware of her experience but her psychological ease with them does not differ from how she feels with Ahmed, who knows about her medical history. In adjusting to her new state of embodiment through having her stoma, she has successfully discerned how she herself could be positioned as someone with and without an illness, and more importantly, the value of noticing that these differing positions are not affecting social interaction towards her. The crucial point in this account is towards the end. Emily relates the emotional difficulties of her condition and her inability to cope when emerging from hospital, but the reparative sentence follows when she says she "learnt to deal with it". What is implied here is that she did not have any choice in the matter, but the reflective properties afforded by the diary have enabled her to verbalise her sophisticated ability to position and be positioned.

In terms of where illness features in the diary, it is once more embedded, but Emily is reflecting on past feelings. She does not ignore the feelings of ugliness she experienced after having the stoma operation and

fully remembers how she felt depressed and unable to cope with the situation. These aspects epitomise what is highlighted in the literature, especially with the development of IBD rating scales like the RFIPC (Drossman, 1991). The strength of the diary method lies in its allowing Emily to reveal how much she has progressed since these negative feelings, and how IBD is not a directive element in her diary accounts or in her life.

By contrast the next entry stands out as an illness-directed account. This is a long entry and has been divided into two parts to facilitate ease of reading.

*A couple of weeks back I was having quite a few problems with my stoma at school, cos it was, erm, every Friday – cos I have a full day on a Friday, I have double Psychology in the morning and then I have third lesson off and then I have double chemistry, and what's been happening is my bag was leaking during my free period, so then I'd change it, and then I'd just panic that it was going to leak again during the last two so I ended up going home, and that happened for a couple of weeks, like after each other, so it looked like y'know quite bad me being off every single Friday, going home at - as good as the same time every week, so it looked like I was skiving off school, which obviously I wasn't. and then on one of the weeks that I was y'know everything just kind of got to me, I was changing it, and I just broke down, started crying at school, so first thing I did was ring up my mum, who came and picked me up.*

*(Emily, diary set 2, entry 7. 2004)*

Up until a certain point, Emily was dealing with the problem similarly to Hayley, by manoeuvring situations around her to change the appliance and be comfortable, noting when the bag was likely to leak. However, unlike Hayley, she reached a nadir, revealed in the account when she becomes upset at school while changing her bag. Up until that point, Emily had described her experience using a person-to-world direction. This then reverses as she begins to speculate how others might perceive her for missing certain lessons.

After this low point, the direction changes once again and Emily returns to a person-to-world position. Instead of speculation and disappointment at not being able to continue with a regular learning pattern, the account returns to the daily details of Emily's life. Looking at the content of this entry, an initial assessment could surmise that this is very much about dependency and concern about others' positioning of Emily's situation. There are attitudinal

concerns, as Emily speculates that others may doubt that she is missing school for a genuine reason due to the regularity of the stoma problems. There are also practical concerns, exemplified her mother's handling of the incidents and the lines of communication that were established to facilitate Emily's educational development. However, both metaphors of person-to-world and world-to-person positioning are present in this account. Dominant illness issues are not entirely dependent on how the world is positioning Emily. While this dynamic is present on some levels, she displays strong positions in relation to her world. She provides much detail about her routines, going as far as to include her lessons on the particular day of the stoma leaks. This is indicative of a time when she is managing the inconvenience, and is changing the appliance whenever she can. Overall, she exerts control over the situation, which is displayed through the person-to world direction. The account continues:

*When I got home she rang my head of 6<sup>th</sup> form because I don't think any of the teachers know about my illness, so its not easy for me to just say something if something happened in one of my lessons, I couldn't just say something because they don't know anything about it, so I could be explaining it for a long time, so the only teachers that know are one of my biology teachers and my health and social care teacher, because they taught my sister, she had those lessons while I was in hospital so they obviously know, but I never had problems when I've got those lessons, which is strange and quite annoying, but yeah.*

*So anyway, mum spoke to the head of 6<sup>th</sup> form and I think he was supposed to be letting the teachers know, but I'm not really sure, cos none of them have said anything to me, but I think everything just got to me because obviously when I got back to school I'd have to be catching up with everything the following week again, and I got so fed up with doing that in year 11 and year 10, cos of missing so much time off that I didn't want to do it again in 6<sup>th</sup> form.*

*It was supposed to be a fresh start and not having to go through that again and spend all my extra free time just catching up with work. I just wanted to get it done in the lessons and have a break and spend my free time doing homework I'm supposed to like everyone else, not extra stuff as well. I think that's why it got to me. I think my teachers do know, cos I still get really tired with my illness and stuff, cos I have to - every morning I get up at like 7, and get the bus.. my bus leaves at about ten to eight, so I get the bus into [name of village] and then I have to walk through the middle of [village] to upper school, so it takes about 20 minutes, so it's a long walk and it's up a steep hill, so that tires me out, let alone being at school all day then having to walk back into town to get the bus back again, so I do get really tired and then when I get home I'm having to do my homework and everything, so I'm hoping that they know about my illness so that they'll understand it I can't*

*actually do some of the work. But I'm not sure if they do actually know at the minute.*

*(Emily, diary set 2, entry 8, 2004)*

While this is not an account of a given day, but a more general account of everyday travel, the level of detail is still the same, weaving through her journey to school, right down to the specifics of bus times. Although this has been triggered by illness related events, a degree of control is regained in the final part of this account. There are many changing directions in terms of how Emily positions herself in this extract. Much of the content is about illness disclosure, as Emily recalls how her teachers had previously taught her sister, and that through this contact they might know about what she has been through. Throughout the remainder of this entry, she is never entirely sure whether her teachers know about her illness or not. She assumes that her teachers do know, as she believes her tiredness reveals what is going on. Whether the extract is treated as IBD embedded or directive, the changing directions of the person-to-world and world-to-person position are evident as Emily moves from speculating who knows about her through to describing her school travel routine in considerable detail. The account began with the description of the problems that Emily was having with her stoma at school, but rather than staying within an IBD directed vein, the account develops into a review of how Emily is coping with catching up with her missed work and the difficulties of travelling to and from school.

Emily did not record anything for about three weeks after this incident and embarked on a new diary set after exchanging the recorder with the previous extracts on it for an empty one. Two more disease absent extracts were recorded (not reproduced in this chapter), but were then followed by this next one. This is also a long extract, but it has been left intact to fully reveal all of the factors that led Emily to making what for her was a big and difficult decision:

*Um, I've decided to leave 6<sup>th</sup> form for the time being cos mum thinks I'm suffering from a little bit of post traumatic stress because obviously when I came out in 2003, and then I went back to school in the summer, I went straight back did my GCSEs and everyone was shocked at how well I did, even I was shocked at getting an A, and all my other grades. Obviously it happened so quick I don't think I even had time to think about my illness. So*

*now I started afresh and I'm learning from the beginning and just had to stick through right til the end and it was very different. I felt didn't really have to learn everything I just had to remember it. I'm finding it so hard. I mean when I used to come home from school mum or dad would ask what I did and I wouldn't be able to tell them I couldn't remember and no-one really know why but that's just how it happened. I got very upset because – well, Chemistry I found really difficult because I had to do coursework that I'd missed because of problems with my stoma before, and I borrowed some of the work off a mate and I looked at it and gave it her back then when I came to do mine I couldn't think for the life of me what I had to do.*

*One subject is alright but to split that subject into two and then split that subject into modules is a lot to learn. It's a lot to learn, and I've got to think about my health rather than my school grades. So I emailed the head of 6<sup>th</sup> form and spoke to him as I had my psychology exam on the Thursday. I thought there's no way I can do it, there's just no point. Everyone said stick it out until the end of AS's which I really wanted to do because I wanted to leave with something, I didn't want to do three months and leave with nothing. I really had no choice as I thought if I couldn't do one exam for one little subject I couldn't do all four*

*Mr. [head of college] has rung me and wished me well with everything, been very helpful. It wasn't an easy decision; I think some of my friends thought forget it I'll quit. I've been thinking about it for a couple of months because I was not getting on at all, I enjoyed my lessons, It was just the homework and the coursework that I just couldn't do. My dad was like why don't you take notes in your lessons and I said Dad, I do, it's not like I just sit there and blank everything. I found myself with no choice but to leave. It wasn't a easy choice. Now I'm not going to see my friends much from school because they're all gonna be there and I'm at home, so I'm gonna have to make more of an effort to meet them.*

*I'm just looking for a job as well. My dream job was to be a physio[therapist] which you obviously need A levels for, so I was looking on the Internet for courses and I found an aromatherapy and massage course which sounded really interesting, it's a home study course it's going to take 6 months then after that I'll do something else. Cos Shelly might be going to the Open University to do teaching and she says you've gotta be 18, so I can do a course from there when I'm eighteen which will be in September. So that is my plan.*

*(Emily, diary set 3, entry 3, 2004)*

This was a lengthy entry in which Emily displayed all of her reasoning and supporting information which enabled her to make this decision. It could easily be categorised as a regressive narrative, one of curtailment, and be reduced to a statistic indicating how many adolescents with IBD are forced to abandon full time education because of their disease. However, looking at the data in terms of emplotment strategies helps to deflect from this, and necessitates examination of the other non-disease related contexts that contribute to this decision making process. In Emily's example above, there are many plots at

work in this one extract, all of which are linked to her decision to leave her sixth form. In the order of the extract, they read as follows:

- 1 The discussion that she and her mother have had regarding her response to events linked to her colitis and subsequent surgery.
- 2 The various reactions to her past GSCE performance.
- 3 The assessment and review of her learning abilities and current educational performance.
- 4 Negotiations of health status in opposition to and in connection with school performance.
- 5 The realisation of enforced distance from existing friends.
- 6 Researching other courses and career options.

If the first and possibly (although it does not specifically refer to IBD related illness) the fourth points are removed from the list, there are elements of the decision making process here which have easily occurred in any health adolescent's life during the transitional period between GCSEs and A levels. Some of these points have been discussed in more detail at other stages throughout the diary process, such as the examination results, while others have not featured unless they were raised during the interviews. Either way, this extract is a perfect example of the additional contexts that are emplotted into individual lives, and which contribute to the making non-disease related decisions. These decisions are made in situations that are partially a product of disease, and could, therefore, easily become disease focused and deemed as a regressive account. However, this does not imply that Emily is being forced unwillingly from her studies; rather, she has had an active role in participating in the events that assisted her to make the decision. These events are emplotted in her diary and might otherwise be ignored without the theoretical background of therapeutic emplotment and an aim to locate activity outside of illness related issues. Emily does not herself account for the illness as a catalyst of the inability to manage which that has accounted for the resulting events, thereby realising that she has been deliberately positioned in this way, and that IBD is not the protagonist that explains the process of decision making in this instance.

In addition to revealing varying levels of illness related presences, Emily also charts her changing emotions at different times in the diary production. Once more these changes are not the focus of the diary, but there is a degree of reflection that is not otherwise present in other diaries where a participant has acute stages of relapse rather than constant residual concerns. After she has left sixth form, she reflects on her emotions and what has happened to her at a New Year's Eve party

*On New Years Eve we went up to the old brewery where we go quite often, um most of the cricket team were up there [...] two of my cousins were there so it was good to see them. Um, I had quite a bit to drink, um but when I drink a lot I tend to get back ache so really it's not very good for me, Have to take it steady with my illness as well- before I was ill I didn't get backache when I drank whereas now I do, so I had to spend along time sat down, it's quite bad I don't really know the reason why it does than but it does*

*Also the brewery was really hot because it's not a massive pub the main bit where the bar is, everyone was in there, there was a dance floor as well which was not exactly big, the place was packed there was that many people in there the majority of them were smoking. Frank smokes, my cousin smokes, her partner smokes, quite a few of the cricket team smoke and the regulars as well it was really hot massive great fire which was hot obviously, but um they had only one window open which was a little window, no air coming in at all, because of my illness when I get hot I get sick, going to the toilet but all the doors were shut as well there was no air getting in at all so it was boiling. We actually got to the brewery about nine cos we didn't want to go too early, people didn't get there til late, there's only so much you can do before 12 then about half eleven time me, Shelly, Frank and Ahmed who's one of the cricket team went up to this bloke called Phil's house cos he was having a party but Shelly got bored quite a long walk as its quite cold. Me and Sarah had big heels on so you can imagine us going up the road. It was good fun got to know the cricket team a lot better because when we go up you don't actually get to speak to them that much, they're either batting, the rest of them just walk round the pitch so it's usually me and Shelly sat there so on New Years Eve I got to know them a lot better I enjoyed it a lot.*

*I got a bit emotional on New Years Eve cos I usually do for obviously reasons really I dunno, it just hits home, and because I was with the cricket team I don't think that helped the first friends I've made since I was ill, they don't know about me it was really weird to be with them, cos obviously I got my operation coming up this year so it was weird to be with them.*

*(Emily, Diary set 3, entry 4, 2005)*

One might argue that Emily's description of the way in which New Year's Eve represents a moment that provokes reflection signifies that she is considering universal themes detached from her own immediate concerns. New Year's



Eve is arguable a time for reflection on the past year's events. Emily's description of the environmental factors of the pub – the heat and lack of air denote what would usually be quite an unpleasant experience; however, this is not her major concern. By situating the account in the context of New Years Eve activities, Emily reveals how she has come to adjust to her condition and how it has affected her. The general phrase "getting emotional" encompasses a huge variety of issues that she has had to deal with. She has already overcome her fears of being seen in public, of answering the door and phone, and has assessed her capacity to make new friends.

In terms of assessing the presence of IBD in this extract, illness related concerns pervade it on numerous levels, but are quite different to Hayley's description of symptoms and related IBD concerns that occurred at the time of recording. Emily mentions symptoms in several contexts. The examples given are her inexplicably painful back, which did not present until she became ill, and feeling hot and sick in a packed pub. Once more Emily also uses the diary to assess the friendships she has made over the year, and concludes the account by revealing that she has an operation coming up (which is to reverse her ileostomy and enable her to defecate rectally once more). This and the other illness related mentions are not directing this account, but they do enhance the different contexts in which Emily describes them.

### *8.3.1 Emily's diary: summary*

Because Hayley's extracts were plotted diagrammatically in order to place her accounts in terms of where IBD was located within the diary entries and the positioning direction they contained, it was logical to attempt the same for Emily. However, this was not as straightforward, and was difficult to plot on a diagram in the same way, in terms of positioning IBD and the rest of the world. Therefore there is no similar diagram for Emily's diaries. Her ways of describing IBD related issues and how she positioned them varied so much within individual accounts, it was not possible, and actually unhelpful, to try and classify them in terms of the diagram. Emily's individual accounts could simultaneously contain disease absent, embedded and directive properties and change positioning directions more frequently, making it difficult to place them on even a rudimentary diagrammatic scale. Rather than this being

problematic, Emily's diary is different, as it reveals the process of how the diary enables her to reflect on her feelings and also recall how she felt in the past.

#### **8.4 Conclusion**

So far, Hayley and Emily have demonstrated how IBD can be absent, embedded and directive in their diaries. They also show how the disease is accommodated into the activities in their daily lives. When analysing the two girls' diaries over continuous recording periods to track the presence of IBD and how they position themselves, there are striking differences. Hayley recorded her schoolwork entries, but when she began to experience a relapse and her symptomatic episodes increased, these are structured separately from her other activities. There is a definite decline which is revealed as her symptoms start to pervade the accounts and usurp the commentary of daily activity, making the road between health and illness more visible than the interviews seen in earlier chapters. When the symptoms are alleviated, Hayley's accounts of everyday life begin to return.

However, Emily's accounts delve into IBD related matters much more frequently. This is not necessarily because she wants to take the account in a disease directed way, but because she has been prompted by the action of recording the diary to reflect on disease related concerns. Her diary entries reveal the presence of IBD in a different way to Hayley's, and raise a question as to which other elements of the diary process are present in other participants' accounts. As with the active interviews, the diaries say something important (about how IBD features in participants' lives over time), but they also *do* something. This chapter has revealed how two participants negotiated IBD in their accounts. By shifting the emphasis away from disease and encouraging participants to record non-disease related activity, the diaries have provided insight on how IBD features in individual lives and what impact it has for participants. But in doing this, they also invite us to question what the diaries actually do in terms of advancing this enquiry forward, how the young people have organised their diaries and what this reveals about the true nature of having IBD as a young person.

## **Chapter Nine**

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### **Sorting things out: organisational strategies in the unclosed diaries**

## 9.1 Introduction

Since the start of this thesis, much information has emerged about how young people manage IBD in their daily lives. The content of the adults' interviews and the young people's diaries with their connecting interviews revealed many issues. Such issues included negotiating IBD in public and private; disclosing it to others; managing symptoms; and seeing how the young people position themselves with reference to their illness. As well as providing insight, the data has also raised some more questions that can assist further in exploring aspects of living with a chronic illness as a young person. The previous chapter looked specifically at the placing of IBD in Emily and Hayley's diaries, and hinted how recording the audio diary as an activity itself can assist young people to make sense of the condition. It revealed the various positions held by the young participants throughout their diaries, including how IBD featured in their lives and what positions they adopted with relation to the themes that were raised by the adults' data.

In this chapter the focus is on the features that best exemplify the concept of the unclosed diary. It looks specifically at how the diary is being used as a vehicle for continuing dialogue between participant and researcher, rather than just forming a private collection of autobiographical narratives. The importance of the storied nature of experience is evident in narrative literature and in the data that has been presented so far in this thesis. In this chapter we therefore look more closely at the construction and organisation of diaries, and how the actions of producing the diary can themselves be a helpful element in making sense of IBD as a young person. The analysis returns to looking at some single data extracts and departs from a sequential extract investigation, as seen in the previous chapter with Emily and Hayley's accounts.

## 9.2 Diaries as prompts

The first example of the diary at work in organisational terms is in the form of how the entries prompted participants to reflect on other events. We begin this section with an account from Emily, which was produced at the end of her first diary set. However, the extract below is an account that told of events several months prior to the recording. It tells of a family holiday, going into great detail about activities and new experiences:

Um, As I said I've been - I went to Canada in February of this year, so it's quite a long time ago but while I was out there I did so much stuff that I never y'know dreamed I'd do after I'd come out of hospital cos it was like hard work stuff it wasn't just like a holiday, because obviously in February it was freezing out there. The warmest day was about minus 6, and the coldest was about minus 20 so it was very cold. Um, while out there we went up the CNN tower so that was scary being as I'm scared of heights. Once you're in the lift it goes about 15mph so that was - horrible for me so but yeah , but going in there was an experience and I went on the glass floor which took a lot of guts cos it's about the scariest thing I've ever done, standing like really high up. Cos It's got a sign that says it can hold 14 hippos or something, but you still think if you stand on the glass you're gonna fall through it. We went up the [inaudible] tower as well which isn't that high compared to the CNN tower but it was good. We went obviously to Niagara Falls, which was good - we went behind the Falls, we went with my grandparents, me and my sister did it was just us 4. My grandma was like really shocked cos they'd been before but that was in the Summer so they hadn't...there was like 15 foot icebergs in the Falls and when we went behind the Falls it was all frozen, so they found that fascinating - I mean me and Sarah found it fascinating as well - but is was such a shock to see it all frozen so that was brilliant, and we went in a helicopter over the falls so again I was petrified because of my fear of flying, but I felt I'm not going to have the chance to do it again so I might as well, so I did and I don't think I've ever felt so ill before. It was very hot in the helicopter which was mainly the problem cos obviously you go from freezing temperatures to like boiling, which made me feel a bit ill. Also on - I think it was our second to last day out there we went dog sledding which was amazing, that was very good, but me and Sarah had to go with the guide as we were too light to steer the thing ourselves cos you've got like 5 dogs and when they run they like, go really quick. , you had to learn all the instructions of how to learn, how to turn how to stop and everything. After that we went snow shoe-ing, which is where you wear big tennis racquet things on your feet That was the first time I fell over since I been out hospital, but being as I fell straight into 4 foot snow I wasn't bothered about it, it's not like I went down hard. So It was really strange to fall over if that makes any sense? I was always so bothered about falling over cos if I landed on my stoma it would have really hurt but it was soft snow - got very cold cos we were crawling in the snow but that was great.

(Emily, diary 1, entry 8, 2004)

This extract was reproduced in full as Emily recorded it, to fully convey what a "great" and "amazing" time she had, and also what the holiday meant to her in terms of her physical capabilities. Emily was absolutely clear about the requirement of the data collection exercise, and that the aim was to capture young people's lives as they were lived, and the possibility of looking forward to future events. Participants recording events that occurred several weeks,

even months ago had not been anticipated. Therefore Emily's extract seemed anomalous in terms of the aims of the prospective study.

However, rather than immediately discounting this account because it did not convey current activity or look forward to forthcoming experiences, it can be used to demonstrate the processes that are at work for Emily here as she remembered her experiences. When the attention did not focus on IBD, but was directed at details relevant to the holiday, Emily noted improvements in her physical abilities and management of the stoma. While this is a specific holiday that she remembered at this point in her diary, and the events described could not be classed as everyday, they are crucial to her assessment of her physical efforts at that time. When looking past the description of those holiday events, it is a generic action that enables her to realise how she has adjusted to her new state of embodiment with her ileostomy bag. While most people would consider a trip or fall to be at best inconvenient or embarrassing, and at worst dangerous, Emily's experience is somewhat dislocated from these typical sensations. Instead the fall is "strange". She acknowledges the previous apprehension relevant to this, as she realised that a fall on her stoma appliance could be potentially very painful, and also questions her own assessment of her feelings towards the fall. Amidst all the narrative action taking pace here, the overwhelming evidence lies in the importance of the facility to tell this story.

Emily also "benchmarks" her own physical limitations within the account. Comparative features are present in this extract, but its retrospective stance allows this to become evident on a larger scale. Emily stated that she accomplished many things that she "never dreamed [she] would do" when she had emerged from hospital. However, what is especially appealing about her description of activities after identifying the hospital as the starting point, is that in addition to her list of achievements of physical endeavour, she also includes emotional and mental ones too. In this extract she confronts two fears – of heights and of flying – yet she overcomes these to participate in the relevant activities that involve these fears. Above all, there is no mention of IBD itself posing any limitations to these activities. Inclusions of feeling ill during the helicopter ride and standing on the glass floor in the high tower are not directly referred to any aspect of IBD. Not only can this show a

management of IBD and related issues in daily life, but also how someone manages to separate additional afflictions. These can confound everyday life but not restrict it. Ultimately, the extract can demonstrate aspects of living beyond the confines of illness.

One interesting feature is the way in which Emily discursively treats illness in terms of organising her account. Her disease directed diary entries are usually recorded about two to three weeks after the main incident occurred. However, the other non-disease related entries, including those which held IBD related concerns that were secondary to or emerged from the main subject of the entry, were addressed much more promptly, either on the same day or were very recent if reporting a past event. Other entries were looking forward to other future events.

In this case, Emily recalled her holiday after being prompted to do so by recording an earlier entry about a forthcoming holiday to a different destination. Here is her own perspective on why she chose to record that particular story, despite it not being a recent event.

*I just remembered how scared I am of flying, but I knew I'd flown for longer when I went to Canada, so flying to Portugal wouldn't be as bad. I hadn't thought about Canada for ages, but all these things suddenly came back to me.*

*(Emily, interview 2, 2004)*

While Emily does not provide a lengthy explanation for her inclusion of the holiday narrative, her data perfectly illustrates the emergent properties of this particular way of using a diary, and how effective it can be in producing detailed relevant accounts that are not directed by disease but encompass its presence in daily life. Emily used this as a measure of achievements indirectly related to her stoma appliance.

### **9.3 Living across contexts**

Emily's account also raises awareness of another key element that is central to this analysis and to this project, which concerns the trajectories of participation across contexts of daily life. This is evident in the diaries and can be demonstrated by looking at contexts in more detail. As IBD has been previously studied mainly as a disease focussed entity, any additional contexts of living with wither ulcerative colitis or Crohn's disease have been

sidelined, or excluded altogether. Individuals live their lives in many different contexts simultaneously. Therefore in addition to the theories of positioning, and emplotment strategies, attention now turns to the ways in which participants identify the changing contexts within their lives, and whether this is deliberately stated or inherent in the diaries.

In terms of deliberately acknowledging different contexts, it is feasible to argue that Maxwell best exemplified this, as he made the effort in one series of diary entries to separate his weekday activities and weekend ones. Maxwell produced shorter individual extracts, and tried different organisational measures to produce his diary. The digital recorders had the facility to store entries into different files. All participants were made aware of this, but none of the others made use of this option, preferring to keep their entries in chronological order in one file. While Maxwell's decision to use different folders is not unusual, the separation of subjects to narrate is interesting. Before commencing this part of the study, it was fair to anticipate that the recorders might have been used in this way, but with the possibility of using one for illness related entries and the other for documenting other events that were not disease related. This was not only quashed by most of the participants opting to record units in the same folder, but the single folder diary production still enabled IBD to be "tracked" in terms of its presence or absence, as demonstrated in Hayley's and Emily's diaries in the previous chapter. Maxwell chose a different form of thematic separation in the practical recording of his diary, therefore implying that participating in non-disease related activity impacted positively on his adjustment to IBD. This diary set begins with the clear statements of how he intended to organise the recording:

*Folder A: this is what I've been doing at school and in the evenings*  
*Folder B: this is for weekends and other stuff*

*(Maxwell, concurrent diary sets 1, entries 1, 2004)*

What followed was a diary set that had two parallel trajectories. Folder A continued with detailed accounts of lessons at school, performance in various classes and the demands of homework in the evening. Unlike Hayley's regular weekly entries, Maxwell did not observe a temporal pattern, but tried



initially to record the two folders simultaneously. After a while Folder B did not continue in concurrence with Folder A and tended to be recorded during weekends. A later entry in Folder A was as follows:

*Today we had food technology, then maths and English, which is just boring really. School's really weird at the moment, as we've got loads of supply teachers in, so we've just messed about really. Tonight I had my accordion lesson. I've got loads of homework. It's been really getting to me. We've got strict deadlines for IT. I think it's the reason why I'm coping with my colitis. There's just so much work. So many essays – I hate essays. I felt all right at school today, no pain or anything, but I do feel less grown up around my friends. I'm smaller and skinnier – I felt immature when I got back to school. Some people have said that I'm small, but I just turn round and say that they're lanky.*

*(Maxwell, Folder A, diary set 1, entry 4, 2004)*

Maxwell's initial decision to separate his diary folders by school days and weekends, rather than symptomatic and non-symptomatic entries, could indicate a positive adjustment to IBD. However, unlike Hayley and Emily, Maxwell does not conclude this entry with a non-disease related activity to "round off" the account. It does not conform to the structured states of resolution that either Emily or Hayley include, conveying a sense of discord. His choice to deliver his diary in this way indicates purposeful awareness for different contexts in which his life is lived. There is the demanding schedule of homework for his first folder and the second concentrates on more leisurely activities. In other words, Folder A is manipulated by an institutional paradigm, while Folder B is recreational. At this point, it is reasonable to assert that the action of producing a diary is a positive resource for making sense of IBD. Participants are not just returning answers to a pre-defined research agenda, but are participating in diary production across several contexts. In the previous chapter, Emily demonstrated this in one extract that dealt with several plots over time, allowing her to make the decision to leave school. Here she demonstrates a cross contextual relationship with regard to an illness related feature of her life, only this time it is a cross contextual issue that occurs within the same event and time:

*The other day, I actually had a shower without my bag on, which is the first time I've done that and I really hated it. (Laughs) I was advised to do that by one of the nurses in the hospital because she said it y'know would be better to wash it than just using tissue, which, I suppose she has a point, but obviously the first thing I*

*thought was what if it gets active while I'm in the shower it's not exactly a pleasant thought. And I just -y'know luckily, it didn't. but I thought - well, It's one thing having it but when you have to look at it it's not a nice thing. Y'know. Living with it you can just about do but to have to stand there and look at it and wash it is the worst thing, in my opinion. I don't - didn't like it at all, and the first thing I did when got out of the shower was I had to grab a handful of tissue and stick it on it while I got dried off and everything else so I didn't like that at all so from now on I'll continue showering with the bag on, because when I get out the shower I have to change it anyway. Cos y'know when the bag gets wet then it's worse than useless, so I have to take it off. I was told that because I've been given these little stickers to stick on the filter that's on the bag when I go in the shower, which I never do. I always change it as soon as I come out because when it's wet. It takes a long time to dry for a start, it's like drying clothes, and if the water gets underneath the sticky bit then the water's in and it'll just come off anyway so I just change it every time I get out of the shower*

*(Emily, diary set 5, extract 4, 2005)*

This extract shows a clear distinction between a clinical and personal agenda. In a clinical context the extract shows the need to clean the stoma without the accompanying bag attached. It is also an acknowledgement of what the nurse considers to be best practice. Emily admits that there is logic to the suggestion, and one can ascertain a clinical reasoning behind this even though she does not say why. It is almost a blank page on which a patient information leaflet could be written, stating how to keep a stoma clean and free from infection. However, Emily provides another context for her actions, which the clinical recommendations do not take into account. Her concerns about the stoma becoming active are rooted within the social norms of embodiment that were raised in Chapter Two when reviewing Burkitt (1999) and discussions of the body. One would not defecate in a shower in the usual anal way, therefore why should that control be abandoned in the same situation? One does not have faecal control with a stoma, but one can still exercise control on the visible display of it, even if this is in a private environment.

The differences between institutional and personal contexts are brought sharply into focus in this one extract. While there are practical reasons for removing the bag, there are personal reasons for not doing so. Other social contexts do not consider the attitudes that individuals may have towards their appliance. In this case, Emily's concern is not what others think,

and how she positions herself (or is being positioned) with relation to them. Instead it is a complete self-assessment of her ability and willingness to deal with the clinical suggestion. The participatory aspects of dealing with the stoma differ hugely in various social practices, as Emily's account clearly shows. Ultimately, she concludes the account with a practical, rather than emotional response, detailing the incumbency of a wet bag, which she would change anyway. Therefore the end result of her showering with or without the appliance would still culminate in a change of bag. While this incident can be summarised as a way of living beyond the confines of disease – by literally covering up the stoma and not being forced to look at something which is displeasing to her – Emily's account reaches another level of reasoning, which conveys the need to participate in non-disease related activities. Her account also raises discussion about the meaning of everyday life, and the facets that this can be broken into depending on the level of participation in daily activity. An everyday activity like taking a shower is managed in a certain way by Emily. When it is suggested that she change this routine, the activity assumes a completely different context. It is no longer an *everyday* activity, and normality is removed from it. Being forced to look at the stoma and wash it without the bag makes the activity disease focussed, and is a reminder of her altered physical appearance.

This account demonstrates how a simple activity like this can become located within two different social practices. There is an argument supporting the nature of subjectivity in narrative within social contexts and how these can change depending on the context of an individual's life at different times (Dreier, 2000). These social contexts are not meant in the sense of social demographics (class, race, gender, etc), but are contexts of everyday life. Rather than trying to utilise a model where contexts are addressed separately in a forward moving trajectory, Dreier tried to encourage the reader to think *across* them. This is illustrated by documenting a family therapy session, which provokes discussion into how family members address issues outside of the therapy session. Observations are made on the clients' tendencies to speak in a language that they think appropriate for the therapy setting: when moved across contexts to another social setting, the narrative changed. This

provokes thought on how this is reflected in adolescents with a chronic illness, and how they position themselves in various contexts.

Throughout this thesis, the aim has been to investigate how participants manage IBD in "everyday life". This has been partially achieved by looking at their relationships and position in the world and whether IBD is present or not. So far this has principally meant life outside of illness, and outside of clinical reference, but when looking at different social contexts, there is much more to be said about the meaning of "everyday life". Rather than looking at it as a series of episodes that are unconnected with IBD, everyday activity is ensconced within several frameworks.

#### 9.4 Recording strategies

In addition to the diary content, positioning and variations of emplotment in the diaries, the actual process of recording became more transparent as participants included entries that explicitly related how and why they had chosen to record their material. The ways in which the young people recorded sometimes differed, and even more interesting was that there was a conscious effort on the participants' part to organise their diary differently. Hayley exemplified this, as there was a distinct change in her recording when she began her fifth entry in her first set of diaries. Instead of reporting what had happened in her day, she attempts to describe events as they are happening, including minor details such as restarting her computer. This change would be noticeable anyway because of the shift in recording direction, but Hayley herself acknowledges the difference:

*School's really hard at the moment cos right now it just revision, revision, revision. And more revision. I just got in now and I'm playing on my Sim golf. Not entirely sure what to say. Hmmm. Right now I'm having to restart my computer. My computer wont restart itself. Doing a recording this way is really hard so I don't think I'll be doing any more again, sorry.*

*(Hayley, diary 3, entry 1, 2004)*

This is a key entry, as it is an example of how participants were thinking about producing their accounts, and identifies what they personally found easy or difficult. After attempting to record things literally as they occurred, Hayley returned to recording events in her recent past or speculated on forthcoming

ones. Even at this early stage of recording, there was a distinct element of the diary becoming part of her life; there are more hesitations and deliberations. In addition to trying out a new recording structure, the sensitivity of the microphone is tested (Hayley recorded an entry with an explicit intention to do this) as she records a whole entry whispering, as the rest the household are asleep. The diaries become also more engaged with speaking specifically to the audience, and assume a conversational practice. (e.g. a recommendation for seeing a film: "if you're wondering about seeing it I think you should"). Overall, Hayley's accounts grow from being based solely on her daily activity to including detailed stories of friends and family members.

The interviews between the diary sets allowed for further discussions on ways of recording and what specifically worked for the young people in terms of compiling their diaries. The question of the process of recording the diary was itself a non-disease related factor that could facilitate positive adjustment to IBD, it was necessary to look again at the interim interviews, to see if this was evident. In addition to this there were other discussions that centred on why a participant had chosen to record a diary in a certain way, and the strategies that they adopted in the organisational structure of their accounts. The diary itself had the dual role of being a tool for revealing the plots of a person's life, but is also a plotted component, to the extent that it was an activity that was not specifically set aside, but emerged as a co-existing activity to other routines that were carried out during a typical day. A question about some background noise in her diary recordings led Anneli to explain in one of her interviews how the act of recording was very much integrated into her daily activity:

*I tend to record stuff with the talky thing while I'm doing other stuff, like in my bedroom if I'm putting make-up on, or just generally doing other stuff.*

*(Anneli, interview 3, 2004)*

Anneli admitted to initially feeling self-conscious which was common for many participants at the start of their recording process, but her above statement made sense especially on listening, as it became clear from the background noise that she was occupied with other activities simultaneously. It also helps to explain how her diaries emerged. The previous chapter noted

the differences in person-to-world and world-to-person directions deployed within Emily and Hayley's diaries, and the environmental factors surrounding each participants recording space may have some direct influence on the positioning and emplotment stance that they assume. Anneli was most certainly positioning herself in the person-to-world direction, and this was partially assisted by the way in which she chose to record her diary, in the privacy of her own room, enabling spontaneous recording rather than deliberate recollections or events or emotions.

Anneli verbalised the way in which she chose to record her diary, but there were other biographical sounds that occurred on them without explanation or introduction. Participants sometimes recorded sounds that demonstrated extra-discursive aspects of their lives. Towards the end of her fourth diary set Hayley had been learning to play the drums and demonstrated her newly acquired skills in a diary entry. While brushing his cat, Maxwell recorded the purring sound. This was very encouraging in terms of how the diary served as a positive resource. It was not only a repository for recording emotions and daily activity, but became an integral part of the participants' lives. Instead of an additional facet of life that was external to the described activities on the diary and interview recordings, the act of recording itself had become something that was not so far removed from everyday life. Although such aspects were not traditionally verbalised, they were activities that were central to the plots of the young people's lives and these sometimes occurred frequently across all the diary sets. When looking at some of the regular people and scenes in a participant's plot within their diary, the question of coherence in the diary accounts is raised. This can help to gain more ground in terms of how participants organised their accounts and subsequently how this revealed how they managed their experiences of IBD in their lives.

### **9.5 Varieties of coherence in the accounts**

An appropriate example to begin with is a reference that is constantly made by Emily throughout her recordings. She referred to a local cricket squad, which featured in several extracts throughout the course of her diary. In terms of social development, the cricket team was an important resource for Emily. It is also a narrative resource as there are several contexts within

which it is diarised. The previous chapter partly focussed on the positioning of IBD in the diaries and how it was absent from, embedded within or directed the course of the accounts. The presence of a constant feature is also an element of content coherence that runs through the diaries, but there are other types of biographical/narrative coherence that have been reported. Habermas and Bluck (2002) noted of the four types of coherence that are present in adult narratives. In every sense, Emily's extract can contribute to this theory positively, as it seems to display aspects of causal coherence that are identified with relation to life story production. However, there are other areas of coherence that do *not* seem to fit the characteristics that the authors identify, especially the definition of thematic coherence. Turning specifically the emergence of the life story in adolescence, Habermas and Bluck (*ibid*) state that thematic coherence in a life story is dependent on three subsidiary abilities: summarising multi-episode stories, interpreting them and presenting an awareness of inferential processes deployed in autobiographical remembering and reasoning. The authors observed that children became more adept at summarising many events as they got older. Their example was a frog story in which no 3-7 years olds, 13% of 9-11 year olds and 50% of adults produced a summary statement of the story.

However, in Emily's account of her holiday, the opposite occurs. While this could be attributed to the instantaneous properties of recording a diary, it is more applicable to the present and forthcoming events that participants spoke of. The extract is an entry that offers great detail on an event that was quite a while ago in relation to the context of the diary exercise. Rather than summarising the episode of the holiday as an event in which she realised that falling in the snow did not have the dire consequences for her stoma appliance as she had previously envisaged, Emily sees fit to fill the extract with ancillary details, matters that would not be commensurate with some theoretical definitions of thematic coherence.

Staying with coherence as an analytic device, it is time to include the youngest and final participant, Philip. Like Baljit's earlier recording discussed in Chapter Seven, Philip's diaries were not lengthy or introspective like those of the older participants. However, his contributions are a good starting point from which to begin this part of analysis, as there are marked differences in

his interviews and diaries. When the diaries begin and start to relate the everyday activity, there some arguments would maintain that coherence is lost on certain levels. Below are some brief separate entries from Philip's diary set that followed the initial interview:

*Hello, I've not managed to record much this week because I've been really, really busy, doing the things I've been busy with. Last weekend I was really busy swimming, also I've got my violin grade one on Monday so I've been doing lots of practice for that. On Tuesday lunchtime I went cross-country running but I didn't do too well because my throat was really dry because I've got a cold. I've also got some stick insects. Their names are Sticks, Twigs and Sticky.*

*In swimming the events I did are 50 metres front crawl, 50 metres back stroke, 200 metres breaststroke, 400 metres front crawl, and then I've got a 100m individual medley next weekend. That's one length of butterfly, one length of breaststroke, one length of backstroke and one length of front crawl.*

*In the individual medley I came last in my age group, but I'm not disappointed with it as I thought I did a good swim.*

*(Philip, diary set 2, entries 1, 2, and 3, 2004)*

There is a high degree of explanation in all of the entries, and similar accounts follow in different activities, such as detailing what Philip had been reading wherein all titles of a book series are listed. Such levels of detail depart from certain coherence models, and are positive findings in ascertaining positive outcome of non-disease related activities rather than concentration on generic facts associated with IBD. It is interesting to note similarities in the reflexive positioning within Philip's diaries too, as he describes a cross-country run at school:

*With the cross country I couldn't do it this time last year because I just didn't have the energy as I'd just come out of hospital*

*(Philip, diary set 2, entry 4, 2004)*

This acts as reference point wherein he considers his physical abilities and assesses his stamina as he realised he could not run to the same standard prior to illness, in the same way as Emily noted her depleted strength in swimming. (Ch. 7, section 7.4) Earlier Philip's detailed listing of his reading and swimming pursuits strengthen the argument for assessing the positive values of non-disease related activities on psychological adjustment to living beyond



the confines of a chronic illness. Much of these entries, for Philip and other participants were verbalised. However, the evidence of participation in non-disease related activities was not necessarily completed in this way either. Although this chapter asks whether narrative coherence plays a part in the successful adjustment IBD, it is perhaps more productive to sub-categorise this and remember that there are several *coherences* in the accounts which can fall under scrutiny, in line with the multiplicities of selves which were discussed in Chapter Seven. In addition to the positioning theories that are applied, there is a high level of *causal* coherence according to Habermas and Bluck's descriptions. Their definition of causal coherence is that it is used "not only to link the episodes within a life phase and to relate life phases, but also to explain changes in the narrator's values or personality as a result of events over time" (p.751).

Coherence operates on personal levels too. Returning to both Emily's and Hayley's diaries, an analysis follows of the social contexts that both girls find themselves in and how IBD relates to them. When looking at the start of both girls' diaries, there are marked differences. Hayley's account is very school based and she is immersed in course work. This is an ongoing, regular pattern of revision and pressure and the regularity of recording reflects the routine that Hayley has become accustomed to. IBD is mostly conspicuously absent from this routine. The sense of a long lasting activity is present and this contextualises everyday life for Hayley at this time. Emily, however, presents a much more varied diary. It is recorded in roughly the same time sequences as Hayley (i.e. every two or three days) yet the collective structures in which the diary operates are hugely different. Rather than focussing on a particular issue, Emily is in constant stages of reassessment of her condition in relation to the rest of the world around her. In Chapter Eight her first extract was initially considered in light of the vocabulary that was used and the knowledge that she was speaking ultimately to someone who knew what this would mean. However, looking beyond this it is clear how Emily is not just recording what she has done, but re-evaluating her positions and attitudes within the diary. This is not the same as the positioning theories that were discussed in the previous chapter – instead this argument relates to the emplotment strategies in the diary and what they reveal about Emily's

management of disease related concerns. It also argues how she develops her own sense of personal coherence, even if her accounts may not fit previously documented coherence models. From the very first extract when she related swimming with her sister, she give a snapshot of how swimming as an activity had changed for her since having surgery. Her bodily awareness is heightened and also indicates that it has been a gradual process of adjustment. Her documentation is not just a diary entry; emplotted into that is her realisation of how she has not been engaging in that activity in the same way. In this sense, this is not a regular event that can be classes as "everyday", as Emily has negotiated an extraordinary element into that circumstance.

There are several ways in which participants' handling of their diaries can be explored, in terms of IBD and also without the consideration of disease. They have allowed a multi-faceted view of disease experiences, whilst going beyond collecting accounts of disease. They capture what it is like to be a young person without always constraining this essence with IBD related contexts.

## **9.6 Conclusion**

This chapter has looked at the ways in which participants chose to organise their material and what particular value the audio diary had as a tool for them to convey their daily life with IBD, regardless of whether the disease was a central concern or totally absent. It has revealed how the diaries have acted as prompts for recording further material, and also demonstrated how the participants' lives were lived across many contexts, which do not fit a clinical agenda (Emily's description of showering without her ileostomy bag does this very clearly). This section does not proclaim any models of biographical coherence to be a standard to which the diaries should adhere if they are to successfully demonstrated adjustment to living with IBD, or that they are being specifically compared and contrasted with such models to form the foundations of this argument. Instead it uses the umbrella of emplotment and recording strategies to see how and in what ways coherence can be interpreted if it is being used as a mechanism in some way to calibrate adjustment to IBD.

This chapter only touches on certain aspects of narrative coherence, and given the volume of fascinating material generated by the participants has frustrating limits in terms of the number of diary extracts and coherence arguments that can be examined. However, it conveys a partial representation of how emplotment and coherence can assist different readings of interview and diary data, to see how young people have factored IBD into their lives without necessarily allowing it to become a dominant force. The unclosed diary has facilitated this analysis to maximum effect, and has yielded much more scope for future research into this area, not just within IBD but other chronic conditions too. 'Sorting things out' is a very generic phrase often applied to practical every day concerns that determine the practical order of a day. In this case, it means much more: sorting where IBD is bracketed in relation to the other facets of daily life, and also in the context of organising the diary for the purpose of this particular study. Whether consciously or not the participants display evidence of organisational strategies that become visible through emplotment and coherence levels, all of which can assist an understanding of how young people learn to live with IBD.

## Chapter Ten

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**Advancing the understanding of IBD and adolescence**

## 10.1 Introduction

At the start of this thesis, the central research question was to find out how young people learn to live with IBD. The questions that emerged from this central issue were:

- How do young people place IBD in their lives and position themselves with relation to the world around them?
- To establish how young people live with IBD, is it more beneficial to focus upon general age-related activities of their daily lives, rather than concentrating on generic factors associated with the condition?
- How can we demonstrate how young people live with IBD over an extended period of time?

All of these questions led to an examination of the content of the data generated for this whole project, and specifically looking at the action within the data. This was particularly evident in Chapter Nine, which looked at how the young cohort of participants organised their diaries, and also further back in Chapter Five, which looked at Tracey and Alan's varieties of positioning and emplotment in their interview accounts. Using interviews with adults and a longitudinal diary study with young people, the project has certainly brought this knowledge further forward in terms of accessing lives and the day-to-day issues that can arise in conjunction with managing Crohn's or colitis. But how much can the questions posed above be answered now that this work has been done? This chapter discusses each of these questions in turn, using the adults' and the young people's accounts.

## 10.2 How do young people place IBD in their lives and position themselves with relation to the world around them?

Throughout the retrospective interviews with the adults, and the data generated from the young people, two main issues arose that helped to answer this question. The first was the definition of living within or beyond illness. The second was being able to trace IBD in the accounts (this was more applicable to the audio diaries) and by looking at varieties of positioning within all the data. One of the most important developments that this project

makes in terms of discovering how young people live with IBD is that it deliberately observed the transition from describing interviewees as patients within a medical sphere, to regarding them as participants. This is not just as participants in a study, but also as active participants in an active data collection exercise. They were active in the sense that they themselves arrived at various positions and re-positions during the course of the interview or of the diary production.

### 10.2.1 *Beyond the confines of illness*

The transition from patient to participant leads to the debate of definitions within other contexts that are central to this project. Not only does this regard the participant as active and encourage new ways of examining IBD and young people; it also suggests closer interpretation and possibly re-definition of certain terms that emerged during data collection. In Chapter Four, the analysis of the adults' data led to considering what it actually meant to be living "beyond the confines" of IBD. From the data it transpired that this did not specifically mean valorisation of activity whilst being diagnosed with a disease. Establishing what it is to live beyond illness was not as simple as locating examples of positive actions or behaviours. Instead it is a phenomenon that is an ever-changing concept within individual lives. The study showed that there are distinct similarities between living within and living beyond illness, and that the two conditions can co-exist depending on the perspective that an outsider takes on an IBD patient's circumstances. It also depended on the way the participants positioned themselves too. Rather than being viewed as problematic, the dichotomy between these two concepts can be viewed as a resource for learning to live with IBD. While this may not be unique to IBD it appeared in several contexts of daily life, and can be interpreted in two ways. It could be argued that a determination not to allow IBD to infiltrate everyday life defines living *beyond* the confines of the illness. Alternatively, equal determination to conceal one's affliction from others at the expense of one's own comfort necessitates an acceptance of living *within* them, by having to go to extra effort to manage inconvenient and sometimes embarrassing symptoms. A clear example of this was in Paul's account of his expedition where he experienced loss of bowel control but was determined to

maintain a undisturbed public face. This simultaneously placed him within and beyond the confines of IBD. Tracey's experiences at her scout camp also fitted this ambiguous definition. Before she received a diagnosis of colitis, the symptoms that she was experiencing were accounted for as a result of the everyday activities that shaped her experience of the camp. It could be argued that she was living "beyond the confines" at this stage, as the symptoms are accommodated and dealt with amidst daily activities. Alternatively, she was *within* the disease as her resulting depleted energy levels were already beginning to cause apprehension about living conditions.

This ambiguity of living within and beyond IBD continued across other related circumstances, particularly with reference to information sources and communication. The data from the adults revealed that health information seeking behaviour followed consistent patterns of initial referral to immediate family members (Ackard and Neumark-Sztainer, 2001). In connection with those findings, some participants related how they turned to a parent (usually their mother) for information. However, extra discursive techniques were enabled through literature that accompanied material from relevant IBD support groups, such as the "can't stop" card that Ethan mentioned in his interview (Ch. 4, section 4.6.3).

Ethan's account of indirect disclosure about colitis also invites discussion about the relationship between narrative accounts and everyday activity. While it is plausible to say that such terms related to IBD in the sense of "can't stop – I have Crohn's disease and need to use your toilet quickly" would have been mutually understood between the participant and interviewer, and amongst others with IBD, it poses questions around the nature of such vocabulary, and specifically how it becomes embedded in everyday life to no longer warrant explanation. It is at this point when there are additional processes that supplement the interviewees' accounts that some into question here. Like the vocabulary that was observed in IBD outpatient clinics as documented in Chapter Two, there are aspects of living with IBD that are embedded into everyday life that would otherwise not be mentioned in mainstream literature. The notion of how physical factors become "embedded" in daily lives is also an interesting avenue to follow; it implies that changes brought about by physical illness/disability are

accommodated into every day existence *without* disrupting it. Instead of becoming conspicuous aspects of life, they are gradually absorbed into routine activity, which is a key element of this research in establishing how the idea of living “beyond” the confines of chronic illness is applied.

In addition to determining what it means to be living beyond the confines of illness, definitive questions also arise in assessing the influence of non-clinical support networks as opposed to clinical ones. This generates discussion of what a non-clinical support network is. An example was demonstrated with Hayley’s experiences of the school nurse, viewing the nurse as invaluable support and not necessarily as a health professional in a clinical context, while Anneli viewed a school nurse as authoritarian and sceptical of her presenting symptoms. As with separating the concepts of living within and beyond illness, it is not as easy to delineate the definitions of clinical and non-clinical entities as individuals participate in similar activities across different contexts. Another view that can be applied to this is that people themselves can act as a non-clinical support strategy, in that the individuals make a conscious decision to test themselves to establish whether they have, or are in the process of making sense of a particular problem - in the case of this research, making sense of IBD. More specifically, in Hayley’s case, expressing a wish to make sense of the numerous medicines that she is taking daily when she set about recording her medication entry. In mentioning Hayley’s data, we are reminded of the various positions that she took with relation to her experiences of Crohn’s disease, and how she placed herself in terms of the environment and in terms of others around her.

### *10.2.2 Positions in the accounts*

In addition to the varieties of positioning argued by Harré and van Langenhove (2002), Bamberg (2004) offered other aspects that can assist the data. Chapter Five introduced the two directions that form the basis of Bamberg’s analysis. These take the direction of world-to-person and person-to-world relationships. He defined the former as a “subject being determined by the outside”, mainly social and biological forces, and the latter being “the unitary subject as ground”. However, like the conceptual framework of living within and beyond disease, the two directions are interchangeable and are



demonstrated by the interview and diary data. This is particularly apparent in Chapter Eight when Emily and Hayley's diaries switch directions, within a diary set, and within individual accounts. In addition to determining the relative influence of non-clinical support in disease outcome, this type of analysis can assist in determining how identity is manifested in the diaries, and how IBD contributes to or is absent from the creation of a self through these narratives. A debate emerges when considering these two directions that relates to the absence or presence of illness. That is whether a world-to-person position emerges in a diary account that is primarily concerned with illness, and conversely, if a person-to-world account is produced when IBD is not in any way present.

Other aspects in the accounts, such as aspects of negative experience connected to IBD, may initially be considered to be regressive narratives, in which individuals are forced to comprehend a problematic aspect of IBD and state this as the dominant subject of the account. In the context of this research, this could present as a disease directed account as defined in Chapter Seven (section 7.5). While some accounts address some negative aspects of IBD and could be construed as regressive, the data in this study does not always convey a regressive position as participants are in constant negotiation of their lives over time. There are several arguments in narrative literature that define the nature of regressive, stable and progressive narratives. These are framed in a global sense and applied to lifestyles and intellectual development (Gergen and Gergen 1986) and also with particular relation to IBD (Kelly, 1997). While these are interesting and indeed viable arguments, an analysis of emplotment and positioning within the diaries reveals that the definition between these narrative characteristics cannot be applied these ways. As the concepts of living within and beyond the confines of illness cannot always be distinct, the nature of the diary accounts also cannot be ascribed to one particular narrative categorisation, especially given the wider expanse of time in which they are produced. Even when the participants themselves tried to categorise their daily activities within the recordings, (such as Maxwell initially beginning two folders for school and weekend activity as seen in Chapter Nine), this was not sustained. It also demonstrates how accounts cannot always be classified according to existing

theories, as they embrace several contexts and environments, physically and psychologically.

Kelly's (1997) definition of a regressive or even a stable narrative was diseased focused and demonstrated a situation that was beyond the control of the subject in question for that particular study. Some data in this project could so easily be interpreted as a negative consequence of IBD and its related symptoms and treatment. At first the project data could be seen as narratives of curtailment, of defeat and ultimately of regression. While Kelly may even classify such accounts as stable narratives, it is possible that his interpretation of the narrative self in this context would have overall negative values. This is not the case with the outcomes of this project, and raises a question of the effects of the actual process of diary production.

Through their diaries the young participants were able to convey further contextual information about the presence of IBD in their lives. It transpired that Anneli, who began her recording with her views on treatment of adolescents with Crohn's disease was actually experiencing symptoms prior to commencing and during the recording. However, the symptoms themselves did not actually occupy as much recording space as the day-to-day activities and positioning of adolescence and IBD. Overall, it proved to be a conceptually fulfilling exercise: even though most data extracts were short, they were already providing more possibilities about the uses of narrative using this method.

Previous research on IBD and adolescence spoke of roles, even qualitative studies that were interested in hearing stories from young people about the disease. Such studies were driven by the identification of roles during adolescents' adjustment to IBD, such as the child/patient or as an adult. While this project does not dispense entirely with the notion of roles, especially within the retrospective study, the concept of positioning allows greater analytic flexibility within these diaries. Harrè and van Langenhove (2002) assert that positioning is an essentially discursive practice, and also acknowledge the emergent *self* within this practice. The same approach can be applied to the diaries. This is because of the conversational element in the diary production that resulted from the supporting interim interviews. What also becomes apparent on further reading of Harrè and Langenhove's notion

is the analytic possibility of searching for aspects of deliberate and forced positioning. While the authors described this in the context of two actors in conversation, it is evident that this also occurs in the diary. In the previous chapter, we saw Anneli's assertion that she wanted to talk about the treatment of young people with Crohn's disease. Throughout all the diaries, claim-making is present and reveals how and in what ways the participant makes a deliberate positioning. In Anneli's case, she deliberately positions others in relation to her position as "someone with a disease". While Anneli's extract can easily be categorised under the heading of adult attitudes and behaviours to young people with IBD, and can be described, it is helpful to acknowledge Anneli's form of positioning during the recording of the diary, and consider if other methods would have captured this in such a candid form.

When leaving the possible interpretations of living beyond illness aside, and just focussing on locating aspects of life that were non disease related in the data, it became apparent that this was not as easy to look for as initially expected. From a personal perspective, I as the researcher was often drawn to the disease related aspects in the accounts. As an outsider not being directly affected by IBD, curiosity often resulted in a strong compulsion to concentrate on the disease-focussed material at the expense of finding out about ordinary daily events. This was an important consideration in terms of analysing the data, and the theoretical resources of positioning and emplotment helped to overcome this by demanding that a comprehensive view of data extracts was taken which include analysis of non-disease related material as opposed to disease-focussed material.

### **10.3 Is it more beneficial to focus upon general age-related activities of young people's daily lives to establish how they live with IBD?**

The aim of this research was to remove the central focus from IBD and pay further attention to other facets of everyday life that were concurrent with disease experience. Reducing the pathologised perspective of IBD necessitates acknowledgment of cross-contextual circumstances in which data are produced. The characteristics of positioning theory and therapeutic emplotment made a viable contribution in locating these different contexts within the data and emergent nature of the retrospective interviews and

diaries. Participants' ability to recognise how they modified or continued to conduct their daily activities with the added variable of IBD was present in all diaries, and across the age group. The variety of positions they took became visible over long periods of time and within single diary extracts.

The interviews with the adults in the first part of data collection contained a variety of issues that concentrated on non-disease related biographical information. However, as much as this focus was maintained either by interviewer or interviewee, disease issues often permeated the data and became a lead issue. This was due to the intrinsic qualities of the interview itself. In following a life story pattern there was always a natural progression of pre-, mid- and post-diagnosis incidents. While the interviews covered a wide variety of biographical events, including holidays, school, and relationship development, IBD was a very noticeable entity in the accounts. Therefore it was less easy to focus on non-disease related activity within the retrospective interviews than with the management of the diaries. It was when the longitudinal diary study began that the fluctuations between health and illness became more obvious, enabling other activities that were not disease related to emerge as equally if not more prominent than IBD. By noting and observing participants' accounts that are disease absent, and seeing what activities form part of their daily lives, we gain a complete, more rounded view of the subjective experience of living with IBD. While informing us about how young people learn to live with ulcerative colitis or Crohn's disease on many levels, by concentrating on non-disease, age-related factors we are able to tell a different, more positive story about IBD and young people, with a clear message that part of being chronically ill involves periods of time when one is not ill.

The action of producing a diary and of participating in an active, co-constructed interview is itself a resource upon which perspectives of adjustment to IBD can be drawn, and positions can be established or even altered during the course of this activity. In analytic terms, there were literary references to the extra discursive aspects of narrative and during analysis of the prospective diary data. In terms of assessing the impact of non-disease related activity, there is a pertinent strategy in seeking what is absent, rather

than present in the diaries, mainly the presence of IBD, and the unclosed diary allows a unique perspective into how this can be achieved

### *10.3.1 Coherence in accounts*

In answering whether biographical coherence can indicate levels of adjustment to IBD, or indeed any other chronic illness, this study has revealed that there are different ways of defining coherence. This is not just in the definitions laid out by selected authors in the literature review, but is affected by the changing positions that are taken throughout diary production and within participants' lives. The term "biographical coherence" is too vague to use as a determinant of young people's adjustment to chronic disease and IBD. When returning to Emily, in the diary extract that told of her Canadian holiday, the lack of summarisation she displays is certainly not due to age related inability to perform this narrative task, or her personal ability in producing accounts. However, her account here does not totally support the arguments that biographical coherence can indicate psychological well being, as the content of her subsequent diaries indicated a high degree of adjustment and acceptance of her condition in social terms.

Due to the biographical disruption that illness brings (Bury, 1982) a need exists for young people to make sense of this. Causal explanations, according to Habermas and Bluck (2002), are extremely important for making links between the self and event/circumstances. The authors also questioned whether there is a typical structure in life narratives that is comparable to the intentional structure of single stories. If one takes their definition of causal coherence to be the model for fashioning an answer, then it is possible to argue that this is a typical element in life narratives. However, another question can be added to this, which is whether this is a typical structure that is located within life narratives that also factor in the presence of a chronic illness. By locating a typical structure in a certain type/definition of coherence, it is possible to assess if this has any salutary effect by comparing these in relation to the interview data at the start and close of the study. While this is not a statistical exercise, and cannot be due to the small sample size of this project, it is a useful starting point from which to possibly undertake larger scale projects of this nature and to establish if there is evidence of a link

between certain types of coherence and disease adjustment. While it is safe to say now that no single model of narrative coherence can be used to assess how participants have adjusted to IBD in their lives, there is another aspect of coherence that can be examined, which is aligned to the diversity of events and contexts in which the participants produced their accounts. It is effectively rendered in the diaries as the young participants continually reassessed and re-positioned themselves in relation to their illness and others around them.

By asking whether narrative coherence can give any indication to psychological well being there is an immediate assumption that lack of coherence is a negative concept. However, this is not necessarily the case when this is viewed in the light of positioning theory. The young participants here have revealed how they have repositioned themselves in terms of illness, independence and identity, and these beliefs have changed over time, whether this has been in their interviews or diaries. Emergent narratives can allow "multiplicities of self" to unfold, which results in a plurality of coherence, meaning that the term must be used carefully and with restraint if it is to be researched with relation to IBD in more detail.

While aspects of coherence may not appear to tally with the data extracts in terms of how narrative coherence is sometimes defined, they can still contribute towards understanding the level of adjustment that young people achieve when examined within the frame of emplotment. Not only aspects of emplotment held within the participant's accounts, but also in the set up of the data collection exercise. In addition to producing the accounts, participants factored in the visits for the interviews between their recordings, and emplotted other characters and concepts in their lives. At all times they were aware that they could include other family members and friends in their diaries, specifically meaning that others could add something onto the recordings if they so wished. They were aware that other people of similar age were participating in the study and were also directed by some of the themes that arose from the retrospective study, thereby plotting them into their data.

When analysing accounts from a coherence point of view, it emerged that there is no single model of coherence that can be specifically applied to establishing a link between this and psychological well-being. Not only are there different types of coherence that authors have defined – some being

broken into several types, while others are simplified into a singular definition – but there are different circumstances in an individual's life and different contexts in which they will produce narrative accounts. Therefore, as the conclusion of the previous chapter said, there are multiple coherences on which these narratives will operate, making it inaccurate and unwise to use a specific model to assess how adolescents learn to live with IBD.

#### **10.4 How can we demonstrate how young people live with IBD over an extended period of time?**

Theoretically, designing a diary study is a logical step toward answering this question, but there were several practical concerns that complicated this. Chapter Six detailed the exact procedure of the data collection, and the rationale behind the exercise. As the participants were fully aware that they had control over the production of their diaries, there was no standardised pattern of recording regularity, individual entry length, and no given specifics on what they should include in the recordings. There were also variations in levels of account detail between participants. This was to be expected, given the creative freedom that the young people had, but it was not problematic, in terms of the data generated and the levels of knowledge that are revealed about living with IBD as a young person. The diaries allow a view of IBD moving in and out of lives at different intervals, and facilitate reflection from the participants in how they have come to terms with certain aspects of their lives that have been and may continue to be affected by IBD. As this was a diary method that was considerably different to a traditional diary output, in terms of being a private, autobiographical venture, we must examine more closely how the unclosed diary design utilised in this research can contribute towards a greater understanding of young people and IBD.

##### *7.4.1 The contribution of the unclosed diary*

As with the issues raised in Chapter Four regarding the accounts of public and private experience revealed by the adult participants, similar issues arose within the production of the audio diaries. They were produced in the knowledge that they reflected personal thoughts and that they would be analysed for research purposes. They were not diaries languishing in a

repository waiting to be discovered. They are personal yet at the same time collaborative, and, like the interviews in the adult study, they are action orientated. The definition of the unclosed diary is that it informs what it is like to live with IBD on an extra level which complements the existing concerns in the literature, but also goes way beyond these by capturing life experiences with IBD as they are lived. They also operate at additional levels to the pure content of the recordings. The diaries had to remain "unclosed" in the sense that they were not scrutinised for the content and nothing else. The second concept of the unclosed diary was that unlike autobiographical diaries, they were private reflections and confidences that were made with a particular audience or objective in mind. They were guided in ways that participants would not have otherwise formulated a diary in an IBD-related study. Previous work on chronic illness that has sought coping strategies has often utilised diaries in a symptomatic way, which depersonalised the lived experience and effectively deleted aspects of everyday life from contention. What this study has showed by using diaries in this way is that they can maintain a level of personal experience whilst simultaneously providing insight on living with IBD.

Content alone was not viewed as the *fait accompli* for the research, and the aim of ascertaining a generalised understanding of adolescence and IBD was not paramount. Therefore looking laterally at the accounts as they were produced in an attempt to find general themes would not have been entirely productive as such an analysis would not account for individual differences in producing accounts and abilities in documenting daily activity. While it is fair to assume that initial reticence and self consciousness are initially present in all cases while participants become accustomed to the act of recording, consistence across all cases in other areas, such as how the diaries are organised, length of accounts, how "retrospective" they are in terms of reporting events in the recent past, cannot be expected.

Like the emergent quality of the retrospective interviews, there is further scope for this quality to be explored in the diaries. This is due to the length of time of the study, and also because of the brief interviews between each diary. The initial interview study with the adults had already provided a platform from which to embark in this direction, and there were themes that could be explored. Again, there was a fine balance to be struck when



managing disease related issues, and making sure that these were not at the forefront of enquiry. Such issues were addressed in the initial interviews, such as what medicines a participant took and how they incorporated this into everyday life, yet an emphasis on all aspects of life that surrounded disease experienced was encouraged.

In addition to gathering general emergent themes, the diaries also revealed more complex examples of positioning and emplotment. The temporal difference afforded by the diaries makes the investigation of individual plots of the transition between remission and relapse and the general question of managing IBD and daily life more engaging. In addition to seeking what the participants reveal to be of concern to them while living with IBD, there is more scope to examine what is being achieved in their diarised accounts, across many contexts, rather than in a specific interview situation.

The short interviews that took place between each recording set also helped inform the direction of future diaries. Although the issues raised from the retrospective study informed the design of the diary study to a certain extent, particularly with the benchmark interview content, the intermittent conversations recorded between diary productions were integral to the development of the diaries. The initial interview was the most disease focussed in terms of researcher direction. This was mainly to establish the complete circumstances in which the participants lived, which would clarify any tacit reference to disease related issues in the diaries.

The unclosed diary also facilitates a cross contextual approach to investigating living with a chronic illness. Even if a diary set is systematically examined chronologically from beginning to end for the purpose of descriptive analysis, there is always the danger of discounting the institutional, recreational and emotional frameworks in which the accounts are formulated. Emily's example of showering without her ileostomy bag showed this. This demonstrates the difference in the types of data generated by the retrospective interviews and the diaries, and it is a clear indication of what the diaries can achieve that interviews cannot. While the retrospective interviews opened up a series of concepts to explore within the diaries, and enabled the analytic perspectives of emplotment and positioning to be developed across

the data, the diaries allow a splendid view into how IBD is factored into lives at the most everyday level, rather than in exceptional cases.

It also enabled the true value of the observational work that was conducted in clinics prior to data collection to emerge, as there is no need for the participants themselves to discursively treat any IBD related feature in their diaries as an exceptional phenomenon. Emily's data is particularly relevant here, as it reveals that the removal of active disease through surgery does not signify the removal of any disease related problems. While it removes the primary symptoms of IBD, it certainly does not remove aspects of the disease. In fact, in Emily's case it encouraged a heightened awareness of everyday activity more so than ever, particularly in her description of showering without her ileostomy bag attached. A new state of embodiment brought about by colon removal and an ileostomy bag necessitate a re-adjustment and acceptance of the body on technical and social levels. While such readjustment occurs in many illnesses, the ways in which this happens on practical levels is not always documented plainly, and is often clouded by a clinical agenda that does not sit congruently with everyday activity. The unclosed diaries document the space between illness and health that Ironside *et al* (2003) sought to achieve within focus groups and interviews. If anything they do this more effectively, as they are produced over time and allow unlimited reflection without the constraints of a schedule.

The luxury of extended time in which to explore individual lives was an enormous benefit of the diary. In Hayley's case, a casual mention of a boyfriend (not in data extracts reproduced in this thesis) is not expanded upon, but more information is offered in the subsequent interview. The temporal organisations of the diaries are also important here. Upon questioning, it transpired that the Hayley's relationship with her boyfriend had continued for four months prior to the commencement of the study. This is another important development in the aims of the diary production. While revealing that the diaries and interviews yielded different types of accounts, there is a positive implication held here that the diary is such a regular activity – not only can aspects of IBD be included smoothly and without explanation due to researcher knowledge, there is similarly no intrinsic need

in Hayley's case to give background information on any new non- disease related aspect of her life.

### **10.5 Conclusion**

Radley and Billig (1996) assert that "people's health status should not be treated as a given, but attention should be paid to the ways in which they constantly construct or reaffirm their own health in difference circumstances and different relationships" (p.221). It is this argument that crystallises the aims of this research. By attempting to establish how young people learn to live beyond the confines of chronic illness, a need exists to access the movement between and across social contexts.

There have been many stimulating revelations in this study. Participants from both stages of data collection have disclosed very detailed and personal information pertaining to IBD and its place within their daily lives. Often there were points in the data collection that yielded lengthy discussions that tended to become illness related, but this did not necessarily detract from determining the aspects of life that were also intrinsic to living beyond the confines of IBD.

To understand how adolescents live beyond the confines of IBD, a need exists to understand the illness and paradoxically focus on it to understand everyday aspects that it demands, whether this is changing a stoma appliance or preparing medication. IBD is an issue, but when analysed in the contexts described in this thesis, it is not the whole story, and specifically is not always the main "character" in the plot of a participant's life. It is through this analysis that the strategies of living beyond it become more obvious. Consideration of stories and their specific purpose provides an ideal platform to examine accounts of daily life in relation to a chronic illness that, given its inconveniencing and often embarrassing symptoms, does not slot comfortably into everyday life and communicative action. While the project has sought and successfully achieved an insight into living beyond the confines of illness, it has also extended the boundaries of diary production. By examining how young people live beyond the confines of IBD the methods of this study have also extended the confines of the traditional use of diaries to enable the view of life as it is lived with a chronic illness.

## Chapter Eleven

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### Conclusion and further areas of research

### **11.1 The initial question**

From the very beginning this research has questioned what it is like for a young person to live with IBD. Rather than framing this question and looking at young people's lives as defined by the disease, the aim was to look at other issues that extended beyond illness as well, to gain a more complete, less disease orientated view. To do this, there were additional questions that needed asking. These were:

- To what extent does IBD feature in young peoples' lives and how do they position themselves with relation to the rest of the world?
- Does the concentration on non-disease, age related factors, as opposed to disease related aspects, give a greater picture of what it is to be a young person living with IBD?
- How can this be demonstrated over a longer period of time?

From these questions, a subset of issues emerged within the data analysis that followed through to the discussion. These issues specifically concerned what is actually meant by living beyond the confines of illness, and also how much levels of coherence in participants' accounts could indicate any level of adjustment to IBD.

### **11.2 Development and summary of this thesis**

In addition to the questions raised above, it is also useful to return to the additional questions raised in Chapter One to see how far this research as answered the main questions above. When searching literature that specifically addressed IBD and adolescence, it soon emerged that there was little evidence that documented the lived experienced of IBD on a daily basis. From an early point it became clear that the literature search needed to be broadened to address chronic illness as a general concern, to help answer the main research question. In addition to the IBD literature, there were also online discussion forums that targeted adolescent audiences. These could partially help to answer some of the above questions. But yet again, they tended to be very disease focussed and revealed little about the lives in which the young people in question lived outside of disease.

Having consulted literature regarding methods and how best to conduct an interview with special relevance to this project, a retrospective interview study was conducted with adults who had had considerable experience of IBD during adolescence. This interview data provided a rich source for themes that could be explored for further data collection, and also demonstrated how the active interview worked.

Using the active interview as a theoretical and analytic reference was extremely beneficial. Looking at the interview content yielded many issues relevant to IBD and adolescence, such as disclosing illness; managing the disease in public and private situations; and feelings towards the body. There are striking accounts of how the body is sometimes viewed separately to the self in periods of relapse, and also how individuals are willing to undertake activities that they knew would be to their physical detriment.

In terms of demonstrating how such investigations can be managed over time, this project successfully followed a group of young people at various stages over a 48-week period, and gained considerable insight into the impact of IBD on their lives. Chapter Six detailed the precise design of the intervention used in this research. While this proves that the unclosed diary method can be successful in terms of accessing experiential accounts of IBD and daily life that are not present in other investigations of the condition, there are also practical concerns to think about. If such a study was to be replicated with a similar sample, flexibility is the key issue that must prevail, both in terms of practical feasibility of accessing participants, and also allowing sufficient time for families' own schedules such as holidays or hospital appointments, which may interrupt data collection.

When trying to answer how much IBD features in young people's lives, the diaries are exceptionally good investigative tools. Both Emily and Hayley can demonstrate this in their diaries, and it is clear that while IBD may feature intermittently, it is not a controlling force in their lives. Looking at the public and private nature of experience in terms of disease, there are also variations on how this can be interpreted. There is the physical space which one inhabits, but there is also a conceptual area of space that one acts within their daily life. This conceptual space follows through into other areas of IBD experience, such as choosing whether to disclose illness related aspects to

others, and also seeking the right moment and most appropriate source of information.

Making sense of life with IBD is also revealed in the way in which participants organise their accounts, in the retrospective interviews and especially within the diaries as they progressed. Participants used their accounts in many ways to assert their existing positions, and to re-position themselves in terms of IBD and the rest of the world. Chapters Five and Nine showed this by looking at the action within the interview and diary data. The overall message that the thesis reveals in terms of all of the questions posed at the beginning, is that to examine how people live with IBD, and indeed with any other chronic illness, we must study the things that surround illness experience, not necessarily aspects that are obviously linked to disease. This is because people live their lives in many contexts and do not always follow a life course that is determined by disease outcome.

### **11.3 Implications for future research**

There are two sets of recommendations that arise from this project. Further research into IBD can benefit from the methodologies used here, and the audio diary intervention would also be a useful tool for investigating other chronic illnesses. The method is particularly suitable for eliciting young people's experiences of living with illness. It does not require individuals to focus on their disease, only if and when it becomes an issue for them. It can afford a degree of privacy; yet can be open to sharing with friends and family if the participant feels sufficiently comfortable to do so. It can be managed at participants' own convenience and is not as time-consuming as a written diary could potentially be.

Now that the data collection has been completed and analysis has revealed the different ways in which young people negotiate IBD in their lives, there are several messages that can and must be conveyed: to clinical personnel, to parents and carers, and most importantly, to young people themselves.

The data that is presented here in this thesis is only a fraction of many lives of which IBD is a part. While IBD is especially prevalent in young people, it is important not to marginalize the aspects of life that encapsulate what it is

to be a young person, whether a chronic illness like IBD is in the frame or not. As the discussion maintains, part of being chronically ill involves periods of time when an individual is not ill, and these episodes in a person's life are equally as important in ascertaining how and when IBD affects the, just as much as disease related episodes. Removing the emphasis from IBD and spreading it among other aspects of daily life is far more productive, and generates data that has not been formally documented in this area of research.

The research has also revealed that the interchangeability between health and illness can be rapid. This is not only evident at different times, but also within single accounts or diary entries. The directions of viewing the world from one's own perspective in an account (world-to-person), and producing an account based on the perceptions of another (person-to-world) are not confined to specific boundaries of whether a person is in relapse or remission. The same also applies to ascribing whether someone lives within or beyond the confines of illness. Overall, to project a level of adjustment in learning to live with IBD, a person can do this independently of, as opposed to in spite of disease.

Finally, a methodological issue must be captured here if understanding young peoples' subjective experience of IBD is to gather momentum. Participants in this study were provided with an opportunity to become *collaborators* in data collection, thereby shaping their experiences of IBD according to their own positioning of it, as opposed to responding to a pre-defined interview direction. This should be a consideration that is widely deployed in illness research, particularly with NHS initiatives such as the Expert Patient programme, and increased service user involvement appearing on the policies and within the practices of healthcare organisations.

In addition to the participant positions in the accounts, there is an overall position in which readers of this thesis externally hold them. They should not be regarded as patients, as this frames their experiences in a clinical setting and eventually colludes with the outcomes and objectives of much of the IBD-based literature. To avoid being presented as the archetypal medical presentation of an IBD patient – one who typically shows *x* behavioural characteristics or deals with acute symptoms with *y* method –



they are participants, not just in the sense of participating in the study, but actively participating in the production and (re) positioning of their accounts.

#### **11.4 A life sentence**

The introduction of this thesis began with the following quote:

*IBD is not a death sentence, but a life sentence.*

There are several finite connotations in that one sentence. There are no cures for IBD; the disease is for life. The management of either colitis or Crohn's and subsequent medical interventions or surgery, is something that has to be negotiated for the rest of an individual's life. The earlier the diagnosis, the longer that life sentence will be. The life sentence that was mentioned at the beginning of this chapter must not be forgotten, but it must be taken to mean life in a positive sense, and not to be concentrating on generic factors associated with IBD.

Reading the diaries and interviews from the participants in both parts of the data collection, there are several non-disease related episodes that comprise individual lives. Research into this area needs to recognise that part of the IBD experience contains episodes in which participants are not ill, rather than just concentrating on symptomatic periods. IBD is an issue, but when analysed in the contexts described in this project, it is not responsible for the whole story of a young person's life, and more specifically is not always the main "character" in the plot of that life.

The key development of the research for this thesis is that it has maintained contact with a group of young people with IBD over time. Most importantly, it has exposed areas of their lives that have not been previously revealed without the disease being a major concern. The design and execution of the unclosed diary has done this, with the help of finding out some key issues from a set of retrospective interviews with adults. The diaries were unclosed in many ways, practically and conceptually, as are the lives of the young people who participated in this study. To advance the understanding of IBD and adolescence, it is important to keep exploring this "life sentence", and that like the diaries, research into IBD and young people remains unclosed.

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## **APPENDICES**

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Appendix A: Glossary of IBD related terms used in this thesis

Appendix B: Patient information sheet (retrospective study)

Appendix C: Complete list of NVivo2 codes

Appendix D: Patient information sheet (prospective study)

## Glossary of IBD related terms used in this thesis\*

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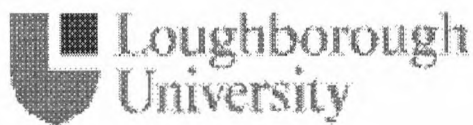
|                                       |   |
|---------------------------------------|---|
| <b>5-Aminosalicylic Acid (5-ASA)</b>  | A substance which reduces inflammation in ulcerative colitis and decreases the risk of relapse.   |
| <b>Colectomy</b>                      | Surgical removal of the colon   |
| <b>Colonoscopy:</b>                   | Examination of the rectum and colon performed by passing a lighted, flexible, tubular instrument  |
| <b>Corticosteroids</b>                | A group of hormones (chemical messengers) used as a drug treatment to control IBD   |
| <b>Crohn's disease</b>                | Crohn's disease can affect anywhere from the mouth to the rectum but most commonly affects the small intestine. It causes inflammation, deep ulcers and scarring to the wall of the intestine and often occurs in patches with healthy tissue in between. |
| <b>Elemental diet</b>                 | A specially prepared liquid meal, containing no solid material but all necessary nutrients.   |
| <b>Endoscopy</b>                      | A general term for examination inside the body using a light tubular instrument, inserted through a natural body opening.   |
| <b>Flare-up</b>                       | Term used to describe the recurrence of symptoms after a period of good health  |
| <b>IBD</b>                            | <b>(Ibd, i.b.d.)</b> - abbreviation for 'Inflammatory Bowel Disease'.   |
| <b>Ileostomy</b>                      | A surgical operation in which the cut end of the ileum (after <b>colectomy</b> ) is brought through an opening in the abdominal wall and fashioned into a spout. Waste is then collected in a bag fitted over the spout and attached to the skin.         |
| <b>Indeterminate</b>                  | Treated as ulcerative colitis, but features of the disease <b>colitis</b> make it difficult to make a clear diagnosis between Crohn's disease and ulcerative colitis.   |
| <b>Irritable bowel syndrome (IBS)</b> | a common condition caused by altered motility of the bowels. It produces diarrhoea or constipation and abdominal discomfort. It is a separate condition distinctly different from <b>Inflammatory Bowel Disease (IBD)</b> .                               |
| <b>Mesalazine</b>                     | The generic name for 5-aminosalicylic acid. Brand names include Asacol and <b>Pentaza</b> .   |
| <b>Nasogastric tube</b>               | A thin flexible plastic tube passed through the nose into the stomach.  |
| <b>Pentaza (Pentasa)</b>              | See <b>Mesalazine</b>   |

|                           |   |
|---------------------------|---|
| <b>Perative</b>           | Gluten free liquid used in general treatment of <b>IBD</b> #  |
| <b>Pouch (ileo-anal)</b>  | an internal pouch or reservoir made from the lower part of the intestine (ileum) which is attached to the anus, therefore maintaining continence and enabling the passage of stools in the normal manner. |
| <b>Reversal</b>           | Informal term used to refer to <b>pouch</b> surgery when a patient has had temporary <b>ileostomy</b> surgery #   |
| <b>Sigmoidoscopy</b>      | The passing of a short lighted tubular instrument through the anus to inspect the mucosa (lining) of the rectum and the lower colon. The sigmoidoscope may be rigid or flexible.                          |
| <b>Steroids</b>           | see <b>corticosteroids</b> .  |
| <b>Stoma</b>              | A surgically constructed opening of the intestine onto the abdominal wall over which a bag can be fitted and sealed to the skin.  |
| <b>TPN line feeding</b>   | Total parenteral nutrition - intravenous infusion of some or all of a patient's nutritional requirements through a catheter (fine tube) placed in the vein.   |
| <b>Ulcerative Colitis</b> | Ulcerative Colitis affects the colon (large intestine) or rectum. Inflammation and ulcers develop on the inside lining of the colon   |

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\* All definitions have been reproduced from the National Association for Colitis and Crohn's disease List of Medical Terms used in IBD  
(URL:<http://www.nacc.org.uk/downloads/factsheets/MedicalTerms.pdf>)  
[accessed 21.09.2006].

Exceptions are those indicated with #



[hospital name here]

## **Inflammatory Bowel Disease in adolescence: an investigation of how young people learn to live beyond the confines of chronic illness**

### **Invitation to participate in research**

**The National Association for Colitis and Crohn's Disease (NACC) is funding research into how young people develop independence while suffering from these illnesses. The research is being conducted by Loughborough University in collaboration with the Adult Gastroenterology division at the [hospital name], and you are invited to participate. Please take time to read the following information, and discuss it with your friends, relatives or your GP if desired.**

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

Although we know much about the symptoms and treatments for Ulcerative Colitis and Crohn's Disease, not much is known about the everyday impact on young people who are diagnosed with IBD in adolescence. We aim to find out how the illness affects young people's personal and social lives, and we would like to speak to people who know what it is like to live with IBD in adolescence. This will mean looking back at their teenage years when their illness was first diagnosed, and discussing how they dealt with the impact on their personal and social lives.

### **Why have I been chosen?**

We are looking for people who are

- ✓ **Aged between 20-25\* and**
- ✓ **Diagnosed with Colitis or Crohns Disease before age 18**
- ✓ **Diagnosed at least 5 years before taking part**

\*The upper age limit may be extended to those who are slightly older than 25 years if they meet the diagnosis criteria

If this applies to you, we would like to hear from you. We hope to recruit about 30 people within this sample group.

### **Do I have to take part?**

There is absolutely no obligation for anyone to take part in the study – it is only if you would like to, and feel it would be of benefit to you to discuss your experiences. If you decide to take part, you will be asked to sign a consent form. You can change your mind and withdraw at any time, and you don't need to give a reason.

### **What would I have to do?**

We would like you to give permission for us to record (audio tape only) an interview.

### **What would it involve?**

We would arrange to come and interview you about how you dealt with IBD during your adolescent years. For example, we would be interested in discussing with you how it affected your relationships with friends and family, and any impact it had on your school and work experience.

### **How long would it take?**

Although the interviews would normally take about an hour it would be very helpful if you were willing to be contacted over the telephone, in case it was necessary to clarify any further issues

### **Where would I be interviewed?**

You will not be required to make any extra visits to the hospital. If you would rather be interviewed in your own home or in another place then this could be arranged.

**If I decide to take part, will my treatment be affected?**

Any treatment you are receiving for Colitis or Crohn's Disease will **not be affected**. This research only aims to look at your own opinions and responses to chronic illness, and is not looking to change anything that is currently being done for you by your consultant, GP, or any health professional involved in your care.

**Will my taking part in this study be kept confidential?**

All information collected about you during the course of the study will be kept strictly confidential.\* Your personal details will not be disclosed to anyone outside of this research, and no names will be given the published work. Any quotations from the interviews used in the report, and any subsequent publications will be totally anonymous.

\* In exceptional circumstances, such as disclosure of harm to others, or child protection issues, we are legally obliged to break confidentiality

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

The research results will be written up as a report that belongs to Loughborough University. Any data that are collected from the research will also be kept securely at the University. There may also be smaller publications that arise from the research. A copy of the results will also be given to NACC, as they will use the results to continue supporting others with Colitis or Crohn's Disease.

**I would like to take part, what should I do now?**

If you would like to take part, please contact

**Sally Skinner  
Department of Human Sciences  
Loughborough University  
Loughborough  
LE11 3TU**

**Telephone: 01509 228158**

**Email: [S.J.E.Skinner@lboro.ac.uk](mailto:S.J.E.Skinner@lboro.ac.uk)**

**(Lead researcher: Dr. David Middleton: [D.J.Middleton@lboro.ac.uk](mailto:D.J.Middleton@lboro.ac.uk))**

**Who am I?**

I am a research student at Loughborough University. I have previously worked for Nottingham City Libraries, and then for the NHS. I was a health advisor at NHS Direct the Nottingham Walk-in Centre. My main interests are consumer health and science information and I aim to conduct further research into health issues in the future. I hope you are interested in taking part in this study and look forward to hearing from you.



NVivo revision 2.0.163

Licensee: Sally Sargeant

Project: Retrospective interviews

User: Administrator

Date: 27/09/2006 - 11:27:48

## NODE LISTING

### Nodes in Set: **All Tree Nodes**

Created: 10/01/2004 - 14:18:14

Modified: 10/01/2004 - 14:18:14

Number of Nodes: 94

- 1 (1) /Diagnosis
- 2 (1 1) /Diagnosis/Crohns Col
- 3 (1 2) /Diagnosis/Crohns Dis
- 4 (1 3) /Diagnosis/Age
- 5 (1 4) /Diagnosis/IBD in family
- 6 (1 5) /Diagnosis/Symptoms prior to
- 7 (1 5 1) /Diagnosis/Symptoms prior to/Family views
- 8 (1 6) /Diagnosis/Family response to
- 9 (1 7) /Diagnosis/investigative procedures
- 10 (1 7 1) /Diagnosis/investigative procedures/attitudes to
- 11 (1 8) /Diagnosis/Personal reaction
- 12 (2) /GPs - general
- 13 (2 1) /GPs - general/GPs, opinion of
- 14 (2 2) /GPs - general/initial explanations
- 15 (3) /Symptom management - medical
- 16 (4) /Support groups
- 17 (4 1) /Support groups/perceptions of
- 18 (5) /clinical support groups
- 19 (5 1) /clinical support groups/stoma group
- 20 (6) /Education - general
- 21 (6 1) /Education - general/expectations
- 22 (6 2) /Education - general/performance
- 23 (6 3) /Education - general/School
- 24 (6 3 1) /Education - general/School/Time off
- 25 (6 3 2) /Education - general/School/excursions
- 26 (6 3 3) /Education - general/School/Changing schools
- 27 (6 4) /Education - general/Education, Higher
- 28 (6 4 1) /Education - general/Education, Higher/Time off
- 29 (7) /Sport - general
- 30 (7 1) /Sport - general/Sport - ability
- 31 (7 2) /Sport - general/Relationships
- 32 (8) /Symptom management - social
- 33 (8 1) /Symptom management - social/toilet location - public
- 34 (8 2) /Symptom management - social/toilet location - private
- 35 (8 3) /Symptom management - social/Daily routines
- 36 (8 4) /Symptom management - social/Faecal urgency
- 37 (9) /Surgery
- 38 (9 1) /Surgery/procedures
- 39 (9 1 1) /Surgery/procedures/Explaining to others
- 40 (9 2) /Surgery/attitudes to
- 41 (9 3) /Surgery/Ileostomy
- 42 (9 4) /Surgery/preparation for
- 43 (10) /Consultant paediatrician practice
- 44 (10 1) /Consultant paediatrician practice/Information and communication
- 45 (11) /Individual knowledge of IBD
- 46 (11 1) /Individual knowledge of IBD/Family knowledge
- 47 (12) /Information sources
- 48 (12 1) /Information sources/Clinicians

- 49 (13) /Understanding, lack of
- 50 (13 1) /Understanding, lack of/Family
- 51 (13 2) /Understanding, lack of/teachers
- 52 (13 3) /Understanding, lack of/friends
- 53 (13 4) /Understanding, lack of/Others
- 54 (14) /Disclosure of disease
- 55 (14 1) /Disclosure of disease/Defence
- 56 (15) /Medication
- 57 (15 1) /Medication/side effects
- 58 (15 2) /Medication/rectal administration
- 59 (16) /Friends
- 60 (16 1) /Friends/reactions of
- 61 (16 2) /Friends/popularity
- 62 (17) /Body
- 63 (17 1) /Body/Physical appearance
- 64 (17 1 1) /Body/Physical appearance/clothing and style
- 65 (17 2) /Body/Physical development
- 66 (17 3) /Body/Exertion during flare-up
- 67 (17 3 1) /Body/Exertion during flare-up/mental exertion
- 68 (17 4) /Body/feelings towards
- 69 (17 5) /Body/Control of
- 70 (18) /Energy levels
- 71 (19) /Decision making
- 72 (20) /Pressure
- 73 (20 1) /Pressure/On self
- 74 (21) /Disclosure of symptoms
- 75 (22) /Investigative experiences
- 76 (22 1) /Investigative experiences/experiences of
- 77 (22 2) /Investigative experiences/preparation for
- 78 (23) /Support - general
- 79 (23 1) /Support - general/Nursing support
- 80 (24) /Protection
- 81 (25) /Illness status
- 82 (25 1) /Illness status/Fashionable
- 83 (25 2) /Illness status/Embarrassing
- 84 (26) /Relationships
- 85 (26 1) /Relationships/Sexual activity
- 86 (27) /Explanation tools
- 87 (27 1) /Explanation tools/Use of humour
- 88 (27 2) /Explanation tools/Public speaking
- 89 (28) /Prescription costs
- 90 (29) /Hobbies~interests
- 91 (30) /Travelling
- 92 (31) /Communication
- 93 (31 1) /Communication/of symptoms
- 94 (31 2) /Communication/with other IBD patients

Are YOU  
aged  
between  
11-16?

Do YOU have  
Colitis or  
Crohn's?

Would YOU like  
to take part in  
some research?

Then  
read on!



 Loughborough  
University

 **NHS**



*Prospective* **IBD in adolescence:**  
An investigation of how young people learn to live beyond the confines of chronic illness

What's this all about?

We know lots about how IBD affects the body, but we would like to know how it affects your daily life and how you live with it. We would like to talk to you to hear how you cope with it, and to see what further support can be given to other young people with Colitis or Crohn's

Why me?

You'll have been told about this project if you're aged 11-18, and if you have IBD. We want to talk to about 15 young people.

Do I have to do this?

Not at all - it is only if you would like to, and feel it would be helpful to others to hear your experiences. If you want to take part, you and a parent/guardian will sign a consent form. Even if you say "yes" then change your mind about it, that's fine - you don't have to tell us why

What exactly would I have to do if I take part?

We would interview you every 6-8 weeks about what you've been doing at school, with friends, at home, playing games, holidays, and anything else that is important to you. To help you remember these things, you'll be given a small tape recorder, to record these things as they happen. You can make a recording wherever and whenever you want!



We will be talking to your parents and carers to get their experiences, and they will know that you are taking part. But anything that YOU say to us is PRIVATE, and we are not tell ANYONE, even your parents and doctors about what you say.\*

Who will know about this if I decide to do it?

OK, so what happens after I've done this?

A long report will be given to The National Association for Colitis and Crohn's Disease, who provide information for people like you. Your own name will not be written anywhere in this report

I'd like to take part - what should I do

That's great! Before you do anything, take some time to think about it, and talk to your family or friends. If you're happy with it, then please contact me, Sally Skinner - at the address below..

### Who am I?

Hi, I'm Sally, I work at Loughborough University. I'm going to write the report for this project, so I'll be the one talking to you! I live in Nottingham, and like swimming, reading and listening to RnB. I hope you want to take part and look forward to meeting you

**Sally Skinner**  
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