



# **Young Adults' Discursive Constructions of Chronic Illness Experience: Accounts of Type 1 Diabetes and Inflammatory Bowel Disease (IBD)**

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## Abstract

This thesis investigates the experiences of young adults living with either Type 1 diabetes (T1DM) or Inflammatory Bowel Disease (IBD), two chronic conditions which are prevalent among this age-group. This is set against the long tradition of research into chronic illness experience; however, young adults are commonly underrepresented in this area, in spite of the contention that the new-found pressures and responsibilities associated with this life-stage may be especially difficult to manage alongside a chronic condition (Arber and Ginn, 1998).

Semi-structured interviews were carried out with respondents aged 18-29 ( $n = 30$ ). Transcribed interviews were subject to open-coding using qualitative software, which led to the systematic identification of predominant themes for analysis. Data was considered primarily as 'accounts' (Radley and Billig, 1996), with a focus on the moral-underpinnings of the respondents' talk. These accounts were examined from a rhetorical discourse analysis perspective (Arribas-Ayllon et al., 2011), which entailed micro-investigation of the discursive devices drawn upon by the respondents in representing their experiences as part of situated identity-performances (Riessman, 1990).

Across the predominant themes identified (self, other and control), some similar trends were identified, but also considerable variation, most significantly *across* the two conditions. In relation to *self*, accounts of T1DM showed respondents constructing greater levels of agency regarding the *integration* or *distancing* of illness vis-à-vis selfhood, whereas in accounts of IBD 'loss of self' (Charmaz, 1983) was more prominent. In accounts of *other-orientation*, those with IBD more commonly constructed 'felt stigma' and 'enacted stigma' (Scambler and Hopkins, 1986) than T1DM-respondents, which had implications for reported disclosure practices vis-à-vis the two conditions. Within the theme of *control*, T1DM-respondents generally constructed greater *condition control* and *lifestyle control* than IBD-respondents. Variation was also observed in reported management-strategies, which reflected the respondents' differing conceptions of their 'healthy bodies' (Balfe, 2009) – those with T1DM focused on future health concerns, their 'longer-term' healthy body, whereas IBD-respondents' concerns centred primarily on more immediate health consequences, their 'short-term' healthy body. These differing conceptions of the 'healthy body' influenced how respondents accounted for their 'risky' social drinking practices, with IBD-respondents producing 'justifications', and those with T1DM primarily constructing 'excuses' (Scott and Lyman, 1968).

In spite of this variation, a consistent thread running throughout the data was the constitution of the morally-driven self. A range of different moral figures were constructed by the respondents, allowing them to perform positive identities throughout. This eased the tension borne out of the conflict between the priorities, desires and demands of young adulthood and the complex considerations surrounding chronic illness.

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## 1. Introduction

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This thesis investigates the experiences of young adults living with chronic illness. Focusing on those with Type 1 Diabetes Mellitus (T1DM), and Inflammatory Bowel Disease (IBD), it explores how individuals manage their daily lifestyle activities alongside their condition, and how they attempt to cope with the psycho-social demands surrounding illness that can be managed, but cannot be cured. Data is in the form of semi-structured interviews, and throughout the analysis there is a focus on the representations constructed by the young adults, the discursive means through which they portray their experiences, their hopes, fears, trials and triumphs, as part of situated identity performances.

Whilst having an academic interest in this area of study, the subject matter also has strong personal relevance. I myself am a young adult with a chronic illness, having lived with IBD for eight and a half years, between the ages of 18-27. This accounts for my interest both in young adults as an age-cohort, and specifically in IBD as one of the two condition sites, having experienced the challenges that this illness presents during the years of young adulthood. This personal experience places me in the interesting position of essentially *being* the subject that I am researching. This is not uncommon in the field of illness experience; many researchers have investigated conditions that they themselves live with; either producing auto-ethnographic accounts of their own experiences (Defenbaugh, 2008; Di Giacomo, 1992; Zola, 2003), or as I am doing here, researching the experiences of others who have the same condition (Frank, 1995; Kelly, 1992a)<sup>1</sup>. I would contend that my personal experiences may be advantageous, as having a deeper level of understanding of this domain of experience may enable me to achieve elements of

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<sup>1</sup> In addition to investigating the experiences of others, both Frank (1995) and Kelly (1992a) also at times introduce their own experiences of illness, which is not something that I will do here.

an *emic* perspective, an insider's view, so far as this is ever possible. This will perhaps allow for a more sensitive interpretation of the issues of concern salient to the young adults in my research (my role as an 'insider', as well as how other researchers have approached this role, will be discussed further in Chapter 5, 5.1).

Whilst the primary audience of this thesis will be academic, I also intend for findings to be accessible to healthcare professionals and young adults with T1DM and IBD (these abbreviated forms will be used from hereon in). As Tierney (2000) notes, such considerations should not only be made after the research is completed, but 'the researcher must take account at the outset who will be interested in the study at the end' (2000: 186). This he sees as forming a broader 'ethic of care not only for whom [researchers] study but also for whom they write' (2000: 189). With these sentiments in mind, these multiple audiences were kept in consideration throughout the data-collection and analytic process; with the aim of generating findings that are both accessible, and could be of some practical use, to both healthcare professionals and young adults with these conditions (see Conclusion, Chapter 10, 10.6 for further discussion of possible practical applications of findings).

In this opening chapter, I will firstly provide a brief overview of the developments in research on chronic illness experience (1.1), before presenting a case for the importance of researching young adults within this area (1.2). I will then outline the respective biomedical trajectories of T1DM and IBD, and the reasons that these conditions were chosen for focus (1.3), before introducing the concept of 'lifestyle', as will be used in exploring respondents' experiences (1.4). Following this, I will briefly discuss the ways in which talk about illness has been analysed in previous research (1.5), and how this informs the analytic framework that I will adopt (1.6). The final two sections of this chapter will outline, respectively, the research questions that will be addressed (1.7), and the thesis structure (1.8).

### 1.1 *Chronic Illness Experience*

Chronic illnesses are those which are long-lasting or recurrent, and although not necessarily terminal, are presently incurable. In her seminal work, Charmaz (1991) purports that 'chronic illness can set people apart from others and take over their lives' (1991: 4). This statement encapsulates quite succinctly the enormity of living with chronic illness – the struggle that many face over the influence illness has upon them, including the physical and social separation from others it has the potential to foster. For some, chronic illness affects every facet of life and can thus constitute what Little, Jordens and Sayers (2003) term 'extreme experience', in that it 'leaves no aspect of identity untouched' (2003: 76). As Charmaz notes, however, this is by no means always the case, and 'most people learn to live *with* their illnesses rather than *for* them' (my italics) (1991: 4). The picture is therefore not entirely bleak, and as will become apparent in the present study, for most, chronic illness does not play *the* defining role within their lives.

Experiences of chronic illness can vary widely depending upon the type and severity of the illness, as well as the personal qualities and lifestyle activities of the individual (Charmaz, 1991; Conrad, 1990). Chronic illness experience is clearly, then, a complex, multilayered area of study, and one of undoubtedly great importance, especially given the significant increase in people living with chronic illness witnessed over the past sixty to seventy years (Taylor and Bury, 2007: 27). Over the past few decades, there has been a growing recognition that it is only through an 'exceptionally detailed and rather deep personal' (Strauss, 1990: v) approach, involving talking to people with chronic illness themselves, asking them to discuss their views, feelings and experiences in their own words, that we can begin to uncover the 'subtleties and personal meanings that inhere to living with chronic illness' (Conrad, 1990: 1257).

As has been widely commented on, prior to this move towards detailed, in-depth investigation of chronic illness experience, research had a largely clinical or biomedical focus, either investigating the biological and physiological aspects of individual conditions, or exploring people's experiences of chronic illness predominantly within medical contexts, from the perspectives of medical professionals, rather than those of

individuals with illness (see Bell, 2000; Frank, 1995; Kleinman, 1988; Mishler, 1984, amongst others).

Underlying the difference between these two research traditions is the widely adopted distinction drawn between a clinical viewpoint of ‘disease’, standing in contrast with the lay view of ‘illness’: ‘disease’ considering ill-health as an abstract ‘thing’ or ‘independent entity’, and ‘illness’ as ‘the subjective response of the patient to being unwell’ (Helman, 1981: 548). The ‘disease’ focus that characterises many medically-oriented studies is generally considered to be an ‘outsider’ perspective, which ‘view[s] illness from outside the experience itself, minimizing or ignoring the subjective reality of the sufferer’ (Conrad, 1987: 2). The most well-known ‘outsider’ sociological approach is Parson’s (1951) classic ‘sick role’, in which illness is seen as a deviant state, which ‘incapacitates for the effective performance of social roles’ (1951: 430). The ill person therefore withdraws from these social roles until illness has passed and he/she is able to resume normal activities. Whilst the sick role does retain some relevance to chronic illness experience, such as in the case of illnesses characterised by relapse-remission cycles, where individuals may be forced to withdraw from social roles in times of relapse, many have argued for the inadequacy of this model in relation to chronic illness (Conrad, 1987; Frank, 1995, among others). This is because for many living with illness, the effect of symptoms and treatment-regimens is a constant feature in their lives which must be managed *alongside* continuing social roles (Radley, 1994: 139-40).

Research that has moved away from this ‘outsider’ focus on ‘disease’, towards an ‘insider’ perspective on ‘illness’ has therefore afforded greater attention to the ongoing presence of illness in the lives of individuals who are chronically-ill, and has explored facets of life which extend beyond their contact with medical professionals. This research spans a range of disciplines, including health communication, medical sociology, medical anthropology and social psychology, and commonly employs qualitative methods, principally using interview-data. It is this multilayered view of chronic illness, considering its role within individuals’ lives as a whole, which is the perspective taken in the present study.

It is important to note, however, that the biomedical model of 'disease' and the subjective view of 'illness' should not be placed in direct opposition. The original polarity of the disease/illness dichotomy has been challenged by many who have argued for the relevance of both conceptions in exploring illness experience (see for instance, Bury, 1982; Persson, Race and Wakeford, 2003). As Bell (2000) argues, the focus on people's experiences beyond the clinical setting must be *in addition to*, rather than opposed to, looking at their experiences inside the medical setting.

A range of aspects of chronic illness experience have been explored in research adopting this 'insider' perspective. This includes the detrimental effect chronic illness can have upon individuals' conceptions of self (Charmaz, 1983; 1991), and the profound disruption it can cause to their biographies (Bury, 1982), as well as how chronically-ill people respond to this impact through adopting different 'styles' of adjustment (Radley, 1989), and attempt to repair the disruption in various ways (Corbin and Strauss, 1987; Williams, 1984). Other research has focused on the stigma that can be attached to chronic illness, and the effect that this can have on the lives of chronically-ill individuals (Green, 2009; Goffman, 1963; Scambler and Hopkins, 1986).

Whilst sharing the common goal of gaining greater understanding of people's own perspectives vis-à-vis their chronic illness, research across the field displays variation in its underlying aims. One strand of research focuses on the therapeutic and emancipatory benefits that talking about illness can have for individuals (Charmaz, 1991; Defenbaugh, 2008; Frank, 1995), whilst a second strand investigates chronic illness experience with the explicit intention of informing healthcare professionals, so as to ultimately improve care and advice in the clinical setting (Brydolf and Segesten, 1996; Hall, Rubin, Dougall, Hungin and Neely, 2005). A third strand of research focuses on patient-healthcare provider interactions, campaigning for ill people's subjective experiences to be afforded greater salience *within* the medical context, both to achieve clinical objectives of improving care and advice, and to improve the personal experience of the patient, thus combining these patient-care and emancipatory objectives. Some of this research has taken a broader focus than just looking at chronic conditions (Charon, 2006; Elwyn and

Gwyn, 1998; Greenhalgh and Hurwitz, 1998; Mishler, 1984); however, some have taken chronic illness as their principal focus (Kleinman, 1988).

## 1.2 *Young Adults and Chronic Illness*

Whilst the field of chronic illness experience is presently experiencing great vibrancy in terms of research focus, young adults as an age-cohort have often been underrepresented in this area, with study samples more commonly comprising of older or middle-aged people with chronic conditions. Whilst there are a number of studies that have investigated young adults' experiences of chronic illness (Balfe, 2009; Brydolf and Segesten, 1996; Sargeant, 2006, see Chapter 4 for discussion), more commonly research focusing on this age-group centres on the prevention of future illness, such as looking into the long-term health risks related to excessive alcohol-consumption (Huerta and Borgonovi, 2010; Watten and Watten, 2010), or issues surrounding young women's screening for cervical cancer (Bano, Kolhe, Zamblera, Jolaoso, Folayan, Page and Norton, 2008; Nair, Bhandari and Nordin, 2007) – two areas which have been afforded particular salience in the UK popular media in recent years. There has not, however, been due research attention paid to young adults' management of *existing* long-term illness.

I would argue that young adults are not only a group worthy of study in this area, but are in fact an *especially* important group. Several researchers have cited a lack of perceived synchronicity between this age-group and chronic illness; Arber and Ginn (1998: 135), for instance, proposing chronic illness to be 'out of time' for young adults. This could make it all the more difficult for members of this cohort to live with a chronic condition, as they must manage not only the symptoms and treatments of the illness itself, but also potentially deal with the perceptions of others regarding this lack of fit between their age and the effects of their illness. Some conditions, for instance, may cause adverse changes to outward physical appearance, as well as restrictions on activities as a result of symptoms, both of which are more commonly associated with those in later life.

Further argument can be made for the importance of this age-group in chronic illness research if we consider young adulthood as being a distinct life-stage, a perspective

adopted by several researchers. Whilst views vary regarding where this life-stage begins and ends, most recognise the move into young adulthood to be a 'major normative life transition...when individuals leave behind so-called youthful freedom and begin to take responsibility for different aspects of their lives' (Raymore, Barber and Eccles, 2001: 198). This transition inevitably involves a 'decisive turning point in developing self-identity' (Blos, 1962: 192), and it has been argued that this is a period when people begin to 'focus on the search for authentic intimacy with people of their own age' (Erikson, 1950: 33). Hillege (2005) proposes that, during young adulthood, individuals are 'making crucial choices about social, vocational and geographic matters, and in Western culture at least, these choices form a matrix from which the adult self begins to emerge' (2005: 52). I would strongly agree with Hillege's proposition, as many young adults will be just beginning their lives away from their homes and families, perhaps starting college or university, or embarking upon fulltime careers. They are therefore likely to encounter a range of different social and professional contexts to which they are not accustomed. I would contend that, under these circumstances of substantial change, managing a chronic condition may be all the more challenging.

In addition to the pressures of change and transition, cultural activities which are commonly associated with young adulthood, such as physical sporting activities (Balfe, 2007), or socialising at night in clubs, pubs and bars (Brain, Parker and Carnwath, 2000; Chatterton, 1999; Griffin, Bengy-Howell, Hackley, Mistral and Szmigin, 2009) are often those which may be especially physically demanding. The physical symptoms and treatment-regimens related to many chronic illnesses could make it difficult for individuals to participate in such activities, potentially resulting in negative psycho-social effects.

Against this backdrop, then, looking specifically at young adults in relation to chronic illness experience is a very worthwhile area of study, and this thesis intends to address this somewhat neglected area, with the aim of contributing to the small body of research which has focused on this age-cohort across a range of conditions.

### 1.3 Conditions: T1DM and IBD

Whilst the interest of the present study is chronic illness more generally, as already mentioned, the conditions T1DM and IBD are focused on. Before explaining my reasons for selecting these particular conditions, I will first outline their respective biomedical trajectories.

T1DM is an autoimmune condition that develops when the body destroys its own insulin-producing cells, which means that levels of sugar (glucose) in the blood cannot be regulated. As a result, those with the condition must self-administer insulin several times a day via injections, as well as carefully regulating their diet and exercise, in order to keep glucose levels within a safe range. T1DM is associated with a number of complications. In the short-term this includes *hypoglycaemia*, i.e., low blood-sugar levels. This presents symptoms such as confusion, dizziness and trembling, and at its most severe can cause the sufferer to slip into a state of unconsciousness, which is potentially life-threatening. Another short-term complication is *hyperglycaemia*, i.e., high blood-sugar. This can present symptoms such as headaches, increased thirst and blurred vision, which in the worst case can develop into diabetic ketoacidosis (DKA), which can also result in fatal coma if it goes untreated. DKA is less common than the serious effects of hypoglycaemia; therefore low blood-sugar is generally regarded as being more serious *in the short-term* than high blood-sugar. In the longer-term, those with T1DM have a higher risk of developing numerous complications such as heart disease or stroke; diabetic retinopathy, which is damage to the retina that can cause blindness; neuropathy, which is damage to the nerves, and can affect various parts of the body; and kidney damage. Whilst adhering closely to the recommended treatment-regimen minimises the risk of those with T1DM experiencing these short- and long-term health complications, this is not a guarantee that they will not experience these health problems.

T1DM treatment-regimens, though not commonly directly resulting in physical side-effects, can *indirectly* result in some adverse physical effects, as those with the condition may find they gain weight more easily, and lose weight more arduously. This is due to the need, in many cases, to eat more regularly than those who do not have the condition, including plenty of carbohydrates, in order to ensure that blood-sugars do not fall below



the recommended level. Injecting insulin on a regular basis can also result in bruising and hardening of the skin around injection sites, which can become unsightly.

IBD is an umbrella term for a group of inflammatory conditions of the colon and small intestine, the two major types of which are Crohn's disease and Ulcerative Colitis (UC). Both conditions present similar symptoms, including abdominal pain, vomiting, diarrhoea, rectal bleeding and weight loss. It is the symptom location that defines the difference between the two conditions. Ulcerative Colitis affects only the colon, whereas Crohn's disease can affect any part of the gastrointestinal tract, from the mouth to the anus. IBD is usually characterised by intermittent periods of disease flare-up and remission, and is treated with various forms of medication, including *Prednisolone* steroids, which themselves can have significant side-effects. These can include those affecting outward physical appearance, such as acne and disproportionate weight gain, predominantly around the torso and in the face. They can also have several longer-term side-effects, such as a lowering of bone density levels, leading to an increased risk of osteoporosis. Another treatment is *Azathioprine*, an immunosuppressant drug, which also has several side-effects, including increasing the individual's susceptibility to virus and infection.

Surgery is a possibility in more severe cases, in which the colon, or part of it, is removed. Removing the inflamed part of the colon relieves the individual of symptoms, but leaves the person with a colostomy bag, or an ileostomy bag in cases where the whole colon is removed, into which faeces are discharged without the control that anal defecation allows. In the case of Crohn's disease, however, because inflammation can present anywhere throughout the gastrointestinal tract, removal of the large bowel does not guarantee that the disease will not return elsewhere following surgery. In some cases, it is possible for the individual to undergo further surgery, where the colostomy or ileostomy is reversed, and the ileum (the end of the small intestine) can be reconnected to the remaining part of the colon (or where the whole colon has been removed, the ileum is connected to the rectum). This returns to the individual some control over bowel function; however, bowel function will not completely return to normal following this procedure. In spite of much

research having suggested genetic, dietary or life event/stress influence, there is no evidence identifying any particular cause of IBD.

There are a range of other biomedical terms relating to treatments and medical procedures for both T1DM and IBD which have not been mentioned here, but which may become relevant during analysis. For this reason, I have provided a full list of terminology in Appendix A. This list also includes further explanation of the medical terms I have already used in the above descriptions.

These two conditions were chosen for focus firstly because of their high incidence amongst young adults. T1DM is commonly known as early-onset diabetes, as it is usually diagnosed in childhood or adolescence (Devendra, Liu and Eisenbarth, 2004). IBD is most commonly diagnosed between the ages of 15-25 (Binder, 2004; Daniel, 2001: 83; Johnston and Logan, 2008). In addition to their prevalence amongst this age-group, I would argue that both conditions give rise to factors that may be *particularly difficult* to manage in young adulthood, relative to other life-stages. Firstly, both conditions are multifactorial, meaning they give rise to a range of symptoms and side-effects which can affect various different areas of an individual's life, and this may be especially difficult to manage alongside the multitude of activities and new-found responsibilities associated with young adulthood, discussed in 1.2, above. In relation to IBD, Brydolf and Segesten (1996) argue that 'problems associated with [the condition] and its treatment have effects on young adults dissimilar from as well as more profound than those on older individuals' (1996: 39). This may also be true for T1DM, as many have found, for instance, that the transition from adolescence to young adulthood witnesses individuals beginning to adopt autonomous management of their T1DM treatment-regimen, which was previously jointly managed with parents (Hillege, 2005; Silverman, 1987). Young adults with T1DM must therefore cope with this extra responsibility in addition to newly-experienced pressures.

Additionally, as mentioned above, the treatment-regimens for both conditions can either directly or indirectly result in adverse effects upon individuals' physical appearance, and subsequently their body image. This may cause heightened psychological stress for members of this age-cohort, given the salience that young adults have been found to

afford to bodily appearance and physical attractiveness (Balfe, 2009; Baumann and May, 2001; Litva, Peggs and Moon, 2001).

In spite of these arguments, research into young adults' experiences of these two conditions is sparse. This is with the exception of a small group of studies, which will be discussed in Chapter 4. This gap has been explicitly highlighted within some of these studies, with Balfe (2009) labelling young adults with T1DM a 'forgotten group' (2009: 128), and Daniel (2001) criticising a 'lack of knowledge, information and research about young adults with IBD, including experiences of living with the disease' (2001: 84). As well as not being widely explored in relation to young adults, these two conditions have not received a great deal of research attention more generally within the area of illness experience, with research affording more salience to conditions which have received greater public and media attention, such as cancer and HIV/AIDS (Baumgartner, 2007; Holt and Stephenson, 2006; Kelly and Field, 1996: 243; Weitz, 1991).

Whilst there are many differences in the respective nature and treatments of T1DM and IBD, which will likely give rise to very different illness experiences across the two, they share several commonalities. In addition to the similarities highlighted above vis-à-vis their multifactorial nature, another commonality is that much of the time both conditions are *not* outwardly apparent; it is largely not perceivable simply from looking at someone that they have either T1DM or IBD, marking a disparity with other chronic illnesses which *are* immediately apparent, for instance cerebral palsy (Meys, van Gestel, Massaad, Molenaers and Duysens, 2011), or latter stage multiple sclerosis (MS) (Green, 2009) (respondents' representations of how they appear to others will be explored in Chapter 7). These commonalities will allow for cross-condition comparisons of experiences to be made. Whilst such comparison will not facilitate generalisation to the experiences of young adults with *all* chronic illnesses, this will at least allow for wider scope than many studies which have looked at only one chronic condition. Additionally, Kelly (1992a) argues that, in relation to many chronic conditions, 'the problems posed by such illnesses share a quality which cuts across particular medical diagnosis and is common to them all' (1992a: 48). It may therefore be the case that, on a very general

level, the constructed-experiences of young adults with T1DM and IBD can be related to those of other chronically-ill young adults.

#### ***1.4 Using ‘Lifestyle’ as a Concept for Researching Illness Experience***

Given the wealth of research focusing on the clinical setting, my interest will extend beyond this, exploring the impact of chronic illness upon young adults’ lives *outside* of this context (that is unless issues related to the clinical setting are introduced by the respondents themselves as being particularly salient). I will refer throughout to the effect of illness on young adults’ *lifestyles*, and *lifestyle activities*. It is therefore necessary to explain what I mean in using these terms.

Whilst there have been many different conceptions and definitions of ‘lifestyle’ from a social, cultural and historical viewpoint, I will consider lifestyle from a very broad perspective, adopting Sobel’s (1981) definition, in which it is taken to refer to ‘any distinctive, and therefore recognisable, mode of living’ (1981: 3). Lifestyle can therefore encompass any of the activities or practices one engages in during his or her daily life, including social and leisure pursuits, as well as activities within a professional or work context. In line with this perspective, Chaney (1996) talks of lifestyle as being ‘all types of social activity that people do that we might use to characterize and identify them’ (1996: 14). Lifestyle, in Chaney’s view then, is strongly linked to issues of *identity*. This aligns closely with the influential work of Giddens (1991), who proposes that lifestyle constitutes a ‘set of practices chosen by an individual in order to give material form to a particular narrative of self-identity’ (1991: 80). Issues of identity and identity-construction will form a central tenet of the forthcoming analysis, and the way in which these issues will be conceptualised within the present analysis will be fully discussed in Chapter 5, 5.4.

Due to this focus on lifestyle issues, I will avoid referring to my respondents as ‘patients’, a label adopted in much research within the area of illness experience (Kelleher, 1988; Kelly, 1992a, amongst others). Respondents will instead be considered first and foremost as *people*, who happen to have a chronic illness. This reflects the fact that most of their

experiences of illness take place outside of the medical setting, and only a 'small fraction of their time is spent in the patient role' (Conrad, 1990: 1259), a view which correlates with my own experiences of chronic illness.

I will also avoid referring to respondents as 'sufferers', a term also commonly used within research in this area (Conrad, 1987; Charmaz, 1983). This label, I would contend, has negative connotations of individuals being somewhat passive and at the mercy of their condition, and as experiencing only negativity. Whilst this may be the case for some, it will be shown that those with chronic illness certainly do not always 'suffer'. The young adults in my study will therefore be referred to either simply as 'respondents', or as 'those with IBD or T1DM'.

### **1.5 'Narratives', 'Habitual Narratives' and 'Accounts'**

There is a degree of variation within the field of illness experience in terms of the types of talk analysed. Many studies simply consider all talk as responses provided by respondents, or as 'descriptions of their experiences' (Kelly, 1992a: vii; see also Anderson, 1988; Brydolf and Segesten, 1996; Kelleher, 1988 among others), whilst others focus on particular types of discursive construction, such as 'narratives' (Frank, 1995; Hydén, 1997; Riessman, 1990; Williams, 1984) or 'habitual narratives' (Riessman, 1990), and some consider the discursive product as a whole as being an 'account' (Radley and Billig, 1996). As a point of departure for my analytic framework, it is first necessary to briefly discuss how previous studies have approached the identification and analysis of these types of construction of illness experience. Whereas up until now I have discussed only *chronic* illness experience, as this is my specific focus, here I will include discussion of research into illness experience more widely. The production of broad-level constructions, such as story-telling and accounting, transcends specific areas of experience (Anderson and Martin, 2003: 135; Scott and Lyman, 1968; Thornborrow and Coates, 2005), and are therefore relevant in investigating talk about all illness, in spite of the many intricate differences that may be apparent between acute and chronic illness in their micro-discursive realisation.

A vast number of studies into illness experience focus primarily on *narrative*. It has been argued that narratives, often used synonymously with the term ‘stories’, afford the researcher unique insight into people’s illness experiences, through their ability to ‘effectively pull the listener into the teller’s point of view’ (Riessman, 1990: 1197), but that they can also enhance the teller’s *own* understanding of his or her experiences of illness. As Kleinman (1988) observes, ‘the personal narrative does not merely reflect illness experience, but rather it contributes to the experience of symptoms and suffering...people seem to be seeking to establish the *meaning* of an illness through their talk’ (1988: 142). This essentially constructionist position underscores the way in which narrative can act as a resource for individuals in repairing the disruption caused by the onset of illness, through allowing them to establish connections between different parts of their life biographies in order to form an understanding of the aetiology of their illness, a process Williams (1984) terms ‘narrative reconstruction’.

There is considerable variation, however, regarding what is taken to constitute a narrative, and what is included within its remit. Bell (2000) talks of this as a scale, where at one end, ‘the definition [of narrative] is so broad that it includes “just about everything” concerning people’s lives’, and at the other end, ‘it has been restricted to those narratives that are stories about a specific past event, and that are composed of a set of particular structural elements’ (2000: 189). Generally speaking, however, at a basic level narrative is accepted by most researchers as being ‘a discourse organized around time and consequential events in a “world” recreated by the narrator’ (Riessman, 1990: 1195).

Whilst narratives are generally considered as being the reconstruction of specific events or occurrences, and are therefore formulated through either the simple past or historic present tense, both Riessman (1990) and Cheshire and Ziebland (2005) note that often in research interviews ill people’s constructions take the form of ‘habitual narratives’, which ‘tell of a general course of events over a period of time’ (Cheshire and Ziebland, 2005: 23), ‘marking repetition and routinization’ (Riessman, 1990: 1197). In a habitual narrative, then, it is still the case that a story is told, but a story regarding what *generally* does or does not take place, as opposed to what happened on one specific occasion.

In terms of the analytic treatment of narratives, many sociological and anthropological works have concentrated primarily on comparison of content in the experiences constructed through narrative, resulting in theorisation about people's illness experiences (see Anderson and Martin, 2003; Kelly and Dickinson, 1997; Weinbren and Gill, 1999). Based on their analyses, some have formed typologies of narratives (Bury, 2001; Frank, 1995; Robinson, 1990). Several recent studies have also begun to explore the *performative functions* illness narratives serve to achieve – the ways in which they allow respondents to construct multiple identities in the interview context (Cheshire and Ziebland, 2005; Gwyn, 1996; Riessman, 1990; 2002; 2003, see Chapter 3 for further discussion).

Radley and Billig (1996), rather than focusing specifically on narratives, look at how people talk about their health and illness more generally, thus considering the discursive product as a whole rather than looking at a specific category of talk. They propose that these constructions should be considered as *accounts*, which they define as the 'activity of socially representing the world' (1996: 223). Radley and Billig contend that people regularly attempt to create an image of moral-appropriacy in relation to their constructed actions and beliefs, and it is this focus on concerns of *morality* that leads Radley and Billig to label these constructions 'accounts' (see Chapter 3, 3.2 for further discussion).

### ***1.6 Analytic Framework: Rhetorical Discourse Analysis of Chronic Illness 'Accounts'***

The present study will take a relatively inclusive approach in relation to the types of constructions investigated. Following Radley and Billig (1996), I will treat the overall discursive products as 'accounts', thus allowing for consideration of how people's talk about illness (and health) is both 'ideological and dilemmatic' (Radley and Billig, 1996: 221), always being produced with the other interlocutor[s] in mind, in terms of what the speaker sees as being an appropriate moral stance within the particular situational context, and in relation to the wider social context. Whereas many others have considered narrative as being the primary form of expression of illness experiences, I will consider narratives *within* the broader framework of accounts, with narrative constructions also explored in relation to their ideological underpinnings. Narratives will be identified as the

construction of past events, with each part of the narrative being connected in some kind of temporal order. As well as the reconstruction of specific events, I will investigate the presence of habitual narratives (re)constructing general experiences. Whilst considering accounts as the larger discursive structure (Arribas-Ayllon, Sarangi and Clarke, 2011), I will also explore the manifestation of accounting at the micro-level, where respondents are found, at particular times, to ‘excuse’ or ‘justify’ their reported-behaviours (Scott and Lyman, 1968, see Chapter 3, 3.2 for further discussion). Through investigating these various types of accounts, it is hoped to formulate a broad, multilayered interpretation of the representations of illness experience produced.

In analysing the accounts produced by the young adults, I will use methods of discourse analysis (DA), as has also been adopted in some previous studies looking at experiences of illness (Cheshire and Ziebland, 2005; Gwyn, 1996, see Chapter 3 for discussion). Bishop, Coupland and Garrett (2003) define the methods and goals of DA as follows:

a form of linguistic and contextual analysis which involves close empirical examination of written and spoken texts, within their social, historical and cultural contexts...[which] allows us to uncover meanings and implications behind patterns of linguistic representation that may be overlooked by less fine-grained textual analyses...the method is qualitative, aiming to provide interpretive depth...trying to ensure that interpretations of data are as faithful as possible to informants’ own values and priorities.

(2003: 41)

This approach therefore aims to carry out in-depth analysis of talk and text above the sentence level, considering the text as a whole, and attempting to identify recurring patterns and trends in language-use, whilst taking into account the wider social and cultural context in which the text is produced (Jaworski and Coupland, 1999; Potter and Wetherell, 1987; Stubbs, 1983).

Within the scope of this broad definition of DA, I will follow the principles of what has been termed ‘rhetorical discourse analysis’, as has been applied recently in the context of genetic testing and genetic counselling (Arribas-Ayllon et al., 2011). This approach also views social action as being accounts ‘embedded within the sphere of social accountability’, which are thus ‘premised on the moral, practical and rhetorical aspects of



social interaction' (Arribas-Ayllon et al., 2011: 57). This type of analysis investigates the construction of accounts at a micro-level, looking at the discursive devices and strategies used by speakers to achieve a range of functions, i.e., 'mending interaction, saving face, or constructing persuasive arguments' (2011: 57). These strategies include, among others: contrast, reported-speech, metaphor and pronominal reference (see Chapter 5, 5.3.3, for further discussion).

In adopting this analytic framework, then, the present research attempts to move beyond many studies within this area which have predominantly focused only on the content of individuals' talk about their experiences (for example: Daniel, 2001; Dovey-Pearce, Doherty and May, 2007; Schur, Gamsu and Barley, 1999). There will be a focus not only on *what* respondents say, but *how* they say it, and what they are attempting to *do* with their talk. I will explore the rhetorical, *performative* function (Butler, 1990) these accounts serve, investigating how respondents are able to construct various different identities at different points throughout their talk. This approach shares similarities with that of several recent studies focusing on narrative (Bülow, 2004; Hydén, 1997; Riessman, 1990; 2002; 2003); however, only a few of these have carried out micro-investigation of the use of these types of rhetorical discourse devices (Bokhour, Powel and Clark, 2007; Cheshire and Ziebland, 2005; Gwyn, 1996). What is more, up until now this kind micro-analytic investigation has not been carried out in relation to individuals of this particular age-group, or people with IBD and T1DM.

### **1.7 Research Questions**

Based upon the underlying aims of the study, and the findings of the literature review (Chapters 2-4), the following research questions were formulated, which will be addressed within this thesis:

Central Research Question:

How do young adults discursively construct their individual experiences of chronic illness?

The central research question can be sub-divided further as follows:

- Which areas of their lives do young adults with T1DM and IBD construct as being most affected by their condition? (Chapters 6-10)
- How do respondents construct their condition in relation to their conception of *self*? (Chapter 6)
- How do respondents represent others' perceptions and reactions vis-à-vis their condition, and their self-presentation to others? (Chapter 7)
- How do accounts portray the degree of *control* respondents have over their lives vis-à-vis their condition, and their control over the condition itself? (Chapters 8 and 9)
- What similarities and differences are apparent in accounts *across* the two conditions? (Chapters 6-10)

### **1.8 Thesis Structure**

The structure of the thesis will be as follows. Chapters 2-4 will review and evaluate previous research relevant to the area of illness experience. The reason for dividing the literature review into three separate, shorter chapters is twofold. Firstly, whilst the review will be very selective, the cross-disciplinary nature of the study, and the broad area within which it is situated, necessitates a review of literature from several different disciplines. Secondly, these chapters will serve different functions. Chapter 2 will selectively evaluate a few seminal sociological works on illness experience, which have influenced much subsequent research. The theories and concepts developed in these studies will strongly influence the present analysis. Chapter 3 will explore interaction- and language-based studies which focus on situated identity-construction, within which it is the methodological and analytic models that will be of principal focus, including the discursive features they focus upon. Chapter 4 will explore research into the experiences of people with T1DM and IBD, including studies specifically focusing on the experiences of young adults with these conditions. The purpose of this chapter is to investigate the

broad themes and findings in relation to this specific group, with these findings forming the basis of comparison with the experiences constructed in my data.

Chapter 5 will outline the methodological approach adopted in addressing the research questions posed, both in relation to data-collection and analysis. This will include firstly detailing how I recruited my respondents and the interviewing approach adopted. I will then discuss the identification of predominant themes emanating from the data through open-coding using qualitative software, which followed grounded theory methods (Glaser and Strauss, 1999). Each of the predominant themes identified informed one of the analytic chapters.

Chapter 6 will address the first of the predominant themes identified in the interview-data, i.e., issues surrounding chronic illness which are related to *self*. This chapter explores how the young adults discursively construct the relationship between their illness and selfhood.

Chapter 7 will address the second predominant theme identified, i.e., young-adults' representations of their *orientation to others*. It will investigate how respondents construct others' perceptions about their condition, as well as others' behaviours resulting from these perceptions, both experienced and hypothetical. It will also explore respondents' reported self-presentation of illness.

Chapter 8 will focus on the third predominant theme, *Control*. This chapter addresses how respondents represent the (lack of) control that they have over their lifestyle vis-à-vis the influence of their condition, as well as their control over the condition itself, in terms of their control over treatment-regimens and the incidence and severity of disease symptoms.

Chapter 9, the final analytic chapter, will also centre on issues of control, but will focus on one specific lifestyle area – the effect of illness on young adults' participation in alcohol-consumption practices and related social activities, here termed *social drinking practices*.<sup>2</sup>

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<sup>2</sup> An adapted version of this chapter has recently been published: (Saunders, 2011).

Chapter 10, labelled Conclusion, will summarise the findings of the analytic chapters and return to the research questions posed. I will then situate these findings within the wider research field, whilst also reflecting on some limitations of the study. I will propose some practical applications of findings, with the aim of benefitting young adults with these conditions, both within and outside of the clinical context; as well as making some recommendations for future research within this area.

## 2. Experiences of Living with Chronic Illness: Some Classic Studies

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This chapter will evaluate seminal sociological and anthropological research into people's experiences of illness and chronic illness, in order to provide theoretical grounding in the field of study. Rather than conducting a broad review of this area, I have chosen to focus on a few studies that are especially relevant to the concerns of the present research. It is felt that a selective, in-depth review of this kind will be more fruitful in informing the forthcoming analysis.

The order in which the studies will be presented is based on their scope of focus and specificity of aims, rather than their chronology. I will begin with the work of Frank (1995) (2.2), who explores people's experiences of illness more broadly, and then look at two classic studies by Charmaz (1983; 1991) (2.3 and 2.4), who takes the more specific focus of *chronic* illness experience. I will then evaluate the highly influential work of Bury (1982) (2.5), whose focus is on one particular aspect of chronic illness experience – the onset of illness. The concepts and theories developed in these studies have been adopted, discussed and critiqued in numerous studies since, however it is beneficial to return to these original works in detail. Whilst I will look at the findings and concepts developed from these studies, which is the point at which many other critiques have stopped, I will also evaluate some of their methods of data-collection and analysis, which will provide a useful point of departure for outlining my own methodological approach (see Chapter 5).

## **2.1 Contextualising Illness Experience Research**

Before discussing these individual works, it is important to briefly contextualise this research tradition. Many studies investigating illness experience are framed as a challenge to a perceived medical hegemony – the dominance that medical perspectives and priorities are seen to exert over people with illness. This is borne out of the general distinction between ‘disease’ and ‘illness’ (Eisenburg, 1977; Helman, 1981), introduced in 1.1, which has been said to characterise the respective ways that medical professionals and lay people conceptualise ill-health. Mishler (1984) has famously extended these ideas in proposing that these different conceptualisations result in different ways of talking about disease/illness, which he termed ‘voices’. He argued that, during medical consultations, normatively healthcare professionals adopt the ‘voice of medicine’, representing ‘the technical-scientific assumptions of medicine’ (1984: 14), and lay people use the ‘voice of the lifeworld’, representing ‘the natural attitude of everyday life’ (1984: 14). Though the premise that doctors and patients uniquely use only one of these respective voices has been challenged (see Fisher, 1991; Silverman, 1987; and Mishler himself in a later auto-critique, Mishler, 2005), most agree that an asymmetry exists in the respective capital afforded to these two ways of speaking, with the medical voice generally given more prominence in medical consultations, and afforded higher status by medical professionals and patients alike. Whilst this perceived asymmetry has led to a wealth of subsequent research investigating the clinical setting (Charon, 2006; Elwyn and Gwyn, 1998; Fisher, 1991; Greenhalgh and Hurwitz, 1998; Kleinman, 1988; Silverman, 1987), which has called for patients’ constructions of their views and experiences to be afforded a greater role within medical contexts, this perspective has also influenced many studies focusing on how people represent the role of illness within their lives more generally. This includes Frank (1995) and Charmaz (1983, 1991), to be discussed below. Significantly, however, it will be shown that Bury (1982) is less critical of the ‘disease’ model, and frames his work as accommodating this tradition, rather than as a challenge to it.

## 2.2 Frank (1995): Investigating People's Talk about Illness

The seminal work of Frank (1995) pioneers the perspective that talking about one's illness has strong *therapeutic* and *emancipatory* potential. Frank thus gives salience to the benefits gained through the *process* of talking about illness, in addition to the insights afforded from what people say about their illness experiences. Frank (1995) explicitly presents his work in opposition to perceived medical dominance in the domain of ill-health. He describes the seriously-ill as being 'wounded, not just in body but in voice' (1995: xi). He thus champions the illness narrative as an emancipatory tool, proposing that those with illness 'need to become storytellers in order to recover the voices that illness and its treatments have taken away' (1995: xi). Frank defines a 'narrative' or 'story' in quite a broad sense, stipulating only that it 'implies a sequence of events connected to each other through time' (1995: 97). For Frank, then, ill people must be able to 'reclaim' (1995: 6) their stories from the medical establishment, as way of reclaiming control of their own experiences.

Frank emphasises that illness stories are beneficial not only to individuals themselves, in allowing them to arrive at a greater understanding and acceptance of their illness, but can also benefit others who can relate to these stories, and as a result, better understand their own experiences: 'storytelling is *for* an 'other' just as much as it is for oneself...the teller offers herself [or himself] as a guide to the other's self-formation' (1995: 17).

Whilst a central tenet of Frank's argument is the individuation of tellers' stories, the contention that no two stories are the same, and thus there is a need to listen carefully to each in turn, he does at the same time acknowledge their social nature:

From families and friends, pop culture and stories from other ill people, storytellers have learned formal structures of narrative, conventional metaphor and imagery, and standards of what is and isn't appropriate to tell...these rhetorical expectations are reinforced when a new story is told, and passed on to affect others' stories.

(1995: 3)

This perspective draws influence from the classic work of Herzlich (1973), who investigates people's conceptions of health and illness through the perspective of 'social representations'. This suggests that people's conceptions of health and ill-health do not derive from models that are personal or individual to them, but are formed in reference to the understanding of wider societal views about health.

In adopting this perspective, Frank posits that people compose stories by adapting and combining narrative types that their culture makes available to them. He identifies three broad narrative types into which illness stories can be classified. The first he terms the 'restitution narrative' (1995: 75). This storyline follows the plot of 'yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again' (1995: 75). Stories following this pattern therefore depict illness as a temporary state, placing faith in medical intervention to restore the ill person to his or her previous state of health. Frank observes this narrative type as dominating most illness stories, but suggests that it is particularly associated with those recently diagnosed, and least often with those who have chronic conditions. I would suggest, however, that restitution narratives could indeed occur in relation to chronic illness. In the case of many chronic conditions, including IBD as is focused upon in the present study, individuals can experience lengthy periods of remission, and thus periods of relapse will be seen as temporary, allowing for a degree of restitution. In the case of all chronic conditions, however, the absence of a cure means that restitution can never be total.

The second narrative type identified by Frank is the 'chaos narrative'. This is the 'opposite of restitution', as instead of envisaging a return to normal health, 'its plot imagines life never getting better' (1995: 97). Stories of this kind are 'chaotic in their absence of narrative order' and 'presuppose...the ill person's loss of control' (1995: 97). This type of narrative thus reflects individuals so deeply affected by their situation, and the influence of their condition upon their lives, that they are unable to coherently express their thoughts. One could question Frank's contention that those experiencing severe hardships due to illness are not capable of constructing a coherent narrative, and that a chaotic illness experience will necessarily be reflected in a chaotic story; however, Frank



makes a persuasive argument to support his claims. Though only drawing primarily on only one example of a chaos narrative, told by a woman who was struggling to manage her chronic condition, whilst also caring for her elderly mother with dementia (1995: 99), Frank demonstrates a lack of coherence and cohesion in terms of both the content and structure of this narrative. Due to the lack of examples, it is unclear whether such 'chaotic experience' would be widely apparent. When chaos narratives are present, however, one would expect them to be most commonly produced by those with chronic conditions, given the enormity of coming to terms with the permanency of symptoms and treatments, and the difficulties in managing the demands of illness on a daily basis.

Frank's final narrative type is the 'quest narrative'. This contrasts greatly with the other two narrative types, as quest stories 'meet suffering head on...they accept illness and seek to *use* it' (1995: 115). The quest narrative, then, depicts illness as a journey, in which some kind of positive outcome results from the hardships experienced by the ill person. It tells of the individual 'self-consciously being transformed' (1995: 118), and implies that the teller has been given something from the experience, usually some kind of insight that can be passed on to others. Those who produce quest stories represent illness not as impacting negatively upon their conception of self (Charmaz, 1983, see 2.3 below), but reframe it in a positive light, as a challenge to be overcome. Such stories can be seen as inspirational, with the ill person depicted as a heroic figure. It can again be posited that this type of narrative is likely to have particular relevance to experiences of chronic illness, as such transformation could be occasioned by the need to face-up to a permanent, incurable illness, and having to manage illness for a lengthy period of time.

Whilst providing an insightful lens through which to view illness experience, Frank's categorisation of narrative types should not be seen to be exhaustive. Several researchers have noted the limitations in the scope of Frank's typology (see for instance Gwyn, 2002: 157; Hydén, 1997: 53-4), and I am inclined to agree with their observations, as it would not be difficult to envisage an individual's story not conforming to any of the three types of telling. For instance, a narrative which represents illness as an unalterable part of life (thus not a restitution narrative), constructed as a coherent story of events (thus not a chaos narrative), but which does not represent the individual as embarking on a journey to

influence others, would not fit within any of these categories. However, whilst it is valid to point out this limitation, at no point does Frank actually claim that *all* stories can necessarily be placed within this typology, and in fact he invites expansion of his typology: ‘Certainly, other types of narrative can and should be proposed’ (1995: 76). These narrative types can therefore be considered as ways in which people *can* talk about illness, rather than how all people necessarily *will* talk about their illness experiences. Also important to note is that Frank stresses that he does not intend for this categorisation to detract from the uniqueness and subjectivity of each illness story, and that it is possible for a single story to conform to different narrative types at different points.

Frank’s use of data examples is rather limited. He justifies this as follows:

being responsible to these stories, thinking with them, depends on telling certain stories over and over, hearing different nuances of potential meaning as the story is told in different circumstances and at different ages of our lives, thus this book returns to comparatively few illness stories.

(1995: 24)

Another reason Frank provides for this is that he does not consider people’s illness stories as ‘data’ used to support his claims, but that the stories are ‘the materials that I use to model theorizing – and living – with stories’ (1995: 23). Frank’s reluctance to consider stories as ‘data’ is perfectly valid. However, being a researcher who places great emphasis on the benefits gained from in-depth examination of extended extracts of talk, I would argue that using a greater number of data examples would allow Frank to more fully demonstrate how individuals claim their ‘voice’ through these different narrative types. Since Frank, some researchers have undertaken the study of these narrative types in a more robust, systematic way. Whitehead (2006), for instance, interviewed 17 individuals with chronic fatigue syndrome, aged 13-63, observing the presence of all three narrative types, and proposing a trajectory within individual narratives, which begins with restitution, moving to a chaos narrative, then back to restitution, and finally onto quest.

Frank draws on stories he has been told or sent over a period of years, as well as examples used in other research, and published stories of illness written by people in the public domain. Whilst these are perfectly acceptable data-sources, using data he has not

systematically collected himself excludes the possibility of Frank attending to issues such as the context in which the stories were produced, and, in cases where interview-data is used, the role of the interviewer in the construction of these narratives – considerations I would contend are very important when interpreting the final narrative product (these issues will be fully discussed in Chapter 5, 5.2.3 and 5.3.3).

Additionally, when using published stories, it could be questioned whether these are typical of everyday illness narratives, given their primary purpose to entertain, and to be consumed by a large public audience. These stories may be sensationalised, and may exclude many of the more mundane, everyday experiences inherent to living with illness. Alternatively, where the mundane *is* present in these stories, such moments may be represented as being particularly salient in the way that they give rise to both horror and sublimity (Radley, 1999a), moments Radley describes as ‘the appearance of the unthinkable in the guise of the innocuous’ (1999a: 783). Although such moments may be encountered by ‘ordinary’ people, these will likely be rare within an individual’s overall ‘illness trajectory’ (Corbin and Strauss, 1988). Frank notes that many of these published stories fall within the category of quest narrative, which is perhaps unsurprising, as of the three narrative types this perhaps has the most dramatic appeal. Frank does suggest that stories categorised as ‘quest’ are not only those constituting dramatic tales of heroism, as found in many of the published stories he looks at. He contends that ‘involvement in patient advocacy is one enactment of a quest story; making significant vocational and personal changes in one’s life following illness is another’ (1995: 116). From this perspective, then, quest narratives *are* also likely to be found within ‘ordinary’ illness narratives; however, I would argue that these may be very different from those found in published writings.

These methodological criticisms should in no way detract from the importance of Frank’s research. His rhetoric regarding the therapeutic and emancipatory potential of illness narratives is highly persuasive, and has influenced much subsequent research, including the present study. This includes the inspiration I draw from his arguments regarding giving those with illness a ‘voice’, as well as his philosophy of treating ill people

principally as *people*, who happen to have an illness, rather than in their role as patients vis-à-vis doctors in interaction. His categorisation of illness narratives will be shown to be a useful theoretical approach in exploring some of the constructions of young adults with IBD and T1DM in the present study.

### 2.3 Charmaz (1983; 1991): *Experiences of Chronic Illness*

Whilst Frank looks at people's talk about illness generally, Charmaz (1983; 1991) focuses specifically on the experiences of those with *chronic* illness. Writing before Frank, she also presents an argument for the inadequacy of medical definitions of ill-health in relation to the experiences of those with illness, a proposition that she argues has particular relevance to chronic conditions.

Charmaz contends that living with chronic illness is inextricably bound with issues of self-identity, and in her earlier work (1983), she proposes that as a result of chronic illness, individuals can experience a 'loss of self', defined as 'the crumbling away of former self-images without simultaneous development of equally valued new ones' (1983: 168). This loss of self, she proposes, leads individuals to 'question their own self-worth and view their developing limitations as losses' (1983: 169). Charmaz thus places strong emphasis on the *suffering* and hardships individuals can endure in the face of chronic illness.

Charmaz (1983) draws on 73 in-depth interviews with 57 chronically-ill people with a range of different conditions, including cardiovascular disease, diabetes, cancer and multiple sclerosis (MS). The interviews selected for analysis were those with people suffering from the most debilitating illnesses, although it is not explained how the extent of debilitation was established, except that many of the respondents were housebound due to their illnesses.

Charmaz adopts a symbolic-interactionist perspective towards the self, considering it not as something fixed and static, but as being constructed through social relations. She talks of individuals holding a 'self-concept', which is based around the '*organisation* of attributes that have become consistent over time' (1983: 170), but proposes that this organisation must be sustained and 'validated in daily life' (1983: 170). This suggests, then, that as individuals we hold a particular self-concept which consists of attributes which are to some degree static and enduring, but may also change over the course of one's life; and that this self-concept does not just exist, but must be socially achieved and reconstituted. With this perspective in mind, Charmaz argues that issues of self are potentially problematic in the case of chronic illness, as the self-images presented to others in social interaction may not be consistent with the self-concept the individual aspires towards, or further to this, present self-images may be 'wholly incompatible with...the individual's criteria for possessing a valued self' (1983: 170). Charmaz aims to explore this issue through investigating 'how illness as an experience shapes situations in which the person learns new definitions of self and often relinquishes old ones' (1983: 170). Charmaz's approach to *self* and *identity* will be returned to in 5.4, as part of a more general discussion of these concepts.

Charmaz follows a grounded theory approach in her analysis. Whilst having several variations, grounded theory essentially aims to 'discover theory from data systematically obtained' (Glaser and Strauss, 1999: 2). Charmaz's methodological approach will be discussed more fully in 5.3.1, in relation to my own methodology. Charmaz identifies several recurrent themes that can contribute to 'loss of self' for chronically-ill people. The first is 'living a restricted life' (1983: 172), in which 'sufferers' cannot participate in normal, everyday activities because of the symptoms of illness, which can lead them to feel a distance between their present self-concept and that which they held before the onset of illness: 'the ways in which they had known themselves in the past became increasingly remote' (1983: 173). This restricted lifestyle can result in 'social isolation' (1983: 176). Charmaz proposes that experiences of being 'discredited, embarrassed, ignored and otherwise devalued...contribute to the growing isolation of ill individuals and to their subsequent reappraisals of self' (1983: 176).

Loss of self amongst the chronically-ill was also found to result from ‘discrediting definitions of self’ (1983: 181). These can be definitions arising in interaction with others, or those developing out of ‘unmet expectations of the ill person’ (1983: 181). An example given by Charmaz, which is especially relevant to the present study, is of a woman with diabetes who reported isolating herself through avoiding parties because she disliked confronting food and alcohol that she could not have, and because she ‘resented being watched and judged by others present’ (1983: 182). These discrediting definitions, emanating both from other people’s perceptions and the individual’s own perceptions, lead to images of the self that are misaligned with the self-concept that the individual wishes to maintain. It can be seen, then, that closely tied to issues of *self*, are ill people’s views regarding how *others* perceive them – something that will be explored in detail in the present study.

The final theme Charmaz identifies as contributing to loss of self is ‘becoming a burden’ (1983: 188). This involves the chronically-ill person becoming more dependent upon others in his or her daily life, and ‘symbolises that the person can no longer claim identities based upon prior external activities, interests and pursuits’ (1983: 189).

Charmaz concludes that the ‘language of suffering these people spoke of was the language of loss’ (1983: 191), and that they rarely spoke of gaining any positive outcomes or ‘heightened consciousness of the world’ (1983: 191) through their illness experiences. Instead they were found to experience ‘heightened self-concern about the person they see themselves becoming and about the valued self-images of the past which they have lost, sometimes irretrievably’ (1983: 190).

Charmaz’s study makes for interesting comparison with Frank (1995), as Charmaz found little or no evidence of ‘restitution’ or ‘quest’ narratives in her data. Her respondents framed their experiences in very negative terms, and did not represent illness as a transformational experience, as Frank claims. The absence of restitution narratives is

perhaps due to Charmaz's focus on chronic illness which, as proposed above, brings about fewer stories of restitution. The absence of quest narratives may be a result of Charmaz's choice to select only the most severe cases of illness. However, Frank does observe some individuals who have experienced very troubled illness 'journeys' constructing 'quest' narratives, so this may not fully explain the disparity in findings.

It could be speculated that it is precisely Charmaz's focus on those with the most debilitating illnesses that results in the bleak picture painted in her findings of chronically-ill people losing their previously held self-images, and struggling to accept a new self restricted by illness. It could therefore be argued that 'loss of self' is most applicable to those severely debilitated by illness, and may not reflect the experiences of chronically-ill people more generally. I would propose, however, that this theory can in fact be viewed as a continuum. Thus, in cases where chronically-ill individuals are not engrossed by illness or confined to their homes, as in the case of Charmaz's respondents, there may still be facets of their prior self-concept that have been lost, and aspects of the self that must be renegotiated in order for them to form a new self-concept which incorporates chronic illness. Charmaz's focus on the most severely-ill should not, therefore, diminish the applicability of this theory to other, less debilitating forms of chronic illness. 'Loss of self', conceived as a continuum, will be shown to be very relevant in relation to the present study. In the case of IBD, during periods of disease flare-up individuals can become severely debilitated, and at these times loss of self may be particularly pertinent. This concept also has relevance to T1DM, as demonstrated through the example given above by Charmaz.

In her later research, Charmaz (1991) investigates people's experiences of chronic illness more generally, rather than focusing on those most severely affected by illness. Her book *Good Days, Bad Days* (1991) explores how people make sense of living with chronic illness, again focusing on how this relates to the construction of the *self*. Charmaz proposes that: 'to observe how chronic illness affects the self, we must look at the degree to which illness impinges upon ill people's everyday life – their work, homelife, free time' (1991: 6). For Charmaz, then, in agreement with Frank (1995), discussed above,

beginning to understand people's experiences of chronic illness is contingent upon looking at their everyday life experiences, focusing on the mundane as much as the extraordinary, and delving beyond the narrow frame of the medical context. This is a perspective that has strong influence upon the present study, in which I aim to explore the experiences of chronically-ill young adults within the context of their lives as a whole.

Charmaz again draws on a large data-set, this time 115 interviews with 55 people with a range of different chronic conditions. She does not provide a comprehensive list of these conditions, but those discussed include carcinoid syndrome, chronic fatigue syndrome, emphysema, diabetes, ulcerative colitis and multiple sclerosis (MS). Forty seven of her respondents were aged 21-70, and 8 respondents were over the age of 70. Many of the respondents were interviewed on more than one occasion, over a period of several years, which Charmaz proposes led to a richer data-set, as this allowed for individuals' experiences to be traced over a lengthy period of time.

In general terms, Charmaz's findings lead her to posit that, whilst chronic illness has the potential to have a profoundly negative effect on people's lives, most are able to 'live *with* their illnesses rather than *for* them' (my italics) (1991: 4), and often people try to 'keep illness at the margins of their lives and outside of the boundaries of their self-concepts' (1991: 4). She notes that, whilst people can at times achieve this, at other times they cannot.

Again viewing the self as comprising of fairly stable self-images which must be socially achieved and reconstituted, and exploring the data through grounded theory, Charmaz identifies three ways in which people represent chronic illness: as an 'interruption', 'intrusion' or 'immersion'. Which perspective is adopted, she proposes, depends not only on the severity of the illness itself, although this does play a significant role, but on the individual's own 'definitions of the experience' (1991: 9). This suggests, then, that those with similar diseases can have very different illness experiences as a result of their differing definitions of illness.



Those who represent illness as an 'interruption' see it as 'temporary, short in duration and with a predictable outcome: *recovery*' (1991: 14). For these people, being ill means 'temporarily putting aside their identities and selves while they recuperate and wait for recovery...since they expect to recover they feel no need to alter their conceptions of self for any length of time...illness is seen as external to the self' (1991: 14). This view of illness relates strongly to Frank's (1995) concept of the 'restitution narrative', discussed above, although whilst Frank suggests this type of narrative to be fairly uncommon in relation to chronic illness, and it is completely absent in Charmaz's (1983) earlier study, in this later study Charmaz found this perspective to be more prevalent, due to the episodic nature of certain chronic conditions. The concept of interruption is certainly relevant to the present study, especially in the case of young adults with IBD, in which flare-up/remission cycles are common. These respondents may, therefore, represent their condition as being an interruption, as opposed to being a constant feature within their lives, which will be shown to have implications regarding how they construct the role of illness within their self-concept.

Experiencing illness as an 'intrusion' has very different implications, as an intrusive illness does not only disrupt the ill person's life temporarily; instead, the individual must constantly attend to both the physical and psychological effects of the condition. The issue of self-concept therefore becomes more problematic than in the case of an interruptive illness, as individuals can no longer hold onto prior self-concepts, and must instead incorporate illness into a new conception of self. As Charmaz argues, an intrusive illness 'forces them [chronically-ill people] to accommodate it...how they accommodate to their illnesses shapes whether or not they can live life as they choose' (1991: 42). Charmaz observes that individuals who represent illness in this way will often view their control over their lives as being 'tentative and limited' (1991: 44), resulting in high levels of uncertainty.

Charmaz identifies differing responses of individuals to an intrusive illness, finding them to either 'embrace, incorporate or contain it' (1991: 65). Embracing illness goes beyond

mere acceptance, with individuals actually welcoming it; they ‘take their images of self from it...illness lends meaning to life and imposes a daily routine’ (1991: 65), a perspective which appears reminiscent of Frank’s ‘quest narrative’, and is very much at odds with the negative views of illness portrayed in Charmaz’s (1983) earlier work. I would argue that here Charmaz’s label of ‘intrusion’ does not display a good ‘fit’ with this response to illness, as whilst ‘intrusion’ has very negative connotations, ‘embracing’ illness reflects a positive representation of its role in the individual’s life. ‘Incorporating’ illness does not go this far, but entails ‘recognising it, taking it into account, and living *with*, rather than for, *it*’ (my italics) (1991: 66). In this case, then, illness becomes part of the ill person’s self-concept, but does not occupy a prominent role. Keeping illness ‘contained’ does not, however, necessarily involve acceptance; instead, the individual attempts to keep his or her illness hidden, at least in public, and perhaps also from the self. Charmaz suggests that for some individuals, if living with intrusive illness and following valued pursuits do not complement each other, they will put the pursuits first, and thus sacrifice their health in small ways. This therefore presents a trade-off between individuals’ health and taking control of their lives.

The concept of ‘intrusion’ is also very relevant to the present study, as it will be shown that many respondents represent their condition as having a constant influence upon their lives, as they must manage the symptoms and treatment-regimens on a daily-basis. Similarly to Charmaz’s findings, there will be shown to be variation in the reactions of respondents to intrusive illness.

The final way in which people were found to experience chronic illness, as ‘immersion’, sees life becoming determined by illness; individuals must ‘reconstruct their lives upon illness’ (1991: 76). Illness thus becomes the primary controlling force on the person’s life, with the individual not enjoying the agency that may be claimed in the case of an interruptive or intrusive illness. Though not as prevalent as ‘intrusion’, ‘immersion’ will also be shown to be present, at times, in my data, as some respondents report periods of illness or disease flare-up resulting in debilitating ill-health.

Charmaz's research has been highly influential in the field of illness experience. She provides a sensitive account of how chronically-ill people adapt to, and live with, their conditions, and her theories about the ways in which chronic illness is experienced are certainly very persuasive. It must be recognised, however, that Charmaz's three conceptualisations are not necessarily mutually-exclusive in terms of an individual's overall 'illness trajectory' (Corbin and Strauss, 1988). Due to the episodic nature of many chronic conditions, it is possible that individuals may, during some periods, feel immersed within their condition, with their whole life being engulfed by their symptoms, but during other periods symptoms may subside somewhat, allowing the resumption of some normal, everyday activities, leading them to represent the condition as an intrusion or interruption. As already noted, the perspective taken by an individual is not solely driven by symptom severity; therefore one person may only experience intrusion in his/her illness where another may see himself or herself as immersed in illness.

As mentioned, Charmaz draws on a large data-set; therefore, even though her principle aim was in-depth investigation of ill people's experiences, with the external validity of her findings not of primary concern, this could allow for tentative claims to be made regarding the generalisability of these concepts to people with chronic conditions more widely. One must always be careful, however, not to diminish the subjective and potentially idiosyncratic nature of illness experience if making such claims.

#### **2.4 *Bury (1982): The Impact of Chronic Illness at its Onset***

Preceding both Frank and Charmaz is the highly influential work of Bury (1982). Like Charmaz, Bury looks at experiences of chronic illness, but concentrates on those only recently diagnosed, in order to explore 'the problems of recognition and changes in life situation and relationships occasioned by the development of illness' (1982: 167).

Bury conducted 30 semi-structured interviews with people with rheumatoid arthritis, recruited through an outpatient rheumatology clinic in North-West England. From this interview-data, Bury theorises that chronic illness can be seen to be a 'major kind of

disruptive experience...where the structures of everyday life and the forms of knowledge which underpin them are disrupted' (1982: 169). He terms this 'biographical disruption'. This disruption marks a 'then' and 'now' divide in the individual's life, with events and experiences being perceived in terms of whether they occurred before or after the onset of illness. Bury sees this disruption as encompassing three mutually-dependent stages. Firstly, there is the 'disruption of taken-for-granted assumptions and behaviours', then a 'fundamental re-thinking of the person's biography and self-concept' (1982: 168), and finally, a response to disruption involving 'mobilisation of resources, in facing an altered situation' (1982: 168).

Bury found that newly diagnosed chronic illness leads to a disruption of friendship and community involvement, arising because of not only functional limitations but also embarrassment on the part of the ill person. He proposes that maintaining an appearance of normality in social situations becomes a conscious and often tiring effort: '[the] erstwhile taken-for-granted world of everyday life becomes a burden of conscious and deliberate action' (1982: 176). Similarly to Charmaz, then, Bury sees chronic illness as resulting in a shift in the individual's self-concept and the images of self projected to others, and proposes that those with chronic illness must adapt to this new situation through 're-evaluation of the relationship between the now-visible disease and selfhood' (1982: 172). As in Charmaz's research, then, Bury found issues regarding the effect of chronic illness on the self to be closely linked to individuals' concerns regarding how others may perceive them.

Bury diverges from the perspectives of Frank and Charmaz in his view of the role played by medical discourse in the individual's adaptation to chronic illness. Whereas both Frank and Charmaz present their arguments as a challenge to medical definitions of ill-health, Bury contends that both 'illness' and 'disease' models can play a significant role in allowing individuals to make sense of, and come to terms with, chronic illness:

Whilst medical definitions may at times be seen as inappropriate in service and welfare provision, this does not displace the role of both lay and specialised medical knowledge in explaining experiences.

(1982: 168)

Bury argues that 'disease-oriented' models (Helman, 1981) can allay some of the uncertainties surrounding chronic illness, and that conceptualising chronic illness through medical definitions allows for objectification, a separation of the disease from the self, enabling individuals to hold it 'at a distance' (1982: 172). Bury contends that this 'assists the claim that one is a victim of external forces' (1982: 172), thus potentially lifting some guilt and blame away from the individual, from his or her own perspective (see also Cassell, 1975; Gwyn, 1996; Radley, 1993). Bury does, however, recognise that the strict separation of disease from the individual is 'precarious', reporting that respondents in his study experienced an 'uneasy balance...between seeing the condition as an outside force and yet feeling its invasion on all aspects of life' (1982: 172). He proposes that, whilst medical knowledge is important, it is incomplete, and must be supplemented by, and set against, 'a body of knowledge and meaning drawn from the individual's own biography' (1982: 179). Bury therefore calls for 'a more careful treatment of the continuity and discontinuity between medical thought with disease and lay thought with illness' (1982: 179), which he views as being over-simplified by Helman (1981) and others (see 2.1, above), a perspective echoed by several researchers since (see Bell, 2000; Fisher, 1991; Persson, Race and Wakeford, 2003; Radley, 1999b).

Bury's theory of 'biographical disruption' has made a very important contribution to the field vis-à-vis the ways in which chronic illness affects people's lives, especially at its onset. In fact, one is hard-pressed to find a study on chronic illness experience in the past thirty years that does not acknowledge the significance of Bury's (1982) work. Whilst criticism could be made that Bury presents 'biographical disruption' as a theory relating to the experience of chronic illness more generally despite using only rheumatoid arthritis as a case-study, the robustness of this theory has since been tested in relation to a range of other conditions; including, multiple sclerosis (MS) (Green, Todd and Pevalin, 2007); stroke (Faircloth, Boylstein, Rittman, Young and Gubrium, 2004; Pound, Gompertz and Ebrahim, 1998); osteoarthritis (Sanders, Donovan and Dieppe, 2002); HIV/AIDS (Carricaburu and Pierret, 1995); and motor neurone disease (Locock, Ziebland and Dumelow, 2009).

Some commentators have suggested that ‘biographical disruption’ may be more complex than Bury originally proposed. Williams (2000), for instance, argues that some individuals may not view chronic illness as resulting in disruption, but may perceive other disruptive events in their lives, i.e., work-related stress or particularly traumatic experiences, as bringing about the onset of illness; thus, biographical disruption can be a *cause* rather than an *effect* of chronic illness. Williams also argues that biographical disruption is not an inevitable result of the onset of chronic illness, and that illness may be ‘a biographically *anticipated* rather than a disruptive (*i.e.* unanticipated) event’ (2000: 51), as many people will place this experience ‘in the context of a lifetime’s general hardship and adversity’ (2000: 51). Williams associates this perspective mostly with people of working-class backgrounds, but also with older people, for whom illness may be expected at their life-stage. This argument is also reflected in the findings of Faircloth et al. (2004), in relation to the experiences of individuals, aged 46-88 (with an average age of 67), who had recently had a stroke. Faircloth et al. extend the notion of biographical disruption to talk of ‘biographical flow’, which suggests that for many older people, illness ‘melds into an enduring chronic illness narrative, part-and-parcel of biography’ (2004: 245). In this conception, then, rather than a great ‘then’ and ‘now’, chronic illness is incorporated within the general ‘flow’ of events and experiences in a person’s life.

It can be seen, then, that some of the criticisms of ‘biographical disruption’ are based on the argument that the theory has less relevance to people in older age. Pound et al. (1998: 490), for instance, propose that the presence of biographical disruption in Bury’s (1982) data is at least partially a result of the ‘relatively young’ age of Bury’s respondents. I would argue, then, that ‘biographical disruption’ may be especially significant in relation to young adults, as unlike the older respondents in Faircloth et al.’s (2004) research, they are unlikely to view chronic illness as in any way inevitable for people of their age-cohort. This makes the theory of ‘biographical disruption’ very relevant to the concerns of the present study. This relevance is in spite of the fact that my focus is on young adults’ illness experiences as a whole, and not only the onset of illness. Whilst some respondents in the present analysis will be seen to focus upon the impact of illness at the time of its onset, in the case of others it will be shown that biographical disruption does not relate *only* to the beginning of their illness trajectory, but that a particularly traumatic event can

cause disruption to occur at a later point (see Chapter 6). This kind of disruption has been conceptualised elsewhere as a 'turning point' (Charmaz, 1991), an experience that 'constitutes a shift both in the sequence of events and self-understanding' (1991: 83). The concept of 'biographical disruption' is therefore relevant not only to respondents who were diagnosed in adolescence or young adulthood, but also to those diagnosed in early childhood, as is the case with several of my respondents, especially those with T1DM.

In my analysis, the presence of 'biographical disruption' will by no means be assumed, and will be explored in relation to each respondent's representations on an individual basis. As Williams (2000) notes:

Prejudging the issue of illness as biographical disruption cannot...be justified. Instead, *timing* and *context*, *norms* and *expectations*, alongside our *commitment* to events, anticipated or otherwise, are crucial to the experience of our lives, healthy or sick, and the meanings with which we endow it. (2000: 51)

In addition to investigating the presence of biographical disruption, I will also explore cases where 'biographical flow' (Faircloth et al., 2004) may be apparent in the respondents' accounts, as whilst this concept was originally developed in relation to older people's illness experiences, it will be shown to be relevant in the constructions of some young adults in my data-corpus.

Few of the studies mentioned in this section explore *how* 'biographical disruption' and extensions such as 'biographical flow' are constructed within respondents' talk. This includes Bury (1982) himself, whose arguments are made using somewhat limited data-extracts, which are short in length, and not considered within the context of the talk occurring before and after. Locock, Ziebland and Dumelow (2009) are one of the few to look at the discursive realisation of biographic disruption; however, their focus is terminal illness. Through taking a discursive approach, then, the present study aims to contribute to existing research that has investigated this concept.

## 2.5 Chapter Summary

This chapter has explored some influential studies investigating people's experiences of illness. Salient themes arising from this research centre on how people with chronic illness represent their condition in relation to their conceptions of *self*. Issues related to self have been shown to tie in closely with issues of control; to what extent those with illness represent themselves as being in control of their lives vis-à-vis their condition. Additionally, concern about the perceptions of others has been found to be an important theme, again often relating to self, in terms of the self-images that are projected to others. These respective studies thus share some broad similarities despite their different data-sites, suggesting some general trends in the way people experience illness, and chronic illness in particular. The findings of these studies and the concepts developed – i.e. restitution, chaos and quest narratives; loss of self; illness as interruption, intrusion, immersion; and biographical disruption – will all be shown to be relevant to the present analysis. Up until now, none of these concepts have been explored specifically in relation to the illness experiences of young adults, thus presenting a gap which the present study will address.

A weakness common to all of the studies evaluated in this chapter is the lack of attention afforded to the role of the researcher, especially in relation to the interviewing process, as already mentioned above in relation to Frank (1995). Bury and Charmaz both provide more information than Frank does regarding the source of their respondents, and their socio-demographic characteristics, and in Charmaz's later work (1991), she includes a brief discussion of the setting of her interviews, and the relationships she was able to build with many of her interviewees. However, like Frank and Bury, Charmaz does not provide a detailed account of how her interviews were conducted, the questions asked, or how her interactional behaviour may have affected the interviewees' constructions (Gwyn, 1996; Mishler, 1986; Riessman, 1990). Such considerations, I would contend, are of vital importance when considering the final discursive product (see 5.2.3 for discussion of these issues). The lack of contextual background provided by Charmaz prevents questions from being addressed such as, for instance, whether her interviewing approach partially influenced respondents in her earlier work (1983) into focusing on only the



bleakest aspects of their illness experience, or whether respondents held the prior-assumption that research of this kind was only interested in the negative aspects of chronic illness, thus contributing to the findings made.

Charmaz does, however, show recognition of her subjective role in the interpretive stage, acknowledging that whilst she attempted to present ill people's experiences from their own viewpoints, 'the rendering of them and the analytic framework in which I couch them remain my own' (1991: 7). She summarises her role as having 'entered the worlds of chronically ill people and...compiled their stories to tell this sociological story' (1991: 7). Elsewhere, Charmaz goes into much greater detail regarding her role in the interpretive stage of her research (Charmaz 1990, see 5.3.1 for further discussion). Again this researcher-role is given very little attention by either Frank or Bury, with little acknowledgment made by either regarding the integral role of the researcher's own prior knowledge, experiences and assumptions in relation to the interpretations made (see Bell, 2000; Conrad, 1990, amongst others). Researcher-reflexivity at the analytic stage will be further discussed in 5.3.

The most important point in relation to the studies reviewed here is that they all analyse ill people's talk primarily at a content-level, which I would argue limits the interpretations that can be made. There is very little attention to *how* stories are told – in terms of their structure, the discursive resources tellers draw upon in their construction, and the *functions* that they serve within the particular context in which they are produced. Frank's categorization of narratives into different types *is*, to some degree, influenced by how they are structured, as part of his definition of a chaos narrative is based on its *lack* of structure. However, his categorisation of narratives is principally influenced by their 'general storyline...underlying the plot' (1995: 75), and therefore based on similarity of content. In spite of Charmaz's perspective regarding the way chronically-ill people construct their identities through social interaction, I would argue that she does not pay enough attention to how this identity-construction is achieved within the research-interview setting. In relation to all the four studies evaluated here, then, there is little recognition of constructions as being *performative* (Butler, 1990), and rhetorical acts as

being intended to persuade the listener *in that particular context*, issues that are considered as central within the present research.

Several recent studies investigating experiences of illness *have*, however, paid close attention to these concerns, specifically focusing on *how* illness experiences are constructed, and the *functions* that talk serves, and it is this research that will be the focus of the next chapter.

### 3. Interaction- and Language-based Approaches to Illness Identity

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The previous chapter explored seminal research into people's experiences of illness within the fields of medical sociology and medical anthropology. One point of criticism made about these studies was that they do not consider the performative, contextually-contingent nature of individuals' constructions. This chapter will explore research that focuses on these interactional aspects of representing illness experience, and which explores how respondents construct their multiple identities, including their illness-identities, through their ongoing talk.

As in Chapter 2, rather than giving a broad review of the research area, I will again focus in detail on four studies which are particularly relevant to the concerns of the present research. I will begin by looking at Riessman's (1990; 2002; 2003) (3.1) work comparing the illness narratives of two men with multiple sclerosis (MS). Several other studies have taken a similar approach to Riessman vis-à-vis attending to the performative, interactionally-constructed nature of illness narratives, for instance Bülow (2004) and Hydén (1997). Whilst Bülow, Hydén and others make important contributions to the field, at a broad-level many of their findings share similarities with Riessman's, and their focus on older people, for instance individuals with Alzheimer's disease (Hydén, 2008; Örvulv and Hydén, 2006), as well as on 'contested' illnesses such as chronic fatigue syndrome (Bülow, 2004; Bülow and Hydén, 2003), makes their research less relevant to my analysis. Riessman's focus is closer to the concerns of the present study, in terms of the age of her respondents and the nature of the condition she looks at, and it is for these reasons that Riessman's work has been chosen for close examination.

I will then go on to look at Radley and Billig's (1996) (3.2) discussion of 'accounts' of health and illness. As briefly discussed in 1.6, this work will strongly influence the analytic framework adopted in my analysis. In the final two sections of this chapter, I will evaluate the research of Cheshire and Ziebland (2005) (3.3), and Gwyn (1996; 2002) (3.4), respectively. Both studies investigate illness narratives using methods of discourse analysis (DA) – carrying out micro-analyses of the discursive features ill people draw upon in constructing their experiences. Again, there are others in the field who have adopted similar approaches (see for instance Bokhour, Powel and Clark, 2007), but both Cheshire and Ziebland, and Gwyn focus on a range of discursive features that will be shown to commonly recur in the present data-corpus. In evaluating these four studies, I will outline how particular features of the analyses are relevant to the present study, indicating how they will be applied to my analysis.

### **3.1 Riessman (1990; 2002; 2003)**

Riessman (1990; 2002; 2003) looks specifically at the *narratives* ill people produce in research interviews (see 1.5). Her interest is as much in the use of narrative more generally as in illness experience, and she thus places the actual telling of the narrative at the forefront of inquiry. As she contends: 'the "how" of the telling is as important as "what" is said, for it is through the choices in form that narrators persuade listeners' (1990: 1195). Riessman therefore addresses what she views as the shortcomings of many previous narrative analyses, the same as those identified in Chapter 2, that commonly the narrative is asked to 'speak for itself; language is viewed as a resource...and 'meaning' is assumed to be self-evident' (2002: 5). Riessman problematizes this notion of the self-evident nature of meaning, delving beneath the content-level of responses to explore the narrator's 'strategic choices about positioning of characters, audience and self' (2002: 8). She draws influence from the work of Bourdieu (1993), in proposing the need to 'intersect with class, historical context...in the telling and interpretation of illness narrative' (2003: 24). She thus places emphasis on considering narratives, not in isolation, but in relation to the cultural and historical surroundings in which they were produced (2003: 20).

This approach certainly has relevance to the present study, as the concerns portrayed by young adults with T1DM and IBD will be shown to be, at times, strongly tied to cultural expectations about the lifestyle activities young adults *should* be seen to engage in, for instance social drinking (see Chapter 9). Respondents' constructions will therefore be considered within the context of wider social and cultural ideas about young adulthood.

Riessman questions essentialist notions of the existence of a stable, static identity, and whilst not entirely rejecting such ideas, she aligns with a social-constructionist perspective that identity is something which is interactionally-accomplished, not by the speaker in isolation, but in collaboration with other interlocutors (2002: 26). In any given interaction, Riessman contends, speakers can produce a 'multiplicity of selves' (2003: 8), thus allowing them to project a preferred-identity through their narrative at any given point. This emphasis on the *performative self* does not intend to suggest that identities are inauthentic, but only that they are 'situated and accomplished in social interaction' (2002: 27). From this perspective, then, identity-performances are seen as contextually-contingent, influenced by factors such as the relationship of the interlocutors. This is something to which I will pay special attention, as recognition will be shown that the accounts young adults produce when interacting with me in interviews may differ greatly to those produced in other contexts. The notion of the performative self will be returned to in greater detail in 5.2.3.

To exemplify her methodological arguments, Riessman (2002; 2003) uses as case-studies interviews with two men, aged 38 and 43, respectively, who have multiple sclerosis (MS). Her earlier paper (Riessman, 1990) uses one of these cases for a similar purpose, so here I will focus on her later work, which builds upon this earlier analysis. Through comparison of lengthy narratives, Riessman demonstrates how each man is able to present himself in a particular way, constructing a positive image of himself, which may at times be at odds with the demands and restrictions imposed by his MS. Each man, she argues, 'positions himself in a narrative account as a man with agency and choice, even if there was no choice in getting the disease' (2002: 21).

In spite of these commonalities in their self-presentation (Goffman, 1969), Riessman proposes that the two men 'do' illness in vastly different ways. In the case of one of the men, Burt, his narrative suggests his condition has caused the breakdown of many of his interpersonal relationships, and he therefore performs the broader illness narrative of 'disabled man living in isolation' (2002: 22). In contrast to this, the other man, Randy, performs an identity of someone whose life has been reinvigorated, and he therefore embraces his illness.

Whilst the two men were found to produce broadly different illness narratives, with Burt's more inclined towards loss, and Randy's towards rebirth and regeneration, Riessman observes that at different times throughout the narratives, the two men perform a multiplicity of different, at times conflicting identities. For instance, at one point Burt discusses his previous working life, which 'reinforces prior components of identity (working man) that connect him to a collectivity (other factory workers)' (2002: 22). Thus in spite of his tendency to perform the identity of a disabled man in isolation, Riessman claims he is able to, at times, present himself as quite the opposite of this, with the identity of working man 'momentarily eclipsing other "selves"' (2002: 22). This allows him to 'sustain a positive impression of himself' by 'preserving key aspects of his masculinity' (2002: 1199). Through this close analysis, then, Riessman demonstrates how the men are able to choose the identities they wished to foreground from a range of possible identities, co-constructed in the interview-setting. This analysis demonstrates the unstable and at times contradictory nature of illness narratives, which cannot be explored when examining only short, de-contextualised data-extracts, exemplifying the benefit of considering lengthy stretches of talk within the context of the discursive product as a whole.

Riessman's research will have strong influence upon the present analysis, as I too will examine how respondents can give salience to various identities at different points in interviews, depending upon the image of themselves they are attempting to portray at that particular point. It will be shown, for instance, how the salience given to their illness-identity, relative to other identities, has implications regarding the influence young adults

construct illness as having upon their lives, and the relationship they construct between illness and selfhood.

One could call into question Riessman's reliance on just two case-studies, which excludes the possibility of generalising her findings to how other people with MS might use narrative to construct illness in the research interview setting. However, this risks missing the intentions behind Riessman's work, which is to explore the use of narrative analysis as a vehicle for identity-performance, with little intention, therefore, to make claims beyond the experiences of these two particular men. In fact, Riessman explicitly argues for the benefits of a case-study approach: 'cases matter: examination and comparison of the smallest details of narrative accounts reveal the contrasting meanings and interpretive complexity of illness experiences' (2003: 23). This is a very valid point, and one which is central to the assumptions underlying the present study; however, had these cases been selected because they displayed particular trends observed within a larger-corpus of people with MS or other chronic conditions, this could have at least allowed the findings to have some wider implications. These cases were, however, taken from an earlier study looking at marital dissolution, and which just happened to produce interesting data regarding the construction of illness, prompting Riessman to return to them for re-analysis. She refers to these as 'accidental cases' (2003: 9). Whilst my analysis will take a similarly in-depth approach, by working with a larger data-corpus, it is hoped that it will be possible to make some broader claims about how respondents manage their multiple identity-performances in interaction.

### **3.2 *Radley and Billig (1996)***

Radley and Billig (1996) shift away from the focus on narrative which dominates much of the field of study, arguing for people's talk about health and illness to be primarily thought of as 'accounts' (see 1.5 and 1.6). In line with Riessman's approach, they also move away from the idea that people are simply expressing their 'beliefs' when talking about health and illness, contending that 'people do not merely have health beliefs...they also construct their state of health as part of their ongoing identity in relation to others'

(1996: 221). They, too, place the purpose and function of talk at the centre of inquiry, and it is this focus that is the reason for this particular study being chosen for close examination ahead of Alan Radley's other work in the field, which spans a range of areas of chronic illness experience. This includes people's 'styles' of adjustment to chronic illness (Radley, 1989); the role that metaphor can play in this adjustment process (Radley, 1993); the consideration of illness accounts as 'aesthetic projects' (Radley, 1999a); and the role of the body in experiencing illness (Radley, 1997).

Radley and Billig contend that, in producing accounts, people are 'making claims about themselves as worthy individuals, as more or less 'fit' individuals in the activities of the social world' (1996: 221). Emphasis is thus placed on issues of *morality* present in accounts; that individuals regularly construct identities which are seen as aligning with socially-accepted moral values. This moral component was touched upon by Riessman, but not explored to the same extent as by Radley and Billig. As they propose, 'being healthy or ill are...claims that we have to sustain against the background of competing moral demands' (1996: 233).

Like Riessman, Radley and Billig pay close attention to the influence of context, including the relationship of the interlocutors, factors not considered by Frank (1995) or Bury (1982), and not fully explored by Charmaz (1983; 1991), despite Charmaz's attention to the socially-constructed nature of the self, as discussed in Chapter 2. Radley and Billig talk of accounts of health and illness as being 'imputed', through the way in which people 'constantly construct or reaffirm their own health in different circumstances and different relationships' (1996: 221). It may be the case, then, that the *moral values* that people afford salience to in the research interview may differ to that in other contexts.

Radley and Billig argue that the function of accounts is, at times, reflected in their linguistic form and content, as warrants and rhetorical devices are often used in order to 'legitimate the position of the speaker' (1996: 228). They argue, therefore, that issues of accountability are 'situated, rhetorical concerns' (1996: 228). Again similarly to Riessman, then, they strongly emphasise that these performances are produced *for* an 'other', with the intention to persuade the listener as to the legitimacy and authenticity of



particular identity-constructions. Considerations regarding how the young adults in the present study may orient to me in interviews, and how this may affect their accounting behaviour, will be addressed in 5.2.3.

Radley and Billig, like Frank (1995) and Herzlich (1973) (2.2), propose that accounts of illness simultaneously draw on individual experiences and socially-established models: 'people do not merely have an individual stance (or attitude), they partake of general beliefs and shared theories about the nature of the world' (1996: 223). There is thus a strong ideological undercurrent to their argument, as they propose that, in representing or depicting the world, people are 'employing ideological themes which 'naturalise' the world' (1996: 223).

As already briefly outlined (1.6), Radley and Billig's ideas will strongly influence my analytic framework. Culturally-accepted models of moral-appropriacy will be shown to be commonly drawn upon by my respondents, which intersect and interweave with the personal, subjective experiences constructed. Constructing morality in the face of illness; what Frank (1997a: 135) terms being 'successfully ill', has been discussed by several other researchers (see Bury, 2001; Charmaz, 1999; Williams, 1993); however, it could be argued that issues of accountability are especially pertinent in the case of young adults with T1DM and IBD. This is because activities which have a cultural association with young adulthood (see 1.2) are frequently at odds with careful management of either of these conditions; therefore, engaging in these activities could be deemed morally-*inappropriate*. When talking of engaging in such activities, then, there is a greater need for accounting-work on the part of the respondents in order to construct positive identities, as will be demonstrated in my analysis.

Although not citing it, Radley and Billig's ideas resonate strongly with the classic work of Scott and Lyman (1968), who define an account as 'a linguistic device employed whenever an action is subjected to evaluative inquiry' (1968: 46). Scott and Lyman, too, emphasise issues of morality in accounts, and central to their discussion is the distinction made between two types of account: 'excuses', whereby one 'admits the act in question is

bad, wrong or inappropriate, but denies full responsibility'; and 'justifications', where one 'accepts responsibility for the act in question, but denies the pejorative quality associated with it' (1968: 47). Scott and Lyman's discussion of accounts therefore focuses principally on issues of *responsibility* with regard to problematic events occurring within interaction, therefore taking a narrower approach to the definition of an 'account' than in Radley and Billig's work. Scott and Lyman's analytic distinction between 'excuses' and 'justifications' will be shown to be very relevant to the accounts produced by young adults with T1DM and IBD in the present analysis, especially in relation to the themes of Control and Social Drinking Practices (Chapters 8 and 9). However, following others (see recently Arribas-Ayllon, Sarangi and Clarke, 2011), my analysis will problematize the excuse-justification distinction.

Whilst Radley and Billig put forward a persuasive argument for the contradictory, unstable and context-dependent nature of illness accounts, they give little information about the source of their data-extracts. It appears that they did not collect their own data, but relied on data used in other studies, although this is not entirely clear. Therefore, whilst they emphasise that accounts must be interpreted within the context of their production, they are not able to fully explore the contextual factors related to the accounts they analyse. Additionally, given that their interest is in the process of constructing accounts as much as the product itself, they do not draw on a great number of data examples, and in cases where they do, extracts of greater length could have more fully exemplified how respondents construct moral identities over lengthy stretches of talk.

### 3.3 *Cheshire and Ziebland (2005)*

Like Riessman, Cheshire and Ziebland (2005) focus on the *narratives* that ill people produce. Sue Ziebland has published widely in this area, including research looking at the narratives of people with colorectal cancer (Rozmovits and Ziebland, 2004); the role of humour for men with testicular cancer (Chapple and Ziebland, 2004); and the relevance of 'biographical disruption' (Bury, 1982) vis-à-vis the experiences of people with motor neurone disease (Locock, Ziebland and Dumelow, 2009). Her (2005) work with Jenny

Cheshire has been chosen for close examination, however, because the discursive strategies that they explore vis-à-vis the construction of narratives are particularly relevant to the accounts produced by the young adults in the present study.

Using case-studies of two women living with hypertension, Cheshire and Ziebland investigate how the women 'integrate the experience of living with hypertension into their life story and make the everyday details of coping...part of their sense of the kind of person they believe themselves to be' (2005: 17). This approach draws heavily on the insights of Linde (1993), who considers narratives in terms of how they create coherence in the teller's 'life story'. Linde defines a life story as consisting of 'all the stories and associated discourse units...told by an individual during the course of his or her lifetime' (1993: 21). Life stories, she proposes, 'express our sense of self, who we are, how we are related to others, and how we became that person' (1993: 219). This approach therefore situates narratives within the context of the teller's personal history. In the case of the chronic illness narratives identified by Cheshire and Ziebland, these are placed both within the context of tellers' entire illness trajectory, as well as within their broader life narrative.

Whilst a central tenet of Riessman's (1990; 2002; 2003) and Radley and Billig's (1996) work is an emphasis on identity as socially and contextually constructed, Cheshire and Ziebland contend that, in order to create coherence in their life stories, individuals hold fairly stable images that constitute their 'personal identity', the person they see themselves as being, thus adopting strands of essentialism in their approach. This is by no means contradictory to the views of Riessman, and Radley and Billig, as both accept that identity is not entirely socially-constructed; Riessman, for instance, proposing that narrative can be used to reinforce stable aspects of self. At the same time, Cheshire and Ziebland share the view that identities are not static, but are interactionally-constructed and validated within social encounters. They do, however, appear to afford greater emphasis to stable aspects of identity than Riessman, and Radley and Billig, contending that narratives allow those with illness to construct their illness experiences *within the frame* of their personal identity.

This notion of ‘personal identity’ can be related to Charmaz’s (1983) discussion of ‘self-concept’ – the fairly stable, although potentially changeable self-images individuals hold (see 2.3). However, whereas Charmaz proposes that chronic illness can cause individuals to become detached from the self-images they held prior to illness-onset, and thus experience ‘loss of self’, Cheshire and Ziebland argue that narrative can be used as a *means of maintaining* these self-images, by presenting illness ‘through a lens of what to [those with illness] are integral aspects of [their] personal identity’ (2005: 26). The present analysis will draw influence from Cheshire and Ziebland’s approach, looking at how respondents perform elements of their ‘personal identity’ through their discursive constructions; thus considering identity as having a degree of stability, but also as being socially-constructed and validated. Details of how I intend to incorporate these approaches within my analysis will be outlined in 5.4.

The two case-studies Cheshire and Ziebland use are taken from the *DIPEX* (database of individual patients’ experiences) website (since renamed *healthtalkonline*). This site presents semi-structured interviews with people with a range of illnesses, and is intended as a resource for patients and their carers, as well as for healthcare professionals.<sup>3</sup>

In identifying narrative segments for analysis, Cheshire and Ziebland use Labov and Waletzky’s (1967) classic structural approach to narrative. Thus a narrative is seen as containing:

At least two Complicating Action clauses where the verbs are in past or historic present tense, and where we can infer that the order of the clauses matches the order in which the recounted events took place. There are also one or more Orientation clauses setting out who was involved in the events, when and where they took place, and giving other necessary background information. In the DIPEX interviews an initial Abstract, summarising the story, is often provided by the interviewer’s question.

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<sup>3</sup> Healthtalkonline and similar resources will be returned to in greater detail in my conclusions (Chapter 10, 10.6). These will be discussed within the context of potential practical applications of my findings.

The Complicating Action section is followed by one or more clauses giving the Resolution of the story; and the narrative sometimes ends with a Coda that returns us from the story world to the present.'

(Cheshire and Ziebland, 2005: 21)

Whilst these sections of the narrative constitute the referential or propositional strand of meaning, narratives are also seen to have an affective strand of meaning, the 'Evaluation' (Labov and Waletzky, 1967), where 'narrators reveal their feelings about the events they are recounting' (2005: 21), which Cheshire and Ziebland propose can occur at any point throughout narratives. They contend that this is 'essential to the narrative, justifying the telling and...showing the kind of person the speaker claims to be' (2005: 22).

Cheshire and Ziebland found the two women to construct very different reactions to the experience of living with the same chronic illness. They observe that the first woman, Rose, aged 72, seems to have no problem seeing her illness as being part of her personal identity, whereas Josephine, 53, 'actively distances herself from her experiences of illness, seeing them as not experienced by "the real me"' (2005: 20).

In relation to Rose's recounting of her first experience of hypertension, Cheshire and Ziebland demonstrate how her evaluative clauses 'connect her subjective state in the story world she is constructing to her present attitude to her illness' (2005: 23). Thus, regarding the medical advice she was initially given when diagnosed, to take bed-rest, her evaluative clause '*I couldn't understand it at the time*' (2005: 22) indicates that 'from her present perspective she does now understand' (2005: 22) why she was given this advice. This affective utterance demonstrates the reflexive potential of narrative for the teller. This is discussed at length by Linde (1993), who talks of the narrator being able to 'observe, reflect, adjust...and correct the self that is being created' (1993: 105). The teller is therefore able to separate himself or herself in the present time from himself or herself as the protagonist of the story, and evaluate the actions of the protagonist. This means that even if the protagonist behaved in a manner which could be deemed morally-inappropriate, because the teller now recognises and accounts for this, he or she is still

able perform a moral self for fellow interlocutors; therefore ‘the speaker is always moral, even if the protagonist of the narrative is not’ (Linde, 1993: 123).

Reflexivity on the part of respondents will also be explored in the present study, as it will be shown that the young adults at times reflect back on their perceptions or behaviours at a particular point in their illness trajectory, often in order to establish a contrast which emphasises the moral-appropriacy of their present self, in the way in which Linde contends.

Whilst Cheshire and Ziebland found many of Rose’s contributions to fit the classic narrative style of recounting past events, they also identified several habitual narratives (see 1.6). Cheshire and Ziebland propose that, whilst these constructions achieve a less dramatic style of narration, by talking about a general course of events over time, Rose is able to ‘show that...aspects of her self identity are constantly reinforced through the repeated events that she recounts in her narrative’ (2005: 23). She is thus able to make a stronger claim to particular enduring aspects of personal identity.

Cheshire and Ziebland propose that habitual narratives may be especially significant in relation to chronic illness, as the routine nature of treatment-regimens, and their permanency, will likely result in many occasions where individuals talk about experiences in a more general sense. Evidence of this will be demonstrated in the present analysis, and similarly, I will examine how their use can serve rhetorical purposes.

The narrative produced by Josephine when discussing her first experience of her condition was found to align with her attempts to *distance* herself from her condition. She adopts a ‘detached speech style’ (2005: 33), with her internal evaluation downplaying the severity of the condition: ‘*sorted me out*’, ‘*my little box of pills*’ (2005: 33), as does the external evaluation: ‘*I don’t think they thought it was disastrously high*’ (2005: 33).

Another discursive device used by both women, which again emphasises the performative nature of the narratives, is comparisons made with others. Rose, for instance, was found to present herself in a positive light through comparing her behaviour with others who have the same condition, who she represents as behaving in a less competent manner than herself. One example is a neighbour Rose portrays as being less efficient than she is in remembering to take her medication (2005: 24). Cheshire and Ziebland argue that it is significant that Rose draws comparison with others who have hypertension, proposing that 'by locating an identity within a group of people who have the same illness as herself, Rose accepts her condition' (2005: 24). Again they propose here that the identity she constructs is 'in harmony with what she believes to be salient aspects of her personal identity' (2005: 24). I would argue, however, that whilst this use of comparison clearly has an important rhetorical function in allowing Rose to construct a positive identity as being responsible and in control of her treatment-regimen, this claim regarding Rose's acceptance of her condition is overly strong, based on this evidence. The context of the interview may have led Rose into making these comparisons with others who have hypertension, and it is equally possible that in another context Rose would make comparisons with those who do not have the condition.

Josephine, in contrast, was found to use people who do *not* have hypertension as the focus of her comparison, which Cheshire and Ziebland argue is reflective of her desire to see 'the "real me" as a person unencumbered by the details surrounding her medical condition' (2005: 34). Again, I would argue that these claims regarding the narrator's use of comparisons are overly strong based on this evidence; however, these interpretations do align with the overall respective narrative performances identified in relation to the women.

I too will investigate respondents' comparisons with others in relation to the present data-corpus, and I will explore the implications comparisons can be seen to have vis-à-vis respondents' identity-construction. Comparisons will be shown to commonly have a moral basis, highlighting a disparity between the teller and those behaving in a less

morally-appropriate manner, as Cheshire and Ziebland observed in relation to Rose. This strategy therefore aligns with the ‘accounts’ (Radley and Billig, 1996) framework I adopt.

A further discursive strategy discussed by Cheshire and Ziebland is the use of reported speech. This is where the teller introduces the speech of others from interactions in which he or she has previously been engaged. Cheshire and Ziebland look at this in relation to the women’s interactions with doctors and healthcare professionals. They found Rose to report what the doctor had said in medical encounters more often than reporting what she had said herself, which it is proposed demonstrates that she views the doctor’s words as being more important than her own. They also note that she reports both what the doctors say, and what she herself says, almost entirely in the form of direct speech. Drawing on research by Hamilton (1998), Cheshire and Ziebland argue that this shows Rose portraying her encounters with healthcare professionals as ‘interactions between status equals’ (2005: 30). Whilst I agree that the presence of reported speech is a significant observation, again I would suggest that Cheshire and Ziebland’s claims are not fully warranted based on the evidence provided, and more evidence is needed to validate claims about Rose’s perceived power relationship with her doctors.

In relation to the discursive device of reported speech, Josephine’s narratives again demonstrate disparity from those produced by Rose. Josephine does report some of her interactions with doctors and other healthcare professionals, but reports her own speech to a far lesser extent than that of medical professionals. Cheshire and Ziebland observe that the content of the doctors’ reported speech shows the doctors ‘telling her how to manage her illness’ (2005: 39), and she thus represents the encounters as ‘typical of doctor-patient interaction’ (2005: 39), not in any way presenting them as friends, as was interpreted to be the case with Rose. Cheshire and Ziebland contend that this demonstrates her using narratives to ‘keep them (doctors) at a distance’, correlating with her strategy of ‘relegating all things concerning her illness to the part of herself who is not the “real me”’ (2005: 39).



In spite of my contention that some of Cheshire and Ziebland's claims regarding the implications of reported speech are overly strong, its use clearly serves a rhetorical function, enabling the two women to create a particular stance with regard to their 'subject position' (Fairclough, 1995) as patients vis-à-vis healthcare-professionals. Reported speech is another feature that will be investigated in the present analysis. It will be shown, however, that this is not used only to report interactions from within the medical context, but is also employed when the young adults are reconstructing encounters with peers, friends and family members. The discussion of reported speech will be returned to in 5.3.3.

Overall, Cheshire and Ziebland make some very interesting observations, which, as detailed, are highly relevant to the present analysis. Whilst it was argued that, at times, their analytic claims are overly strong in relation to the evidence they present in the data, on the whole their interpretations are well-founded and insightful.

It is important to note the significant age difference between the two women in Cheshire and Ziebland's study (53 and 72). Age and life-stage have been shown to be salient factors in influencing how people can experience illness (Faircloth et al. 2004; Pound et al. 1998, see 2.4), and this is central to the assumptions underlying the present study (see 1.2). Acknowledging the influence that the women's respective ages *may* have had on their narratives would allow Cheshire and Ziebland to speculate as to *why* the two women construct illness in these differing ways, and to situate their analysis in relation to wider social issues relating to illness and ageing. For instance, it may be the case that Rose, the older of the two, integrated illness more readily into her personal identity because she sees illness as an inevitable part of her life-stage, unlike the younger woman, Josephine.

As similarly noted in relation to Riessman (1990; 2002; 2003), Cheshire and Ziebland's use of only two case-studies minimises the potential to generalise findings to a wider population of people who have hypertension; although again it is in-depth investigation, not generalisability, that is their principal aim. Cheshire and Ziebland stress that this study is the first to use transcripts from *DIPEx* for sociolinguistic and discourse-analytic

questions; however, whilst this is a very valid data-source, I feel certain questions can be posed of this data. In the standard research interview, the interviewer is a collaborator in the discourse, and thus the influence that his or her presence has on the interviewee is not only a given, it is an integral part of the process (Holstein and Gubrium, 1997). As has been stressed so far in this chapter, respondents' contributions can be conceived as 'performances' for the interviewer (interviewing as an 'active' process will be discussed at greater length in 5.2.3). Using interviews from the *DIPEX* website adds a whole new dimension to this performative aspect, as interviewees would presumably have been aware that their responses were to be published on the internet for mass-consumption. Whilst it could be argued that the respondents will still be producing a performance, but simply one where they have a larger audience in mind, I would contend that their awareness that anybody can access these interviews may lead to something approaching the observer's paradox (Labov, 1972), where respondents alter their behaviour due to an awareness of being observed. This, I would speculate, may lead respondents to perform to a level at which the identities being constructed *could* become somewhat inauthentic, which in turn may have some influence on the narratives Cheshire and Ziebland have chosen to analyse. With this said, *DIPEX* does represent a rich source for accessing a wide-range of experiences of different illnesses, and can therefore clearly be of great use to researchers within this field.

### **3.4 Gwyn (1996; 2002)**

The final study to be looked at in this chapter, preceding Cheshire and Ziebland, is Gwyn (1996; 2002). Similarly to Riessman, and Cheshire and Ziebland, Gwyn's interest is in how individuals construct their lived-experiences through narrative, which he broadly terms the 'voicing of illness'. Gwyn uses a larger data-corpus than these two studies, however, drawing on 22 interviews with 28 respondents, who either have a chronic illness themselves, or are a close relative of someone with illness. Some interviews were multiparty, including both the ill person and spouse or close relative.

Gwyn wanted to encourage his respondents to 'take control of the interview' (1996: 84), through discussing experiences salient to them. With this in mind, he designed his interviewing approach so as to elicit talk which closely resembles informal conversation. Following Wolfson (1976), he terms these 'conversational narratives'. Throughout interviews, Gwyn placed strong focus on reflexivity, and awareness of his own role, which is a very positive aspect of his work. I see such considerations to be essential when developing an interviewing method, and aspects of Gwyn's approach are therefore adopted in my own interviews (see 5.2.3 for further discussion).

Gwyn identifies narratives simply as 'a sequencing of events in chronological order' (1996: 96). He adopts insights from Labov and Waletzky's (1967) structural approach, his primary interest being the *Evaluation* component of this model: 'it is through evaluation that the interviewee's authentic voice is most discernable' (1996: 163). Gwyn shows how evaluation on the part of tellers can be used to construct positive identities aligning with cultural models of moral appropriacy. He gives an example of a man telling a story of how he almost died of heat stroke in India before the Second World War. Gwyn shows how, at one point, the narrator, Ben, uses 'internal evaluation', in the form of a 'comparator', comparators being 'indirect evaluations made by hypothesising as to the possible alternative outcomes to the story' (1996: 104). Ben talks of how the nurse treating him placed a sheet over him, presuming him to be dead; however, she then pulled the sheet back to find that he was 'still fighting' (1996: 132). Ben thus speculates about the possibility that he could have been buried alive. Gwyn argues that this strategic use of a comparator acts to 'boost Ben's own heroic status' (1996: 132) by implying physical resilience and fortitude on his behalf, part of the chosen identity being performed at this particular point in the narrative.

The performance of battling heroism on the part of those with illness will be shown to be present in my data also, and like Gwyn, I will explore how the construction of these identities is accomplished through various different discursive strategies, including comparators, again marking the relevance of Radley and Billig's proposition, cited above, that we construct illness 'against the background of competing moral demands' (1996: 233).

Drawing on the work of Radley (1993), among others, Gwyn investigates the use of figurative language within narrative reconstructions. He contends that metaphorical representations are central to the voicing of illness, and contribute significantly to the explanatory models participants construct regarding their illnesses:

Metaphor...fills out these narratives, giving them conceptual and communicative substance, and helping us to identify a specific culture of illness, in which individuals express their conflicts, their fears and their pain, as well as their laughter, and their resonant silences.

(1996: 164)

Gwyn begins by investigating metaphor in relation to 'two conceptual structures...the first relating to the body and the second relating to the causes of illness' (1996: 168). With regard to the body, Gwyn contends that there is a strong tradition in Western culture of regarding the body as 'radically other to the self' (Shilling, 1993: 199), which leads to 'the reification of the body and bodily processes' (Gwyn, 1996: 168). He found this reification to be most commonly exemplified through the conceptual metaphor of *body as a machine*, or as a system, which includes referring to body parts acting like faulty pieces of machinery, or failing to obey the instructions of the brain. Within this conceptual structure, Gwyn proposes that 'body parts are seen to be in need of inspection, maintenance and even replacement' (1996: 171).

In investigating metaphors relating to causes of illness, Gwyn observes a distinction between explanations which present illness as coming from *within* the person, 'endogenous causes', and those where illness is attributed to outside influences, 'exogenous causes', using terminology borrowed from Herzlich (1973). Gwyn thus identifies a 'dual process...with individuals either becoming ill with 'the loss of good stuff' or else with the 'getting of bad stuff'' (1996: 205). A common metaphor within this domain was found to be that of 'the candle being burned at both ends', suggesting 'energy being wasted, thus debilitating the individual and lessening her [or his] resistance to disease' (1996: 177). In these cases, then, 'disease itself is not endogenous, but our own actions facilitate its appearance' (1996: 177). Gwyn posits, therefore, that such

explanatory models raise questions of responsibility and accountability for one's own health, a theme he observes as occurring frequently within his data. He found one particular type of responsibility to involve taking "common sense" precautions such as eating well, taking reasonable exercise etc' (1996: 177). In this case, then, the actions of the individual can actually encourage or deter the onset of illness. Representations of illness as exogenous, on the other hand, function to *remove* responsibility from the individual.

In spite of the apparent diametrical opposition of such views, Gwyn found that narrators often adopt both endogenous *and* exogenous explanations of illness-causation, contradicting themselves within the course of their narrative, thus again highlighting the unstable and potentially contradictory nature of narrative, which only becomes apparent through the analysis of lengthy stretches of discourse.

Metaphors constructing illness as either endogenous or exogenous will be shown to be employed by respondents in the present data-corpus, either implying accountability for the onset of illness, or removing responsibility from the individual, as similarly observed by Gwyn. However, in the present corpus this does not relate only to the initial onset of illness, but often addresses the cause of disease symptoms returning in the form of flare-ups/relapses.

A third type of conceptual metaphor Gwyn investigates is *illness as war* or *illness as invasion*. Gwyn found that, frequently in narratives, 'illness presented itself in the form of an attack and was consequently perceived as something which had to be *fought*' (1996: 186). He proposes that 'the commonest representation by far within the illness is war concept is that of the individual having to fight his or her own fights where illness is concerned' (1996: 188), and that 'ultimately the goal is not to "lose" to illness... by not "lying down to it"' (1996: 189). This, Gwyn notes, is consistent with the theme of personal responsibility; thus again the individual affords himself or herself some degree of agency and accountability vis-à-vis illness experience. This type of metaphorical representation has been widely discussed in the research field, most famously by Sontag (1978; 1991) in relation to cancer and HIV/AIDS. Sontag takes a critical view of the role

of battle/war metaphors in conceptualising illness: ‘as long as a disease is treated as an evil, invisible, predator...most people will be demoralised by learning what disease they have’ (1991: 7). Metaphors of *illness as war* are also observed in the present data-corpus, and their use will be explored in the analytic chapters to follow, drawing comparisons with Gwyn’s findings, as well as considering the functions they serve in relation to Sontag’s arguments regarding their negativity.

### 3.5 Chapter Summary

Gwyn’s research makes an important contribution to the field of illness experience and the area of discourse analysis more widely. Evaluating Gwyn’s methods and findings in detail, along with those of the other studies explored in this chapter, has provided strong evidence for the advantages of adopting an interaction-based, constructionist approach in this area, as well as the benefits of using DA methods in analysing representations of illness experience. Such methods have been shown to facilitate the investigation of how multiple identities, including illness-identity, are constructed as an ongoing process, and how constructions can be viewed as rhetorical, performative acts aiming to persuade fellow interlocutors. I have highlighted throughout how the approaches adopted, and the discursive features investigated in these studies, will be applied to the forthcoming analysis. See 5.2.3 and 5.4 for further discussion.

Whilst Gwyn’s interest is specifically in chronic illness, similarly to the other studies evaluated in this chapter, he does not pay particular attention to demographic variables in his sampling. As noted in the introduction to this chapter, some researchers *have* taken a more systematic focus, for instance looking specifically at the illness narratives of older respondents (Hydén, 2008; Örvulv and Hydén, 2006). Up until now, however, there have been no studies that have adopted an interaction-based, constructionist approach, or used methods of DA, in investigating the experiences of young adults with T1DM and IBD, as I will do in my analysis.

The next chapter will conclude my review of the relevant research literature, through evaluating the small body of research into people's experiences of T1DM and IBD, including studies into young adults' experiences of these two conditions.

#### 4. Lived-Experiences of Type 1 Diabetes (T1DM) and Inflammatory Bowel Disease (IBD)

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In the last two chapters, I have firstly evaluated seminal research into chronic illness experience more generally, and then looked at studies which adopt interaction- and language-based approaches in exploring this area. Whilst I have noted that research into lived-experiences of IBD and T1DM is not extensive, and that young adults are often overlooked within this research area, there is a small body of work, mostly in the fields of medical sociology and medical anthropology, which has addressed this gap. It must be noted, however, that these studies do not use DA methods, and only a few take a social-constructionist approach. This body of research will be the focus of this chapter.

In contrast to the previous two chapters, in which I evaluated individual studies in turn, this chapter will be structured thematically. This is because, given that I am using a similar target-respondent sample to these studies, the *themes* emanating from these studies, in terms of the lifestyle priorities and concerns expressed by respondents, as well as the concepts and theories developed in relation to these, are highly relevant to my research. Despite there being many differences between the findings of studies into experiences of T1DM, and those investigating IBD, research into both conditions reveals, at a broad level, similar predominant themes emerging from the data. For this reason, rather than being divided into separate sections, these studies will be reviewed alongside one another, under the thematic headings.

Whilst some of these studies do not consider age as a variable, others focus specifically on young adults with these conditions. Within the themes identified, I will separate these two sets of studies. The reason for this is that, given my specific focus on young adults, it will



be useful to identify any findings which may be specific to young adults as an age-cohort. I will, however, still make comparisons between the findings across these studies.

It is also important to note that the themes identified in the research literature at times overlap considerably and interrelate with one another. This demonstrates the complex, multifaceted nature of chronic illness experience, as reflected in the qualitative data collected in these studies.

#### **4.1 The Impact of T1DM and IBD upon the Self**

##### *4.1.1 Research using a Non-Specific Age Sample*

The first theme emanating strongly from the findings of studies into the experiences of both T1DM and IBD is how respondents represent their condition in relation to their constructions of self.

Paterson, Thorne, Crawford and Tarko (1999) investigate the experiences of individuals with T1DM, aged 24-81, focusing on the concept of *transformation* in illness experience. Based on their findings, Paterson et al. attempt to arrive at a suitable conceptualisation of 'transformation', which they propose has not been adequately defined in past research literature. In reviewing previous work, they conclude that 'transformation' is widely viewed as an ongoing process, a 'special form of transition from one way of being to another' (1999: 787). In relation to chronic illness, they propose that individuals are able to 'experience life, themselves, and others in a way that was inaccessible; that is, they can be transformed by the experience to experience *positive* and *rewarding* outcomes' (my italics) (1999: 786). Transformation is very much at odds with Charmaz's (1983) 'loss of self' (see 2.3), as transformation suggests that self-images can be not only lost, but *gained*, through illness experience. This demonstrates similarity with the more positive picture painted in Frank's conception of the 'quest' narrative (see 2.2).

Paterson et al.'s respondents ( $n = 22$ ) were individuals who were 'able to make trustworthy decisions about diabetes self-care management, and to maintain good overall

glycemic control' (1999: 790). It is not explained as to whether this particular group were chosen because they are most likely to have undergone a transformational experience, though this is probably the case given Paterson et al.'s initial interest in transformation. Data was collected through three different methods. Firstly, a 'think aloud' technique which entailed the use of handheld tape recorders with which respondents recorded decisions they made regarding diet, insulin, physical activity, and several other T1DM-related issues throughout an entire one-week period three times over a calendar year. Paterson et al. note that the advantage of this method is that it 'reveals the participants' everyday decisions in a current manner rather than a retrospective or simulated account' (1999: 790). Interviews were also conducted at the beginning of the study, and an additional three interviews were carried out, each within one week of the think-aloud decision recording sessions. Focus groups were also conducted with the same respondents at the end of the research process.

Paterson et al. report that transformation was defined by respondents themselves as 'a profound new awareness of what you could be', leading towards 'coming to terms with me as a diabetic and me as the person I wish to be' (1999: 791). They described it as an 'ongoing discovery...that I could control my diabetes. It didn't have to control me' (1999: 792). It is unclear from Paterson et al.'s remarks, that transformation 'was defined by respondents', whether these findings were deductive or inductive; whether respondents were presented with the concept of transformation and were asked for their own definition of it, or whether these comments were made by respondents and *subsequently* classified by Paterson et al. as demonstrating evidence of transformation. When outlining their methodological approach, however, Paterson et al. claim that their findings are inductive.

All respondents reported an initial transformational experience, which they described as the 'most dramatic and significant...heralding new and enhanced awareness of self in relation to the disease' (1999: 792). Several respondents stated that they made a conscious decision to see illness-related problems as challenges, not threats, as this presented more opportunities for growth. Through this cognitive shift they were therefore able to afford themselves a greater degree of agency, and hence more control over their T1DM. There

are no examples provided, however, of how this new-found control is actually achieved in respondents' everyday lives.

These findings suggest a transition occurring in how respondents portray T1DM in relation to their representation of self, suggesting a 're-structuring of self' (1999: 788), in which T1DM is integrated within their selfhood in a more positive manner than it had been previously. Paterson et al. note, however, that people with T1DM should not be seen as 'transformed' or 'untransformed'; and instead consider transformation to be a dynamic, non-linear process.

Transformation, and Paterson et al.'s findings in relation to its presence for those with T1DM, is very relevant to the present study. It will be shown that several respondents in my data-corpus represent themselves as restructuring their illness experiences in this way, in order to foreground positive outcomes. In my analysis, however, there will be a focus on the *performative* aspects of representing oneself as having experienced transformation in illness experience, as such representations are found to commonly support morally-appropriate identity constructions.

Through taking a grounded theory approach, Paterson et al. were able to follow an inductive method, deriving themes from the data itself. However, the approach used cannot be seen to reflect pure grounded theory, as Paterson et al. began with a particular agenda to investigate the presence of transformational experiences in respondents' constructions, and I questioned above the inductivity of some of their findings. This does not necessarily reflect a weakness, however, as having an idea of the focus of the research prior to data-collection would have allowed the researchers to delve deeper into this area of interest during the data-collection process. It could therefore be said that they explored the data through the 'lens' of transformation, and took an inductive approach to the findings *within* this broad concept. This approach displays similarity with my approach in the present study, as like Paterson et al. my aims are mainly inductive, and I too follow grounded theory methods, however data is explored within the frame of the research questions posed (see 1.7), which are based on the findings of previous research in this area (see 5.3.1 for further discussion).

Paterson et al. took a reflexive approach, conducting ‘simultaneous data-collection and analysis as well as systematic efforts to check and refine developing categories of data’ (1999: 789). This concurrent data-collection and analysis ‘directed further literature review, hypothesis development, sample selection, and interview questions’. (1999: 789). This reflexivity is a positive aspect of the research, and I draw influence from this in adopting a similar approach in the present study (see 5.3.2).

However, whilst Paterson et al. afford considerable attention to how the data-collection process feeds into the data-analysis, there is a lack of attention given to the data-collection process itself, in terms of how the ‘think aloud’ technique, interviews, and focus groups were conducted. There is little discussion of the role of the researcher in the interviews and focus groups, or the socially-constructed, performative nature of respondents’ talk, and they instead adopt a more essentialist position. This approach is common to many of the studies that will be reviewed in this chapter, therefore rather than continually highlighting these issues I will return to the discussion of these considerations in 5.2.3, in relation to my own interviewing approach.

Another potential weakness is that Paterson et al. do not consider demographic variables such as age in their analysis. It may be the case that age has an influence on the transformation process, or that people of certain ages are more likely to experience transformation than others, but this is not explored.

#### 4.1.2 *Young Adults*

Brydolf and Segesten (1996) also report findings regarding respondents’ representation of illness in relation to self, but they look at IBD, and focus on the experiences of *young adults* and *adolescents*, aged 11-31. The researchers are from a nursing background, and whilst the research was not driven by medical priorities, respondents’ reported experiences are analysed with a view to improving healthcare practices.

Interviews were conducted at the homes of 28 respondents about their experiences of Ulcerative Colitis (UC), both at the time of the interview and at the time when their symptoms first appeared. A grounded theory approach was taken, with comparative open-coding carried out, leading to the identification of categories within the data.

A major category Brydolf and Segesten identify is 'alienation'. This is primarily discussed not in terms of physical alienation from others, but 'alienation from their former selves' (1996: 40). This alienation was as a result of changes respondents reported witnessing in themselves due to the effect of their condition, changes not only in terms of what they were capable of doing, but also changes in bodily appearance: 'disease and treatments caused physical changes such as...loss of weight or rapid weight gain, leading to different body image and body sensations' (1996: 40). This is demonstrated in the following extract<sup>4</sup>: "I had taken cortisone so I got swollen cheeks, and became clumsy and my weight increased at least 10 kilos. My weight was 19 kilos [*sic*], I couldn't walk downstairs, my legs collapsed, I became more angry" (1996: 42).

Brydolf and Segesten propose that the alienation respondents experienced led to 'reduced living space in order to cope with the new situation' (1996: 42). 'Living space' is defined as the 'the sphere one acts within one's daily life...includes routines, physical, social and cultural activities' (1996: 41). Brydolf and Segesten observe that this reduction in living space is 'self-imposed' (1996: 42) due to respondents' lack of self-confidence stemming from this alienation.

These findings demonstrate clear evidence of 'loss of self' (Charmaz, 1983), with respondents experiencing separation from their former, valued self-images, and struggling to form a new concept of self which integrates their IBD. The largely negative experiences reported by Brydolf and Segesten's respondents therefore demonstrate considerable disparity with Paterson et al.'s (1999) findings of transformation. Several reasons could be put forward for this difference. It could be that this is a cross-condition disparity, and that due to the respective nature of the conditions, IBD more regularly leads

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<sup>4</sup> Brydolf and Segesten do not include any details about the respondent who produced this passage.

individuals to experience alienation from former self-images, whereas those with T1DM are more commonly able to restructure the self and develop new positive self-images.

Another possible explanation could be Brydolf and Segesten's focus on adolescents and young adults, contrasting with the much broader age-range included in Paterson et al.'s sample. It could be that some of Brydolf and Segesten's respondents *will* undergo transformation at some point in the future.

A further explanation for this disparity can again be found in the respective sampling choices. I have already speculated that Paterson et al.'s purposive sampling could have resulted in a greater likelihood that evidence of transformation would be found, but Brydolf and Segesten's sampling may also have influenced findings. Their respondents had all undergone surgical treatment during childhood, which *may* have resulted in a sample of adolescents and young adults who generally have a more severe form of UC than the average person with UC in that age-range. It could therefore be questioned whether the same level of alienation from former images of self would be observed in a more generalised sample, and whether more positive experiences might also be constructed.

Brydolf and Segesten's findings are very relevant to the present study, and it will be shown that some of the respondents in my sample also represent themselves as experiencing alienation from their former selves, and a subsequent reduction in their living space, similar to that observed here. However, I will look for evidence of this not only in relation to those with IBD, but also in the accounts of T1DM-respondents, exploring any cross-condition similarities and differences that may be present.

#### **4.2 *The Construction of T1DM and IBD in relation to Others***

The second major theme identified as emanating from research literature, which is closely tied to the theme of 'self', addressed above, is how respondents construct their condition in relation to *others*. Findings address how respondents represent themselves in relation to others who do not have the same condition, how they represent the views of these others

vis-à-vis their condition, as well as how their condition impacts upon their relationships with others, such as friends, family and peers.

#### 4.2.1 Young Adults

Schur, Gamsu and Barley (1999) investigate the experiences of young adults with T1DM, aged 16-22 ( $n = 8$ ). They take an interpretative phenomenological approach to their interview data, aiming to access, as far as possible, an 'insider's perspective', with the eventual goal of the research being to 'enhance healthcare workers' efforts to meet their [young people's] needs' (1999: 224).

Having carried out reflexive coding of the interview data, one of the predominant themes Schur et al. identify concerns 'interpersonal threats from diabetes and self-protective strategies' (1999: 230). They report that respondents described 'experiencing *difference* from others...both in the ontological sense of 'being' different, and because of the self-care behaviours and routines they had to engage in' (1999: 230). Respondents are reported to have expressed 'a pervasive fear of stigma, a fear of being discovered as different and of being judged by others as less capable than the norm' (1999: 231).

In discussing respondents' fears of stigma, Schur et al. draw on the seminal work of Goffman (1963), who defines stigma as 'an attribute that is deeply discrediting' (1963: 13). Goffman distinguishes between two different types of stigma; those where 'the stigmatized individual assumes his or her difference is known about already or is evident on the spot' (1963: 14), and is thus 'discredited'; and those where 'the stigmatized individual assumes it is neither known about by those present nor immediately perceivable by them' (1963: 14), in which case the individual is 'discreditable'. In the case of T1DM, individuals are largely *discreditable*, and as a result Schur et al. found that respondents were able to employ 'stigma management' (Goffman, 1963: 69), avoiding other people's reactions by 'hiding the visibility of their diabetes and seeking to maintain their identity as a well person' (1999: 231).

Schur et al. observe that, in spite of the fear of stigma, few respondents reported having actually experienced stigma as a result of their T1DM. This finding resonates strongly with the work of Scambler and Hopkins (1986), who distinguish between ‘felt stigma’, which is a *fear* of experiencing overtly negative reactions, and ‘enacted stigma’, the *actual* experience of stigma. In the case of Schur et al.’s respondents, then, it is primarily ‘felt stigma’ that is being reported.

Respondents reported viewing the disclosure of their T1DM to others as ‘both a self-protective strategy and a threat’ (1999: 232). It is self-protective from the perspective of ‘safety telling’, which involves ‘informing and educating others about how to provide appropriate assistance if necessary’ (1999: 232) in cases where the individual may experience short-term health problems, such as hypoglycaemia (see Appendix A). However, disclosure also ‘evoked fears of rejection, and of being perceived as different’ (1999: 232), again demonstrating evidence of ‘felt stigma’ (Scambler and Hopkins, 1986).

Schur et al.’s findings are highly applicable to the present study, especially given the similarity in age-range focused upon. The present analysis will similarly explore issues of stigma, both ‘felt’ and ‘enacted’, drawing on the insights of Goffman (1963) and Scambler and Hopkins (1986) amongst others, but I will explore these issues comparatively in relation to T1DM- *and* IBD-respondents.

A weakness of Schur et al.’s study is the very small sample size used. Despite the aim of the study being to gain in-depth understanding of the experiences of young adults with T1DM, as opposed to wide-spread generalisability, the small sample limits the potential to identify trends which may be indicative of the experiences other young adults with T1DM, which is something I hope to do through my analysis.

#### 4.2.2 *Research using a Non-Specific Age Sample*

Hall, Rubin, Dougall, Hungin and Neely (2005) report some similar findings to those of Schur et al., but in relation to the experiences of people with IBD. Though not specifying



the age-range of respondents, their focus was on the perspectives and experiences of individuals with 'poor quality of life' (2005: 444).

Fifteen respondents took part in semi-structured interviews, and a further 16 participated in focus groups. Respondents were all located in North-East England, and were accessed via an earlier questionnaire-based study, in which 283 people with IBD were asked to rate their quality of life. Those with the lowest quality of life scores in the questionnaire study were invited to participate in the later study. Hall et al. do not fully explain what they mean by health-related quality of life in this context, nor do they adequately rationalise why this sampling choice was made, other than stating that these particular respondents 'would be in a position to reflect upon a range of experiences regardless of...their current disease activity' (2005: 445). Based on Hall et al.'s analysis, 'health-related quality of life' appears to refer to the physical and psychological impact of the chronic condition on respondents' ability to partake in everyday work, family and social activities, as well as to maintain desired interpersonal relationships. These activities and relationships can be seen as constituting part of their desired 'lifestyle' (see 1.4). The concept of 'health-related quality of life' therefore relates closely to the category with which I will be working in my analysis.

Through open-coding of the interview transcripts, using grounded theory methods, the core theme of 'health-related normality', as perceived by respondents themselves, was identified. This was found to consist of three interrelated processes: the 'continued re-assessment of normality, the fight to maintain normality, and maintaining the appearance of normality to others' (2005: 446).

In relation to 'maintaining the appearance of normality to others', differences were found in the 'way individuals reported the need to appear 'normal' to others' (2005: 451). For the majority, attempts to appear normal simply entailed not disclosing their symptoms to others. This non-disclosure was due to fear of 'not being understood, embarrassment and being a burden to others' (2005: 451). A minority of respondents went so far as to suggest that they felt 'dread' (2005: 452) of being labelled by others because of their IBD. As similarly found by Schur et al. (1999) vis-à-vis young adults with T1DM, respondents

more readily reported ‘felt stigma’ rather than ‘enacted stigma’ (Scambler and Hopkins, 1986). However, Hall et al. did find some respondents to report a lack of understanding on the part of others. For instance, it was reported that the ‘discreditable’ (Goffman, 1963) nature of symptoms at times led others to suggest that the condition was not as serious as the individual had made out. Whilst, in this example, the *absence* of symptoms led to ‘enacted stigma’, in most cases it was the taboo, socially-unacceptable nature of IBD symptoms, as perceived by respondents themselves, that led to fear of experiencing stigma.

Additionally, some respondents reported that their condition negatively affects social relationships, due to the restrictions that physical symptoms impose upon their ability to engage in social activities. This finding is not observed by Schur et al. in relation to young adults with T1DM, suggesting a potential cross-condition disparity. However, it must be noted that Hall et al. do not focus on young adults, and these sample differences must be taken into account when comparing findings.

Hall et al. conclude that the individuals in their study represent their IBD as embarrassing, taboo, and often misunderstood by others. As such, maintaining the appearance of normality is especially salient to them.

Hall et al.’s research presents interesting insights regarding how people with IBD represent the impact of their condition upon their lives. However, the fact that Hall et al. do not consider age, or any other social variables, as factors in their analysis could be viewed as a weakness, as age in particular could be a significant factor in determining how respondents define ‘health-related normality’, as well as their reported behaviours in pursuing this. It could be hypothesised that certain facets of the appearance of normality may be afforded more salience by certain age groups. For instance, given the bodily changes taking place during adolescence, this group may experience greater concern regarding symptoms and treatments which adversely affect their outward physical appearance. This is something that Hall et al. are unable to explore.

The respective findings of Schur et al. and Hall et al. have been shown to relate strongly to issues of *normalcy*, in terms of what individuals with these conditions represent as being 'normal', both from their own perspective and in the perceived views of others. They appear to largely compare themselves with conceptions of normalcy in relation to *not* having a chronic condition, rather than what is 'normal' for somebody who has the same condition as them, thus leading to fear of stigma due to their perceived separation from this 'norm'. This theme is very relevant to the present study, and my analysis will explore issues of normalcy, stigma and disclosure in relation to the accounts of young adults with T1DM and IBD.

### **4.3 Control**

A third salient theme emanating from research in this area is the *control* respondents represent themselves as having over their lives, in relation to the influence of their condition upon them. The theme of control is closely tied to themes of *self* and *others*; as the control chronic illness exerts on individuals' lives can influence the role they afford illness within their selfhood; and in cases where the condition exerts control over many aspects of life, this can affect social relationships, as observed by Hall et al. (2005), discussed above.

#### *4.3.1 Research using a Non-Specific Age Sample*

In investigating the experiences of people with diabetes, Kelleher (1988) identifies issues surrounding respondents' 'control' over their lives as being a salient theme. Kelleher analyses data from 30 semi-structured interviews. He does not specify the age-range of his respondents, however he does state that 20 were randomly selected from GP lists of three practices in London, 5 were newly diagnosed and recruited on their first hospital visit, and 5 had been recently hospitalised. Kelleher's sample includes both respondents who have T1DM and respondents who have type 2 diabetes (T2DM). He does not distinguish between these two conditions in his analysis, referring to his respondents collectively. I would contend that considering these two conditions homogenously is rather problematic, as whilst they share many similarities, there are key differences in relation to treatment

and condition-management, which could result in those with the respective conditions representing their experiences in very different ways.

Kelleher proposes that, in his data, ‘control’ refers to respondents being in control of their lives in relation to the influence of diabetes, as opposed to control over the condition itself in terms of having good glycaemic control. Despite this, it will be shown that Kelleher does also address issues of condition control in his analysis.

Kelleher develops conceptual categories for ‘strategies’ reportedly adopted by respondents in living with their condition. He firstly talks of those who have good diabetes-management, and do not allow this to affect their lifestyle activities in any way, as ‘coping’ (1988: 146). These are respondents who ‘manage DM and their treatment-regimen without altering their lifestyle’ (1988: 140). This seems an unusual finding, as given the dietary and treatment issues involved in maintaining good glycaemic control, it is surprising that respondents would not have to alter their lifestyles in any way. Several studies have, for instance, pointed towards an apparent incongruence between having good glycaemic control and having good lifestyle control, as one is often detrimental to the other (Balfe, 2009, see below: 4.1.1). Kelleher describes such individuals as having ‘high control’ (1988: 146). This description appears suitable here, as these are individuals who are in control of their diabetes, yet are concurrently in control of their lifestyle. The use of the term ‘coping’ seems strange, however, as Kelleher appears to frame ‘coping’ as being synonymous with having a high degree of control over the condition, thus appearing to represent coping as being a category *within* the theme of control, though this is not made entirely clear.

The overlapping use of the terms ‘control’ and ‘coping’ is reflected in much of the research literature investigating experiences of T1DM and IBD, though unfortunately there is not room here to explore all of these studies (see Dovey-Pearce, Doherty, and May, 2007; Hall, Rubin, Dougall, Hungin and Neely, 2005; Kelly, 1992a; Schur, Gamsu and Barley, 1999). None of the studies into these two conditions attempt to establish a conceptual distinction between these two terms. I will not attempt here to disentangle the use of these terms, as my main interest is in comparison of findings rather than how the

respective studies use the terminology. However, in my analysis I will attempt to arrive at a conceptual distinction between these two terms which is workable in relation to my data, which will then be maintained at an analytic level (see 8.1).

The second of Kelleher's categories is labelled 'normalising' (1988: 146). Those within this category did not have 'high control' of their diabetes-related health, yet Kelleher proposes that they still viewed themselves as being 'healthy' (1988: 146). They had given up some social activities such as eating out or socialising regularly, but appeared not to be concerned about these restrictions, and accepted them as being part of a 'normal lifestyle' (1988: 146). They also 'accepted as normal the symptoms they experienced and did not make a great deal of effort at controlling their DM to eliminate these symptoms' (1988: 147). An example of normalising Kelleher gives is from an interview with 'Mr L': "I tend to think that if I have any of these symptoms it's probably due to the fact that I've got it and that's it. That's an effect of it, you know what I mean" (1988: 147).

There could be said to be two types of 'normalising' identified by Kelleher – that regarding restrictions upon the respondent's lifestyle, and that regarding symptoms that he or she experiences in relation to diabetes. There is also a potential distinction between respondents' view of what is 'normal' for them as somebody with diabetes, as opposed to what is 'normal' in relation to somebody who does not have diabetes, as a new conception of normalcy is constructed here which takes on board the limitations imposed by their diabetes.

Some of Kelleher's claims regarding this strategy can be questioned, however. Whilst the example presented above does appear to display Mr L showing acceptance of his diabetes, the claim that respondents see themselves as being 'healthy' is not fully warranted. This is a term introduced by Kelleher himself, and there is no evidence in the sparse data-extracts he presents of respondents claiming to see themselves as 'healthy'.

Kelleher suggests that his respondents have a degree of *agency* whereby they *could* choose to adhere to their treatment-regimen more stringently in order to minimise the symptoms that they experience, and thus gain greater lifestyle control; however, they 'did

not make a great deal of effort to do so' (1988: 147). The question here is therefore whether respondents choose to *use* their potential agency. The notion of agency is one which will be explored in the present analysis in relation to accounts of both T1DM- and IBD-respondents.

The final strategy Kelleher identifies is 'worrying and agonising' (1988: 150). He found that a large number of respondents had trouble accepting their diabetes and the role it has within their lives, and considered themselves to be 'unhealthy' (1988: 150). For these respondents, diabetes was a constant concern. An example is given from 'Mrs D': "I do get irritable sometimes. It's a terrible feeling. I was never miserable, always happy, you know. I can sit here now with the family and not say one word some days, just sit there with the hump for no reason at all' (1988: 152).

A weakness of Kelleher's research is that he does not use a great deal of data to warrant the claims being made. Data-extracts are limited in length, and principally focus on the content of interview responses, without considering the function of constructions within the context of their production, the benefits of which were outlined in Chapter 3. Additionally, the categories identified vis-à-vis respondents' diabetes-management are treated as being mutually exclusive, and there is little recognition that in the reality of lived-experience these categories will likely interrelate and overlap somewhat.

As mentioned, Kelleher does not specify the age-range of his respondents. This could be significant, as in relation to any chronic illness it is likely that variables such as age and life-stage would influence the behaviours that people engage in in living with their condition. I would in fact argue that this may be especially significant in relation to T1DM, as many of the health complications associated with the condition (see 1.3) commonly develop over a period of many years, therefore the illness experiences of those belonging to different age-cohorts may differ widely. This lack of demographic information is a weakness in Kelleher's work, as the claims he makes across his data-corpus as a whole regarding the 'strategies' used by respondents are therefore more difficult to warrant.

In spite of these apparent weaknesses, Kelleher's study provides some interesting insights regarding individuals' lived-experiences of T1DM. The present analysis will make comparisons with Kelleher's findings, as well as explore whether some of the strategies Kelleher observes could be applied to the experiences of both IBD- and T1DM-respondents.

#### *4.3.2 Young Adults*

The theme of 'control' has also been found to be salient in studies into experiences of IBD, for instance Sargeant (2006). Unlike Kelleher, Sargeant focuses specifically on adolescents, aged 11-16, and young adults aged 20-25, exploring how they experience living with IBD on a day-to-day basis, as well as over the course of time. Sargeant aims to investigate not only the impact of illness-related issues on adolescents' and young adults' lives, but looks at 'facets of young people's lives with IBD that aren't primarily concerned with the disease itself' (2006: 7), thus aiming to consider IBD experiences in relation to respondents' lives as a whole.

The study is divided into two sections. The first draws on interviews with 20 adults aged between 20-25, all of whom were diagnosed in their teens. These interviews produced retrospective 'accounts'<sup>5</sup> of respondents' experiences of IBD in adolescence. This generated themes which informed the second part of the study, an audio-diary method, where 6 participants, aged 11-16, were given a digital recorder and were encouraged to 'record aspects of their lives that were of importance to them' (2006: iv) over a 48-week period. Respondents were aware, however, that IBD was the central interest of the research. Sargeant refers to this method as an 'unclosed diary' (2006: iv). Each participant was interviewed prior to this process, as well as every six weeks, in between diary-sets.

Sargeant develops the dual concepts of adolescents and young adults either living 'beyond' or 'within the confines of their illness' (2006: 82). Those accounts that she

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<sup>5</sup> Sargeant's use of the term 'accounts' appears to simply describe respondents' discursive constructions. The term is therefore not used in the same way as Radley and Billig (1996), or Scott and Lyman (1968), discussed in 3.2.

classifies as demonstrating individuals living ‘within the confines of illness’ are ones of ‘restriction in terms of physical space and bodily limitations’ (2006; 82), whereas accounts of living ‘beyond’ are those of ‘liberation and empowerment, especially those concerned with defying the body’s physical limitations in some way’ (2006: 82). These concepts appear, then, to refer primarily to *lifestyle* control, rather than control over the symptoms of the condition itself. Sargeant stresses that the distinction between living *beyond* or *within* illness is far from clear-cut, and she talks of notions of restriction and empowerment as ‘interchangeable within accounts’ (2006: 82).

An example Sargeant gives of the interchangeability of these concepts involves a fourteen year-old girl, Haley, who, because of her enjoyment of sport decided to take up golf, as she found this activity not to be detrimental to her joints, with which she suffered problems due to arthritis, related to her IBD. She was therefore pursuing her love of sport in spite of her condition, and hence living ‘beyond’ the confines of her illness. However, Sargeant notes that she can equally be seen to be living ‘within’ its confines, as ‘there is potentially a question over whether Haley would have taken up golf had she not been diagnosed with IBD’ (2006: 126). Sargeant’s contention that both concepts are present here is supported if we look at Haley’s talk:

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.

(Sargeant, 2006: 126)

I would contend that the emphasis Haley places on the fact that she took up golf because of her inability to participate in more strenuous sports, such as rugby and football, which she refers to using the possessive ‘my’, demonstrates that from Haley’s own perspective, she is as much living within the limitations imposed by her condition, or perhaps even more so, than she is living beyond them through being able to play golf. Although Sargeant talks of the interchangeability of these concepts, I would contend that this example suggests a continuum, whereby Haley is projecting living *within* the confines of



illness to a greater degree than she is living *beyond* them, and thus positions herself nearer to the living *within* illness end of the continuum.

These dual concepts have implications regarding *agency*, as through showing that some adolescents and young adults are able to live 'beyond' the confines of illness to a certain extent, this suggests a degree of agency vis-à-vis their lifestyles. This appears to be a different type of agency to the one implied by Kelleher in relation to those with diabetes, however, as he suggested, in relation to those who he classified as 'normalizing', that respondents could, if they wished, make more effort to 'eliminate...symptoms' (1988: 147). This suggests potential agency regarding control of the *condition* itself, which in turn could lead respondents to have greater control over their lifestyles. Sargeant, however, makes no suggestion that young adults and adolescents with IBD have agency in alleviating symptoms, with living beyond illness suggesting actions *in spite of* disease symptoms. This may suggest a cross-condition disparity, and these issues will be fully explored in the forthcoming analysis.

The concepts of living *beyond* or *within* illness will be shown to be very pertinent to the concerns of the present study. Whilst Sargeant focuses exclusively on IBD, constructions of living *beyond* and *within* will be shown to be relevant to those with T1DM also, and I will explore the similarities and differences *across* the two conditions in relation to their construction. Again, the reported behaviours of young adults in relation to these different ways of managing their condition will be shown to be strongly related to their multiple identity-constructions – the images of themselves they wish to *perform* within the interview context.

In addition to her findings, I also take influence from elements of Sargeant's methodological approach, in which she pays significant attention to her role in the interviewing process, and the 'active' (Atkinson, Coffey and Delamont, 2003; Holstein and Gubrium, 1997) nature of her interviews. This will be fully discussed in 5.2.3.

#### **4.4 Social Activities involving Alcohol-Consumption**

##### *4.4.1 Young Adults*

A final theme identified within the research literature is young adults' participation in social activities involving drinking alcohol, such as going to pubs, clubs and bars. The focus of this research is individuals' participation in these activities in spite of the *additional* health risks that these behaviours could pose (these risks will be discussed at the beginning of Chapter 9). Though present in a few studies looking at T1DM, this theme is generally not afforded a principal focus in studies into IBD-experiences. This includes those looking at young adults; studies where this theme may be more expected due to the cultural association between these activities and young adulthood (see 1.2). Whilst this may present a cross-condition disparity, the reason for this absence could be that many of these studies use samples of respondents with the most severe forms of IBD; therefore findings primarily surround individuals' *lack of* ability to partake in such sociable activities (see Brydolf and Segesten, 1996; Hall et al., 2005; Kelly, 1992). The data in the present study supports the latter explanation, as this theme will be shown to be relevant in relation to young adults with both T1DM *and* IBD.

Focusing on university students with T1DM, Balfe (2009) found issues surrounding alcohol-consumption practices to be central in the reported experiences of this group. He identifies university students as being a particularly salient sub-group of young adults, given that 'going to university will be the first time that many young adults with diabetes will be away from home and attempting to regulate their diabetes without the structuring support of school or family...in an environment...more than a little structureless and chaotic' (2009: 129). Semi-structured interviews were carried out with 17 university students, aged 19-25, based in universities in the midlands of England.

Balfe found that a central concern of respondents was the concept of 'normalcy', which he proposes is 'constructed and maintained' (2009: 137) through the body. Through thematic coding, he develops an explanatory framework for the data based around Shilling's (2003) concept of 'body projects'. This concept concerns the centrality of the

body in performances of one's identities. Shilling (2003), and Turner (1984) before him, both talk about the body as an ongoing, 'reflexively organized project' (Shilling, 2003: 188) which can be manipulated, cultivated and continuously worked-upon. It is posited that constructing and presenting the body in different ways and engaging in different 'body practices' (Balfe, 2009: 130) can enable 'identification with valued subject positions' (2009: 130). Balfe argues that individuals can choose to participate in multiple body projects, through a diverse range of lifestyle practices. It is also proposed that, whilst body disciplinary practices might be experienced in a highly individual way, they are 'regulated by, and acquire meaning from, broader social discourses' (2009: 130), and are thus in some ways prototypical, showing a concern with the display of 'normal' behaviour.

Balfe proposes that students engage in developing three separate, but interrelated body projects: 'student bodies', 'toned bodies', and 'healthy bodies'. Through participating in each of these projects, he observes, they intend to produce an embodied 'normal identity' unaffected by T1DM. In terms of the 'student body' project, respondents reported being worried that other students would view them as having a disability, and that their T1DM would prevent them from engaging in 'normal' student activities. Balfe proposes that they respond to these concerns by engaging in 'proactive practices' that enable them to 'situate, strengthen, and embody their identities as normal students' (2009: 133). The key practice was found to be *alcohol-consumption*. Balfe notes that consuming alcohol in student spaces, such as student bars and nightclubs, allows students with T1DM to receive 'empirical validation from others' (2009: 133), legitimating that they are 'normal'.

This is a significant finding, as whilst respondents' concerns about others' perceptions, and their desire to be seen as 'normal' in relation to those who do not have a chronic condition, was shown to be prevalent in the findings of Schur et al. (1999) and Hall et al. (2005), discussed above (4.2.1 and 4.2.2 respectively); in the case of both studies, non-disclosure is the predominant way that respondents were found to manage their concerns about not being perceived as 'normal'. Balfe's findings suggest, however, that in the case of university students with T1DM, particular types of practice are engaged in to create this appearance of normalcy, those which reinforce cultural expectations regarding

behaviour that people of their age, and specifically those within the university environment, *should* engage in.

With regard to the ‘toned body’, concerns about body shape were found to be prevalent in interviews. For many, this concern is borne out of the fact that they feel their T1DM causes them to ‘gain weight more easily and lose weight more arduously than other students’ (2009: 134) (see 1.3).

The ‘healthy body’ project concerns the health of the *inner body*. As a group, the respondents were found to be highly anxious about the effects that long-term complications of T1DM could have on them in the future. They also viewed taking care of their health as a moral practice, and at times when they did not engage in ‘correct’ management practices, they often described feelings of ‘self-directed anger and guilt’, causing them to ‘call into question the adequacy of their identity as a ‘good’ person with diabetes’ (2009: 135).

Balfe observes that, whilst students simultaneously engage in these three separate body projects, often the practices they use to construct one body project undermine their ability to produce another. For instance, in engaging in T1DM-management practices to maintain a ‘healthy body’, such as injecting insulin, respondents risk drawing negative attention to themselves, thus undermining their desired presentation of self. Conversely, practices that students use to identify with the ‘student body’, such as consuming alcohol, often undermine their attempts to manage their T1DM, and thus produce a ‘healthy body’. Balfe contends that when individuals cannot successfully engage in body projects, and therefore cannot produce ‘desired narratives of the self via their body practices’ (2009: 136), they risk suffering ‘identity damage’ (2009: 136), often expressed and experienced in emotional terms.

It was found, however, that respondents can use strategies in order to address the difficulties they experience in balancing their different body projects. One such strategy is ‘bracketing the risks associated with their body project practices’ (2009: 136). For example, respondents reported that when they engage in risky drinking practices, they

limit this to times and places when other students are around and they feel on display, i.e., central sites of student sociability such as bars and nightclubs. Bracketing their practices in this way means respondents are able to 'prioritise the actualisation of different body projects in different contexts' (2009: 137). Balfe seems to be suggesting here, then, that it is possible for students with T1DM to create a balance between 'good' T1DM-management practices and participation in 'normal' student behaviours, although only through compromising one or the other depending on the given context.

Balfe's findings vis-à-vis alcohol-consumption can be seen to relate strongly to the themes of *Others* and *Control*, discussed above (4.2 and 4.3 respectively), again demonstrating the interrelated nature of these themes. It appears that the concerns expressed by Balfe's respondents about drinking alcohol are primarily related to their concerns about others' perceptions of them, with alcohol represented as the primary marker by which they feel others will judge whether or not they are 'normal'. Respondents' choice to participate in social activities involving alcohol can also be seen as an attempt on their part to gain control over their lifestyle, to some extent defying the demands and risks related to their condition.

Balfe's use of the 'body projects' framework is a particularly appealing theoretical model, in demonstrating the competing demands and pressures on young adults with T1DM, and how these can be seen to interrelate. This will be shown to be significant in the present analysis, in relation to alcohol-consumption practices, but also with regard to other areas of lifestyle. Balfe's attention to the moral issues surrounding the competing demands of good condition control and partaking in culturally expected activities will also be afforded salience in the present analysis. Expanding on Balfe's work, however, I will explore how these concerns over issues of morality are manifested at a discursive level. I will also investigate these concepts in relation to young adults both with T1DM and those with IBD.

One criticism of Balfe's analysis is that the data-extracts he uses to exemplify his analytic points are limited both in length and number. Using longer extracts, and focusing on how respondents' pursuit of multiple body projects is constructed within the interview talk

itself, would give greater insight into this process, something which I aim to do in the present analysis.

Another potential limitation of the study, and one which Balfe himself acknowledges, is that most of his respondents participated for ‘therapeutic reasons’ (2009: 138); they experienced difficulty balancing their T1DM with their university lifestyle and wanted to talk about this. It could be argued, therefore, that these students are more likely to report experiencing tensions between these multiple body projects than other students with T1DM who have not sought therapeutic intervention. This could affect the applicability of Balfe’s findings to the experiences of other young adults with T1DM. However, I would argue that the *concepts* Balfe develops *will* likely be applicable to others samples, even if his findings vis-à-vis how different bodies are negotiated could differ.

#### **4.5 Chapter Summary**

The studies reviewed in this chapter give interesting insights into the lived-experiences of individuals with T1DM and IBD. Some of these studies have been shown to have aims very close to that of the present study, in specifically looking at *young adults’* experiences of these conditions. However, all of the studies evaluated in this chapter investigate either IBD *or* T1DM. As highlighted throughout this chapter, the present analysis will expand on this research through investigating experiences of both conditions together, allowing for cross-condition comparisons to be made. Other studies in this area, which I have not had space to talk about here, will also be introduced in analytic chapters, as relevant, in making these comparisons (this includes Dovey-Pearce, Doherty and May, 2005; Hillege, 2005; and Kelly, 1992a).

The predominant themes identified as emanating from the studies reviewed here can be seen, to some extent, to correlate with those derived from the research reviewed in Chapters 2 and 3, with issues related to *self*, *others*, *normalcy* and *control* being found to be prominent. This supports Kelly’s (1992a) claim (see 1.3) that, at a very broad level, there are commonalities in illness experience that span different conditions, and also to some degree across age-groups. Some of the findings in this chapter have, however,

pointed to issues which may be especially salient in relation to young adults, such as Sargeant's (2006) findings vis-à-vis living *within* and *beyond* the confines of illness, and Balfe's (2009) findings in relation to alcohol-consumption practices, however Balfe's study is specific to university students.

Having now conducted an extensive review of the research literature relevant to the present study, the next chapter will fully outline the methodological approach adopted in my research.

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## 5. Methodology

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### 5.1 *A Qualitative Approach*

A predominantly qualitative approach is adopted in addressing my research questions, which are reproduced below in an abbreviated form (see 1.7 for full outline):

How do young adults discursively construct their individual experiences of chronic illness?

- Which areas of their lives do young adults with T1DM and IBD construct as being most affected by their condition?
- How do respondents construct their condition in relation to *self*?
- How do respondents represent their condition in relation to *others*?
- How do accounts portray respondents' degree of *control*?
- What similarities and differences are apparent in accounts *across* the two conditions?

The data consists of audio-recordings of 30 semi-structured interviews with young adults, aged 18-29, who had been diagnosed with either T1DM or IBD for a duration of at least six months. Whilst generating a substantial amount of data for analysis, this number of interviews was realistic in relation to practical considerations regarding accessibility of respondents, and the available time-frame. Open-coding of the data-transcripts was carried out, and extended extracts were selected for detailed, discursive analysis.



This qualitative approach is highly appropriate in relation to the purpose of the study, which is to carry out in-depth investigation of the data-context in order to gain an *emic* perspective, an insider's view, of the experiences of young adults with T1DM and IBD, as far as this can ever be possible. As Charmaz (1991: ix) puts it, gaining an insider's view vis-à-vis chronic illness entails looking at 'how people with chronic illness create meanings of their illnesses and of themselves' (Charmaz, 1991: ix). As proposed in Chapter 1, my personal experience of IBD may place me in a better position to pursue these goals; and it was my aim throughout the research as a whole to construct a balance between elements of an emic perspective, and an *etic* perspective, an outsider's view, adopted through my researcher-role (the extent to which I presented my 'insider' knowledge to respondents will be fully discussed in 5.2.3, below).

The relative merits of attempting to create this kind of emic/etic balance have been afforded much attention in qualitative research, most notably in the field of ethnography, with many expressing the view that 'deeper levels of understanding are afforded by prior knowledge' (Taylor, 2011: 6; see also Adler and Adler, 1987; Bennett, 2003; Edwards, 2002; Ellis and Bochner, 2000; Hodkinson, 2005; Wolcott, 1999). The source of this knowledge, and the *kind of* 'insider' the researcher positions himself or herself as being, can differ, however. For some researchers investigating illness experience, their insider knowledge comes from a professional perspective, such as those working in healthcare professions (see Brydolf and Segesten, 1996; Hillege, 2005). For others, insider knowledge has been gained through coming into close contact with chronically-ill friends and family members (Charmaz, 1983: 1991). This of course differs somewhat from my perspective here, as my insider knowledge stems from possibly having gone through similar experiences to the people I am researching, a similar position to several others researchers, for instance Kelly (1992a), who like me investigates the experiences of those with IBD, himself having Ulcerative Colitis (UC).

Such insider knowledge does not make my interpretations of respondents' constructed-experiences any more valid or robust than the interpretations of individuals without this prior experience; however, at very least I can have greater confidence in my analytic claims. My role as an 'insider' in relation to this group also extends to me being a fellow

young adult, perhaps affording me a greater degree of sensitivity and understanding regarding the lifestyle issues and priorities of people of this age, and how these can, at times, conflict with the demands presented by chronic illness.

Whilst having these potential advantages, at the same time these experiences inevitably place me in a position of greater involvement, especially in the case of such a highly emotive subject. This could make it more difficult to detach myself from the context under investigation than would be the case for somebody who has not had these experiences. However, it is now widely accepted that all researchers in the qualitative tradition, regardless of their previous experience of the context being studied, bring a wealth of assumptions and subjectivities to the research process. Saville-Troike (2003: 4), for instance, proposes that ‘complete escape from subjectivity is never possible because of our very nature as cultural animals’ which, it can be argued, ‘leaves little room for analytic distance’ (Taylor, 2011: 15).

Several studies have adopted quantitative methods in researching chronic illness experience, such as standardised questionnaires (Calsbeek, Rijken, Bekkers, van Berge Henegouwen and Dekker, 2006; Skinner, Hampson and Schaw, 2002), which has advantages in allowing for the potential to generalise findings beyond the immediate data-context. I believe, however, that the sensitive and highly individualised nature of chronic illness gives rise to a range of experiences which are not easily quantifiable, and therefore standardised questionnaire items cannot capture the full complexity of the experience of living with these conditions. As Radley (1999b) argues:

objectification of health and illness in terms of ready made scales or inventories will bypass entirely the way that experience is constructed, and the way in which it is made to matter (more or less) in the lives of those concerned. (1999b: 27)

Of course no methodological approach can fully account for the entire spectrum of experiences people with chronic illness encounter; however, I would argue that semi-structured interviews are most suitable in yielding rich, multifaceted data, allowing the

researcher to 'facilitate participants' deliberations without restricting their responses to a narrow set of predefined areas' (Dovey-Pearce, Doherty and May, 2007: 78).

Whilst it is generally acknowledged that qualitative research does not have generalisability as a principal aim, it is hoped that the reasonably large sample-size in the present study may allow for at least the identification of trends indicative of the experiences of other young adults with these conditions, due to the shared lifestyle priorities and concerns of this group. However, I do not wish to diminish the subjective nature of illness experience, something on which I place strong emphasis.

## **5.2 *Data-Collection***

### *5.2.1 Respondent Demographics*

Due to the specificity of my aims, I was systematic in my criteria for study respondents in order to facilitate robust analyses. The age-range 18-29 was chosen as I feel that this reflects the full spectrum of young adulthood. It could be argued that this relatively broad age-range may result in significant variation across the corpus in terms of respondents' lifestyle activities and lifestyle priorities, making it more difficult to compare experiences of the impact of illness upon their lives. However, whilst there were notable differences within the corpus, e.g., several respondents were studying at university whilst some were in fulltime employment, and some were married whilst others were single, none of the respondents had children, a factor which I felt would be most likely to result in significant differences in lifestyle priorities. It was therefore hoped that, across the corpus as a whole, respondents would share broadly similar lifestyle priorities and concerns, allowing for comparisons to be made across their respective illness experiences.

Fifteen of the respondents within the corpus have IBD, and 14 have T1DM. There is also one respondent who has both conditions. There was, therefore, a considerable amount of data generated in relation to each condition, through which cross-condition comparisons could be made. All respondents, except one, had an illness duration of at least six months, a criterion which ensured that respondents would have significant experience in managing

issues relating to their condition. One respondent, Emily (see Appendix K: Interview 23; presented separately to main thesis. In order to preserve anonymity, all respondents were given pseudonyms in the transcripts), had been diagnosed only three months before her interview. Emily was very eager to participate in the study, and her interview generated interesting discussion, therefore I decided to include her interview in the corpus. The disease duration for those with IBD therefore ranged from three months to eleven years, and for those with T1DM, four years to seventeen years. It should also be noted that three IBD-respondents had a colostomy or ileostomy (see Appendix A). In these cases, then, the respondents' *present* experiences may differ quite significantly from those who have active IBD, because as a result of this procedure individuals may no longer experience disease symptoms. These respondents can, however, provide interesting insights into their experiences of IBD prior to surgery. Additionally, whilst disease is no longer present, having this surgery results in other management-issues and changes to daily life to which individuals must adapt, and these can significantly affect individuals' lives (Kelly, 1992b; Savard and Woodgate, 2009). As this surgery is as a result of having IBD, I will consider these experiences within the remit of IBD-experience.

The majority of the respondents are white British, from a middle-class background, and all currently live in South Wales, or South-West England regions. Nineteen respondents are female, and 10 male. Gender differences are not of primary analytic concern. This variable would have been explored had the data revealed significant differences along the lines of gender, either in relation to meta-commentary on the part of respondents, or my own identification of trends, but neither were found to be the case, and due to the qualitative approach being adopted, this gender imbalance does not affect the reliability of the findings.

### 5.2.2 *Recruiting Study Respondents*

Respondents were recruited on a voluntary basis. It could be argued that volunteers may have a special quality marking them out from the wider population. For instance, respondents in the present study may be those who have an especially high level of interest in issues relating to their condition. This could have implications in terms of the

external validity of the study; however, there was little alternative but to recruit respondents in this way; and as mentioned above, generalisability is not of primary concern in the present study.

Advertisements for respondents were framed in a particular way (see Appendix B). Influenced by the seminal work of Mishler (1986), I attempted to 'empower' (1986: 117) respondents by framing them as 'research collaborators' (1986: 126). For instance, volunteers were asked to 'help' with rather than 'participate' in the study; and whilst throughout this thesis the interactions under investigation are referred to as 'interviews', they were presented to respondents as 'conversations', both in the advertising material used, and in subsequent correspondence.<sup>6</sup> In addition to this, the short-term benefits of participation to the respondents themselves were emphasised, as it was stressed that they would be *given the opportunity* to talk about their experiences, drawing on the notion of talking about illness as being cathartic and therapeutic (Frank, 1995, see 2.2). It was therefore hoped that respondents would feel that they were gaining something positive from participating in the study.

Several respondents did in fact explicitly express this view upon meeting me, saying that that they felt that, through sharing their illness experiences, they were in some way 'giving back' to others who also have the condition, hoping that their experiences could serve to help others. I was pleased to hear this, as it allayed my concerns that I was imposing upon these individuals.

Prior to the recruitment of respondents, ethical approval for the study was gained through submitting a research proposal, interview consent form (Appendix C), and advertising posters to the ENCAP Ethics Committee at Cardiff University. Volunteers were then sought through several different avenues concurrently, in order to maximise response frequency. Advertising was firstly carried out within Cardiff University, and then at other nearby universities such as UWIC (University of Wales Institute, Cardiff), UWE

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<sup>6</sup> The one exception is the consent form sent to respondents (Appendix C), where I do use the term 'participation'. Given the importance of this document in relation to ethical requirements, I thought it best to use more formal terminology.

(University of the West of England), University of Glamorgan and Swansea University. This was in the form of posters on display boards, advertisements sent via emailing lists within individual university departments, notices on the Students' Union websites, announcements made in undergraduate lectures, and an advertisement in the Cardiff University student newspaper (Appendix D). Fifteen respondents were recruited through advertising at these universities.

Secondly, I made contact with Care-coordinators and medical consultants at the respective diabetes and IBD clinics at a hospital in Cardiff, explaining the aims of my study, and asking their permission to display posters on clinic notice boards. For this it was necessary to go through the hospital's ethical approval process. Whilst most of those contacted were very amiable, one of the IBD-consultants responded in a somewhat hostile manner, appearing to misunderstand my intentions, believing that I wished to interfere with the running of the clinic in some way. I contacted him again, however, and apologised for this misunderstanding, explaining that it was my intention only to recruit volunteers for interviews which would take place *outside* of the clinic context, following which he gave permission for me to do so. Four respondents were recruited through advertising in these clinics.

In addition to granting me permission to advertise for volunteers through clinics, one of the IBD-consultants, and the Coordinator of the diabetes clinic agreed to meet with me to discuss my research. These meetings were a great success, with both individuals showing interest and enthusiasm for my study. As a result of these meetings, I arranged to remain in correspondence with both clinics, updating them on the progress of my research, and also to provide them with a copy of my findings upon completion (see 10.6 for further discussion).

A third advertising avenue explored was contacting the national associations for diabetes and IBD: *Diabetes UK* and the *NACC* (the National Association for Colitis and Crohn's Disease, also now referred to as *Crohn's and Colitis UK*) respectively, asking if they could help me in any way in recruiting study respondents. Unfortunately, *Diabetes UK* informed me that they were only able to assist large-scale, national studies; however, the

NACC were very helpful, and in exchange for a donation covering the postage costs, they sent letters on my behalf to all of their members within the specified age-range in the South Wales and South-West England areas. Nine respondents were recruited as a result of letters sent by the NACC.

Advertisements prompted those interested to contact me via email, telephone or post for further information. Once contact was made, I sent respondents a sheet containing further information about the study (Appendix E), a consent form outlining their rights regarding participation, as well as additional information and advice sheets about their particular condition. For T1DM-respondents, this information was taken from the *Diabetes UK* website ([www.diabetes.org.uk](http://www.diabetes.org.uk)) and for IBD-respondents, from the NACC website ([www.nacc.org.uk](http://www.nacc.org.uk)) (Appendix F). Respondents were also sent an extract from an interview with a young adult with the same condition as them. For T1DM-respondents, this extract was taken from [www.dipex.org](http://www.dipex.org), the Database of Individual Patient Experience website (since renamed [www.healthtalkonline.org](http://www.healthtalkonline.org)), and for IBD-respondents, from [www.ccfa.org](http://www.ccfa.org), the Crohn's and Colitis Foundation of America website (Appendix G). These additional materials were sent simply as a way of introducing respondents to the study, with the sample interview transcripts demonstrating the kinds of topics that could be discussed in the interviews. Additionally, as will be shown in the following section, one of the questions I asked respondents was whether they found this kind of online information/advice useful in helping them to manage their condition. With this said, for the most part I intended for respondents themselves to introduce the themes discussed in interviews (see 5.2.3, below). If, having received these forms and materials, respondents still wished to participate in the study, they again contacted me to make arrangements to meet.

### *5.2.3 The Interviewing Process*

All interviews were arranged at the convenience of the respondents. In most cases I visited the respondents in their own homes. Some preferred to meet me at my university building, where the interviews took place in a quiet room. Two of the respondents expressed a preference to meet at my house for reasons of convenience.

All interviews were audio-recorded using an *Olympus VN-2100PC* digital voice recorder, which provides a high degree of sound clarity when compared with many other recording methods. This would prove beneficial during transcription and analysis of the data.

Interviews were conducted between 21<sup>st</sup> December 2007 and 21<sup>st</sup> August 2008. They varied in length, with the shortest lasting 42 minutes and the longest, 2 hours and 46 minutes. I aimed to elicit lengthy, detailed responses, and with this in mind I adapted the approach of Gwyn (1996) (introduced in 3.4), who framed his encounters as ‘conversational narratives’, an approach developed from the work of Wolfson (1976: 192). In opposition to the traditional question-answer format of interviews, this approach aims to foster a dialectic between the interviewer and the interviewee, in which they are engaged in a type of talk approximating informal conversation. This intends to make respondents feel comfortable and at ease, reducing power asymmetries between interlocutors, with the ultimate aim to elicit greater disclosure.

It was thought that adopting a pure conversational narrative approach, in which respondents are asked to talk freely about any aspect of their experiences, would not be entirely suitable in the present study. This is firstly due to the specificity of my research aims; but also I felt that this approach may not be effective in relation to this age-cohort, as respondents may not be as forthcoming in producing lengthy, narrative answers as was the case with the older respondents who constituted much of Gwyn’s sample. I therefore attempted to create a more goal-oriented version, adopting some of these ideals, whilst maintaining some institutional features of the traditional interview structure.

This approach was initially fostered through practical considerations, such as the location of interviews. Conducting most of the interviews in respondents’ homes, as Gwyn did also, intended to create a relaxed, informal environment, and to put respondents at ease.

In terms of the interaction within the interviews, in line with a more traditional interview structure, I began with a set of pre-planned questions, which covered a variety of potential lifestyle issues relevant to the two conditions (Appendix H). These were derived from my



research questions, biomedical information about the two conditions, as well as from the findings of previous research literature (see Chapter 4). Whilst many questions were common to both conditions, some were condition-specific.

Gwyn also used pre-planned questions, though only as 'something to "fall back" on should the flow of talk cease' (1996: 88). Whilst my questions were perhaps afforded more prominence than Gwyn's, then, like Gwyn I intended for the interviews to be largely participant-led, with the responses of the interviewees determining which questions were asked, and in what order. Questions therefore served only as a guide, and the respondents were encouraged to discuss any topics or issues relevant to them. Such an approach afforded me the freedom to follow up on interesting themes introduced by the respondents themselves, allowing the conversation to move in different directions depending on the issues that the respondents viewed as being important within their own subjective illness experiences.

I decided not to take any notes during the interviews, another similarity with the approach taken by Gwyn. Whilst this excluded the possibility of capturing any aspects of respondents' non-verbal communication, it was thought that my note-taking may lead the respondents to feel less at ease, and thus less comfortable disclosing their experiences.

A pilot interview was initially carried out with a T1DM-respondent, Timothy, on the 21<sup>st</sup> December 2007, in order to test the effectiveness of the interviewing approach (see Appendix K: Interview 1). This pilot interview proved successful, and I subsequently decided to include this within the main corpus. Based on this interview, I refined my general interviewing approach, as listening back I felt that at times I was leading the interview too much, introducing topics that *I* thought may be important, rather than encouraging Timothy to initiate the themes of discussion (see for example, Interview 1: lines 438-481), which is something I tried to work on in subsequent interviews. There was therefore a focus on *reflexivity*, that is, 'turning one's reflexive gaze on discourse...turning language back on itself to see the work it does in constituting the world' (Davies, Browne, Gannon, Honan, Laws, Mueller-Rockstroh, and Petersen, 2004: 360). Throughout the interviewing process, I continually evaluated my interviewing skill,

aiming to hone my approach in order to meet my aims. In later interviews (see for example, Appendix K: Interviews 25-30) I therefore tried to afford respondents greater control over the direction of the conversation. With this said, there is still evidence in later interviews of me leading the direction of the conversation to some extent. However, even when this was the case, I was still very facilitative concerning the ways in which topics were responded to.

Throughout the interviewing process, I was very conscious of my self-presentation to respondents, taking heed of Jorgenson's (1991) proposition that, whilst the interviewer is 'observing' the interviewee, concurrently the interviewee is 'observing' the interviewer:

Interviewers embody multiple identities in the research context...the ways in which interviewees make sense of and respond to the interviewer's questions depends on how those being interviewed represent the interviewer and his/her objectives to themselves, whether as friend, detached scientist or 'generalised other'.

(1991: 223)

I attempted to come across in a friendly, informal manner, aiming to build a rapport with interviewees, again in order to reduce wherever possible any potential interactional asymmetries which may arise within the encounter, as well as to display a suitable level of sympathy and empathy towards respondents' reported experiences. At the same time, however, a degree of professionalism was maintained throughout. I intended to display a certain degree of knowledge about the conditions under study, but did not explicitly disclose the extent of this knowledge to respondents, thus implicitly inviting them to adopt the role of 'expert', if they wished to do so, again contributing to the construction of respondents' role as 'collaborators' (Mishler, 1986: 126), rather than 'participants', in the research. However, sometimes my questions may have made respondents aware of my degree of knowledge of the two conditions.

Additionally, I chose *not* to disclose to respondents my own personal experiences regarding either of the two conditions, and especially relevant in relation to IBD-respondents, the fact that I myself have UC. This contrasts with the approach of some

other researchers who have been in a similar position, such as Kelly (1992a), who *did* disclose his UC to his respondents. Whilst this disclosure may have fostered even greater rapport with respondents, I made this non-disclosure decision as I did not want to influence respondents into treating any information as 'given'. Disclosure on my part would also have put me on a different footing in relation to the respective condition groups, as an 'insider' vis-à-vis IBD, but an 'outsider' vis-à-vis T1DM, which could have influenced the way experiences were constructed by the respective groups, subsequently affecting my cross-condition comparisons.

This attention to my self-presentation again had the purpose of creating an interactional environment conducive to producing 'conversational narratives' (Gwyn, 1996). This importance afforded to my own role within interviews demonstrates that these encounters are viewed as being 'active' pursuits (Holstein and Gubrium, 1997). This is the idea that the interview does not aim to extract any underlying 'truth' from respondents, nor discover their internal mental processes, but is in fact a 'social performance' (Atkinson and Delamont, 2003: 104), where both the interviewee *and* the interviewer are performing multiple, co-constructed identities. It was shown how such considerations are given salience in the interaction- and language-based studies reviewed in Chapter 3, however, as highlighted in Chapter 4, with the notable exception of Sargeant (2006) (4.3.2), none of the studies I evaluated into experiences of T1DM and IBD pay attention to this particular aspect of the researcher-role, and instead ascribe to the positivist notion that interviewees' responses are reflecting their inner thoughts and feelings (Silverman, 2006: 120).

This notion of *performativity* is well articulated by Potter and Wetherell (1987: 164), who propose that the analysis of interviews should focus on 'how talk is constructed and what it achieves rather than whether it is an accurate description of the participants' internal state'. From this standpoint, the inevitable biases and subjectivities brought to the interview process by the interviewer need not be viewed in a negative light, as they may be from a positivist perspective which views interaction simply as the transfer of information from one interlocutor to another. Instead, the subjectivities of the interviewer are important in contributing to the construction of the encounter. Treating the interview in this way, as socially and contextually-constituted, assumes that meaning is *created*

within the interview through interaction between the two interlocutors. As Holstein and Gubrium (1997: 114) propose, the interview ‘is not merely a neutral conduit but a site for *producing* knowledge itself’.

In the present data-corpus, the active nature of encounters is explicitly recognised at times in respondents’ talk. A good example of this is from an interview with Rosie, who is aged 22 and has IBD. In this extract, Rosie is discussing how, when visiting somebody else’s house, she is immediately concerned about toilet access (see Appendix K: Interview 4: 348-369. See Appendix I for transcription conventions):

1. R: if I go to the loo she’s gonna hear everything that was my (.)
2. first thought on walking into the room (.) and that’s my first
3. thought going into most people’s houses where’s the loo? (.) is
4. it within hearing distance? (.) of where everyone’s gonna be (.)
5. um (.) so yeah actually that’s I hadn’t really thought about that
6. (laughing) before but that is the first thing that I think of (.) um
7. (.) and I was worried that (.) you know (.) thankfully I was
8. okay I was only there for one night (.) I would (.) be worried if
9. I was staying somewhere for more than that because (.) I would
10. know that I would have to (.) like rush to the loo at some point
11. (.) and um (.) and she’s one of my best friends and I still
12. worried about that and I’ve known her since I was eleven (.) so
13. (.) um (.) I would feel very uncomfortable with someone I
14. didn’t know very well (.) um in that situation (.) so I feel for
15. people who (.) do try to start relationships and (.) if they’re
16. having a bad time or something (( )) yeah (.)
17. BS: mm mm=
18. R: =I hadn’t really thought about that (chuckles) (.) quite
19. scary really (.)

It can be seen, in lines 5-6 and 18, that Rosie explicitly comments that her concerns about others overhearing her using the toilet had been subconscious, and it is only through

discussion of this issue within the interview that she has become aware of this thought-process. Rosie is therefore not simply relaying her experiences, but the interaction is leading her to 'other' herself in articulating different facets of her experiences. The interaction is therefore 'producing' knowledge in the manner posited by Holstein and Gubrium (1997).

In general, I experienced success in constructing this conversational narrative approach. In the majority of interviews, talk flowed freely, and I was in fact quite surprised by the extent of the personal details that respondents were willing to disclose. This may have been a result not only of my attempts to put respondents at ease, but also because I too am a young adult, and they may have therefore viewed me as part of their 'in-group' in this respect, and presumed that I would share similar lifestyle priorities and concerns to them, leading them to feel more comfortable in being frank and open about their experiences.

With this said, there was a degree of variation in the interaction in interviews. Some were more dialogic, with my contributions being relatively frequent. This was often due to respondents producing shorter turns, and thus requiring more prompting and follow-up questions on my part. Other interviews were more monologic, with respondents producing lengthy narrative responses, and my contributions being very minimal. This variation appeared to reflect respondents' respective personalities, some being more shy and reserved, and perhaps understandably nervous in an unfamiliar interactional context, whilst others came across as being more confident, and perhaps just generally more talkative.

In a few interviews, respondents at times became slightly emotional, but this was not to the point where I felt it was necessary to ask these respondents if they wished to terminate the interview, as would have been done immediately if the discussion was considered to be in any way detrimental to their emotional well-being, either based on my own judgement or through indication from the respondents themselves. At all times, therefore, I remained aware of my own responsibilities towards the well-being of respondents.

One problem I encountered was that, in one interview, the father of the respondent asked to sit in on the interview, and with the respondent having given her permission, I of course agreed to this also. However, whilst I was happy for the father to contribute to the discussion, his understandable frustrations and concerns about his daughter's condition meant he began to dominate the interview somewhat, resulting in the respondent's contributions being quite minimal. In this case, therefore, I decided that the data could not be included in the corpus; however, the recording was saved in order that it may be used in future research.

### **5.3 Analysis of Data**

#### *5.3.1 Preliminary Analysis: Transcription and Thematic Coding*

The interview data was transcribed in full, a process carried out concurrently with interviewing, thus allowing for observations based on transcribed data to inform subsequent data-collection. The decision to transcribe all of the data was prompted by the inductive aims of the study. As I intended my analysis to largely focus upon themes emerging from interviews, I did not wish to omit any of the data at this stage, as I did not know what might prove to be of use. This decision resulted in a very laborious, time-consuming process. One of the advantages, however, was that this enabled me to familiarise myself with the data to a great extent.

The transcription reflects the jointly-constructed nature of the encounters. As Ochs (1999) notes, transcription is not a neutral way of visually representing spoken data, but is necessarily a 'selective process, and the transcription style used must reflect the theoretical goals' (1999: 168) of the research. With this in mind, the conventions chosen, adapted from O'Connell and Kowal (1995) (see Appendix I), incorporate a level of detail sufficient to capture the interactional elements potentially relevant to the construction of experience.

Transcripts were subject to open-coding, which entailed the rigorous examination of the data on a line-by-line basis to identify recurrent themes and concepts, with sections of

data being coded within each theme or concept. All of the data in each interview was coded in this way. Through this process, I intended to take account of the data-corpus as a whole, allowing me to be more confident that the extracts subsequently chosen for detailed analysis were somewhat representative of the data (see 5.3.3, below). What is more, coding the data in this systematic way is advantageous in that it 'prompts the researcher to study the data, to dispel earlier preconceived assumptions about the data' (Charmaz, 1990: 1167).

Coding began whilst transcription was still ongoing, thus these were not seen as separate, neatly defined processes; but instead coding was reflexive and recursive, with themes being constantly reappraised and relabelled in light of the findings of subsequent interviews. There was therefore, following the grounded theory approach, constant comparison of segments of an interview with other interviews. This was carried out until 'methodological saturation' (Glaser and Strauss, 1999) was reached, the point at which no new themes are apparent. In carrying out this coding, I used the qualitative software package *MAXqda*<sup>7</sup>, which, whilst having analytic advantages (see 5.3.2, below), has methodological benefits in aiding the organization and management of large data-corpora, enabling easy access to, and retrieval of, coded segments of text. This allowed the coding process to be far more time efficient than manual coding using a pen and paper.

This coding was predominantly inductive, again following grounded theory methods, where the researcher ultimately aims to 'construct theory from the data' (Glaser and Strauss, 1999: 6); therefore at this stage, it was intended that themes and concepts would *emerge from* the data. The identification of codes and the labels given to them was primarily based on my own subjective interpretation of the talk, but was also influenced by themes derived from research literature; therefore this is not a pure grounded theory approach. It could be argued, however, that pure grounded theory is somewhat idealistic, given that the researcher's assignment of codes will always be influenced by his or her prior knowledge and assumptions, which includes those based on the findings of previous research.

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<sup>7</sup> Given that I was working only with textual data, *MAXqda* was chosen in preference to other packages such as *NVivo* and *Atlas.ti*, though these three packages all share similar capabilities.

Whilst, then, in 5.2.3 above, I acknowledged my active role in interviews, it is important to also recognise this active role in relation to the analysis of the data, not only at a more detailed level, but in the transcription and coding of the data, as active choices in selection and interpretation are being made throughout this process. In terms of coding, Charmaz (1990) proposes that ‘the *interaction* between the researcher and the data result in creating categories’ (1990: 1165); therefore, ‘however implicitly, the researcher’s definitions of reality clearly shape what categories he or she constructs’ (1990: 68). This is perhaps even more salient in my case, given my personal experiences of one of the conditions under investigation. As I have already argued, though, the subjectivities and presuppositions the researcher brings to the process should not be perceived as negative, but as an integral part of the research.

Charmaz proposes that ‘to the extent possible, the codes and categories should reflect emerging ideas rather than merely describing the topics’ (1990: 1167). I attempted to adopt these ideals, as whilst some of the codes created simply describe *what* was being discussed by respondents at a particular point, for instance ‘food-consumption’, others have a conceptual basis, such as ‘control’, which will be fleshed out and explored in greater detail in subsequent analysis.

Coding yielded several macro-themes, and a range of micro-themes. Macro-themes were considered to be larger, more general lifestyle-related issues *within* which several other micro-themes could be categorised; therefore coding was to some extent hierarchical. Appendix J shows the full list of macro- and micro-themes, along with a description of the content of talk coded within each theme. Appendix K (presented separately from the main thesis) displays the 30 interview transcripts in full, with the thematic and conceptual codes which are assigned to each part of the data visually presented alongside the transcripts.

Coding the data in this way was not unproblematic. Multifaceted, qualitative data of this kind inevitably, at times, interweaves many themes simultaneously, and it was thus necessary for me to decide very early on in this process whether I should code single



data-segments under multiple themes. I promptly came to the conclusion that this was unavoidable, but that this need not be seen as a weakness, and is instead simply reflective of the nature of the data.

Whilst in relation to more structured qualitative data, secondary coding can be carried out to ensure inter-coder reliability, and thus enhance the robustness of the findings, the semi-structured nature of my data, and the subjectivity of the coding-process, meant that secondary coding would have been largely unfruitful, as well as being impractical in a PhD project of this kind.

Analysis which is based on thematically coded data, though common in this area of research (see Hall et al., 2005; Hillege, 2005, among others), is not without its critics. Conrad (1990), for instance, highlights what he frames as an opposition between a 'categorical' approach to analysis, and a 'narrative' approach. He defines categorical analysis as follows:

the observer...codes the data by theme or category, breaking up the data from the individual case; the researcher uses these coded data to create an analysis of the social situation; and as s/he presents the analysis, presents excerpts from the data to illustrate this or that point.

(1990: 1258)

Though acknowledging that he himself predominantly employs this method, Conrad proposes that the process of coding and categorizing 'shatters the data and disembodies it from the person who produces it...the data becomes coded extracts removed from the context and often the individual' (1990: 1258). Conrad discusses how, in contrast to this, narrative analysis 'stresses the importance of the 'story' the respondent has to tell, analysing the structure or content of the narrative, with an emphasis on understanding the type of narrative or the individual's use of language' (1990: 1258). Conrad asks can narrative analysis 'show greater respect for the integrity of the data, while reducing the possibility of analytic generalisability?' (1990: 1258).

Whilst Conrad makes some valid points about the differences between these two approaches, I would challenge his diametrical opposition of categorical and narrative analysis. I made the criticism myself, in Chapters 2 and 4, that many studies investigating illness experience make use of only short, sparse data-extracts to support the points being made, which are at times de-contextualised from the interview as a whole. However, this is not an inevitable result of the coding process itself, and I would argue that categorizing need not necessarily ‘shatter’ or ‘disembody’ the data, and that there is room to combine principles of both categorical and narrative analyses. Categorising data into themes is certainly advantageous, as whilst the construction of illness experience is undoubtedly a personal, subjective phenomenon, this is never *entirely* the case, as experiences are composed using socially and culturally-available models and representations (Frank, 1995; Herzlich, 1973; Radley and Billig, 1996). Thus, as I proposed in 5.1 above, it may be possible to uncover trends amongst individuals’ constructed experiences. Thematic-coding is a useful way to identify such trends at a broad level, prior to investigating the intricacies of experience through more fine-grained analyses. The coding process is therefore a systematic way of representing the whole data-corpus to as great a degree as possible.

The present study will therefore combine what Conrad terms ‘categorical’ and ‘narrative’ approaches (although whilst I adopt some principles of this approach, I will not analyse only narratives), through analysing lengthy stretches of talk, enabling me to explore some of the tensions and contradictions inherent in the construction of illness experience. This will allow me to avoid ‘disembodying’ the data, as Conrad cautions can be the case when examining only short data-extracts.

### 5.3.2 *Identifying Predominant Macro- and Micro-Themes*

Following the thematic coding, it was necessary to identify the predominant themes that would be the focus of detailed analysis. Whilst many studies rely upon the researcher reading through the data many times and using their analytic skill to get an impression of the most predominant themes emanating from the data, I decided to take a more systematic approach.

The analytic capabilities of *MAXqda* came in useful here, as the programme allowed me to calculate the frequency of occurrence of all the codes I had created in relation to the data. This is quite a superficial measure of the predominance of these codes, however, as it may be the case that one code had a high frequency of occurrence across the data-corpus, but was only discussed briefly within these interviews. I therefore calculated the frequency of *words* coded in relation to each theme across the data as a whole. This gave me a better representation of the amount of discourse coded within each of the themes identified (a table showing the word frequencies in relation to each of the codes is displayed in Appendix L).

Whilst the frequency of words coded within each theme gave me an idea of the most salient themes emanating from the data, it is important to note that I am *not* intending to make any quantitative claims based on this frequency data. It would be misleading to assert that one particular lifestyle area is more salient than another in the young adults' lives simply because it is more frequent within the interview data. What is of greater interest to me is *how* these themes are oriented to by the respondents. These frequencies are therefore simply intended as a systematic way of representing the data as a whole, and to enable the selection of predominant themes for in-depth analysis.

The predominant macro-themes identified for analysis are labelled 'Self', 'Other-orientation' and 'Control' (see Appendix J for definition and further description). It is noteworthy that these predominant macro-themes correlate with those identified vis-à-vis relevant research literature (see Chapters 2-4). Whilst this congruence can be partly attributed to the influence of this research literature on the coding process in the present study, this similarity does provide some validation for my preliminary findings.

There are a few themes which have a high frequency of occurrence which I chose not to select as the main focus for analytic chapters: for instance, 'Medication and side-effects'; 'Information and advice'; 'Medical care'; and 'Symptoms and Pain'. There are various reasons for these themes not being chosen for focus, including the fact that, despite these high frequencies, these themes are commonly not discussed in their own right, but are

talked about in relation to other themes, e.g., ‘Symptoms and Pain’ is commonly discussed in relation to issues of ‘Control’. The reasons behind these omissions are fully outlined in Appendix L.

Having identified the predominant macro-themes, I again contacted all of my respondents, approximately 12 months after I had finished conducting my interviews, providing them with a list of these themes and descriptions of the talk coded within them, and asked their opinions as to whether these represented what *they* saw as being the main lifestyle issues in relation their condition. Approximately two thirds of my respondents replied, all of whom were in agreement with the themes I had identified. Introducing these additional perspectives can add to the robustness of preliminary findings, but this was also intended to further cast respondents in the role of ‘research collaborators’ (Mishler, 1986: 126), giving them an active role in the research process.

Remaining in correspondence with my research respondents was something to which I paid special attention, keeping them updated in relation to my findings and progress. This included a few occasions on which I sent a short email to each respondent outlining my progress since I had last been in correspondence with them. This I feel is important with regard to conducting ethical research. These considerations will be returned to in 10.6.

### 5.3.3 *Detailed Data-Analysis*

Extracts coded within the predominant themes were selected for more detailed analysis. This selection was based on careful reading of the coded transcripts, through which I identified patterns, both in the content of talk related to these themes, and in the discursive construction of the talk. The extracts selected reflect these patterns, and are those in which particular trends apparent throughout the data-corpus are displayed together within single stretches of talk, making it easier to examine these patterns. However, I also wished to account for the variation within my corpus, so I was careful to select extracts which did not align with these trends, allowing me to represent the data more comprehensively.

As already briefly noted, in 5.3.1 above, it is not always possible to divide data of this kind exclusively into individual themes; therefore segments of data are commonly coded under multiple themes. This is especially the case in relation to the larger, macro-themes, which commonly overlap considerably; for instance, issues relating to *Self* and those centring on *Control* may frequently co-occur and interrelate. This reflects the 'messy' nature of the data, with the lived-experience of chronic illness being too complex to be neatly categorized.

For the purposes of my analysis, however, these themes *will* largely be kept separate, with each analytic chapter focusing on one macro-theme. I will draw upon the methodological insights of Tracy and Naughton (2000), who propose looking at data using different 'lenses', essentially meaning different ways of, or different perspectives on, viewing the same data. Tracy and Naughton propose that lenses 'make available what might otherwise go unnoticed, as well as draw attention away from features of a scene that might deserve more careful scrutiny' (2000: 79). However, they talk principally of using different theoretical models to explore the data. I will use this notion of lenses to refer to the way in which I will focus on different elements of the data, in order to foreground the presence of particular themes, in spite of the fact that some other themes may also be present alongside these. This could therefore be termed the use of different *interpretive lenses*. I will, however, attempt to draw together the findings of these different themes in my conclusions (see 10.3), in order to make some broader interpretations of the data as a whole. Having made this point about themes co-occurring, it is important to note that in many extracts it *is* the case that one macro-theme is afforded salience by respondents, meaning it *is* possible in many cases to investigate these themes separately.

Again, as has been emphasised throughout this chapter, during this analysis I am not discovering what is inherent *within* the data, but forming my own interpretation of the data having interacted with it. This analysis therefore seeks to glimpse into the world of the respondents, but in doing this takes into account the influence of my own assumptions and presuppositions. Thus, whilst the interview process has been posited to be one of collaboration, the analytic stage can also be viewed in this way. As Bell (2000) proposes, researcher and researched are 'co-authors after the interview when a researcher re-

presents and transforms the interview texts and discourses' (2000: 186). Talking of 'co-authorship' could be seen to be a little idealistic, and perhaps even overstated, but Bell's point that the researcher-researched relationship continues well beyond the interview stage is certainly well-founded.

In my presentation of these co-constructed discourses, it is important to acknowledge the duty I have towards the respondents. My responsibility regarding the respondents' well-being must therefore extend beyond my face-to-face contact with them. As Gwyn (1996) proposes, being given access to experiences as directly constructed by the individual is an 'unusual privilege [which] entails certain responsibilities along with inherent ambiguities' (1996: 251). I therefore attempted at all times to approach analysis in a sensitive and respectful manner.

As proposed in 1.6, my data will principally be considered as 'accounts' (Radley and Billig, 1996), which will be analysed through methods of discourse analysis (DA), and more specifically I will adopt the principles of 'rhetorical discourse analysis' (Arribas-Ayllon et al., 2011). Whilst focusing primarily on the rhetorical aspects of talk, my analytic framework will draw upon aspects from a range of different analytic approaches, thus constituting what Roberts and Sarangi (2005) term 'free-range discourse analysis' (2005: 639). This will include Radley and Billig's (1996) approach to looking at accounts, as well the accounts framework proposed by Scott and Lyman (1968); Labov and Waletzky's (1967) classic structural model for analysing narratives; insights from Riessman's (1990, 2002, 2003) interaction-based approach to narrative; the discourse-analytic approaches taken by Gwyn (1996) and Cheshire and Ziebland (2005), respectively; and Linde's (1993) discussion of narratives as constituting part of a teller's 'life-story', all of which were outlined in Chapter 3.

The analysis will draw upon a range of theoretical models developed in research into illness experience in the fields of health communication, medical sociology and medical anthropology, many of which have been discussed in the preceding literature review chapters. This will include Charmaz's (1983) theory of 'loss of self'; Bury's 'biographical disruption', and extensions of this theory, i.e., 'biographical flow' (Faircloth et al., 2004)

(see 2.3 and 2.4, respectively); Goffman's (1963) conception of 'stigma'; Scambler and Hopkins' (1986) distinction between 'felt stigma' and 'enacted stigma' (4.2.1); Sargeant's (2006) dual concepts of 'living *beyond* and *within* the confines of illness' (4.3.2); and Balfe's (2009) extension of Shilling's 'body projects' framework (4.4.1).

There are also some other key theories and conceptual models that will be drawn upon that have not yet been introduced. This includes Sarangi's (2007) conceptual framework regarding different perspectives taken towards the 'other' in individuals' discursive constructions: 'self-vs.-other', 'self-as-other' and 'self-and-other'; Schneider and Conrad's (1980) 'closet metaphor' vis-à-vis disclosure of chronic illness; Scambler and Paoli's (2008) concept of 'project stigma'; and Scambler's (2004) twin concepts of 'felt deviance' and 'enacted deviance', which extends Scambler and Hopkins' (1986) concepts of 'felt stigma' and 'enacted stigma'. The reasons for me not having explored this work in the literature review chapters is that, in the case of Sarangi (2007), these concepts are applied to the context of genetic counselling interactions, and Scambler and Paoli's (2008) focus is specifically on the stigma experienced by female sex workers in relation to people's perceptions of HIV/AIDS. Schneider and Conrad (1980) and Scambler (2004) do both focus on chronic illness experience, but each look at only one specific area of experience, whereas the other sociological studies reviewed in Chapter 2 take a more holistic approach, looking at the impact of chronic illness on all areas of life, which is why they were chosen for more detailed evaluation. The theories and concepts mentioned here will be shown to be especially relevant to the respondents' constructions of their orientation to others, and they will therefore be outlined in full at the beginning of Chapter 7.

As introduced in 1.6, methods of DA are contingent upon examining lengthy stretches of talk in order to identify patterns in respondents' constructions. In 5.3.1 above, as well as at various points in Chapters 2-4, I emphasised the benefits of analysing lengthy data-extracts, and the importance of this approach in meeting the aims of the present study. The necessity for these extracts to be presented within the main body of the text, in addition to the full transcripts being displayed in Appendix K, results in lengthy chapters, but given the nature of this analysis, this is well justified.

The analysis will investigate the respondents' use of various rhetorical discourse devices in constructing their experiences and their different identities, including constructions of their illness identity. I will look at the use of metaphorical and figurative language, drawing upon the work of Radley (1993), and Gwyn (1996, see 3.4). Radley (1993) argues that, in relation to chronic illness, metaphor is the predominant 'communicative structure' through which people adjust to their condition (1993: 110). He proposes that 'its primary function is to give affective expression to experiences relating to matters of stigma, uncertainty, fear and pain' (1993: 120). From his perspective, then, metaphor has therapeutic benefits in helping the individual to come to an understanding of his or her condition, and to negotiate a relationship with it. The ways in which metaphor will be investigated in the present study were discussed in 3.4.

Another device that will be investigated is 'constructed dialogue' (Tannen, 1989); more commonly referred to as 'reported speech', introduced in 3.3. This can be in the form of either indirect speech, used to '*describe* what was said', or 'direct speech, to *demonstrate* what was said' (Hamilton, 1998: 63). This device can serve various rhetorical functions, such as to 'offer the audience the feeling of direct experience' (Hamilton, 1998: 63), thus heightening the excitement and drama of reported-events. It can also be used to 'authenticate different versions of events' (Arribas-Ayllon, Sarangi and Clarke, 2008: 1524), as proposing that somebody else saw events in the same way can enhance the reliability of the teller's constructions.

I will also explore respondents' use of 'contrast structures' (Smith, 1978), or 'comparisons' (Cheshire and Ziebland, 2005), introduced in 3.3, where tellers highlight disparity between their behaviour and that of others, often as a way of constructing a positive identity, through representing these others as behaving in a less competent, or less morally-appropriate manner than themselves.<sup>8</sup>

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<sup>8</sup> For ease of reading, in the analytic chapters I will not continually cite authors in relation to these rhetorical discourse devices, or types of discursive constructions such as accounts and habitual narratives.



Respondents' pronominal use will be shown to be significant. The choice of pronouns made can 'index shared or non-shared perspectives in exclusive and inclusive terms' (Arribas-Ayllon et al., 2011: 76), thus allowing the respondents to represent their reported perspectives and behaviours vis-à-vis their condition as either personal to them, or as being shared by others, representations which will also be considered in terms of their implications for the construction of morality.

#### **5.4 Identity and Identity-construction**

Issues of identity and identity-construction will form a central tenet of the forthcoming analysis, as has been highlighted from the beginning of this thesis, and is reflected in the findings of the research literature evaluated in Chapters 2-4, and in the research questions that I have posed. This attention to identity-construction spans across all three of the predominant macro-themes identified, as it is through situated identity-performances that accounts are constructed in relation to these themes, with respondents drawing upon the rhetorical discourse devices outlined above, at various points, as resources in this construction. Identity research has witnessed significant recent developments in the fields of sociolinguistics, discourse/interaction studies, sociology and social psychology, and approaches to its study differ widely. It is therefore necessary at this point for me to outline how the notion of identity will be considered in the present analysis, drawing together ideas from some of the approaches already discussed in Chapters 2-4.

Recent years have witnessed a general shift away from an 'essentialist' perspective towards identity, that an individual's identity, in terms of his or her attitudes, behaviours and beliefs, is fixed and enduring, determined by 'biological and cultural characteristics inherent to the social group' (Block, 2006: 34) to which he or she belongs. This shift has been towards a 'social-constructionist' position, which considers identity to be fluid and changeable, and actively achieved through interaction with others. There has therefore been a move from identity being seen as *product*, to being considered a *process*, something which we *do*. Whilst it is recognised that identity can be constructed through various different modes, it appears generally accepted that this social construction of identity is achieved predominantly through language. This perspective addresses

drawbacks of essentialism, which fails to account for individual agency – one’s ability to be creative in his or her identity-construction – and assumes that behaviour is solely prescribed by socially-determined characteristics. In line with this social-constructionist position, Goffman (1969), through his dramaturgical metaphor, and later Butler (1990) in her work on gender, propose identity to be ‘performative’, something ‘manufactured and sustained through corporeal signs and discursive means’ (Butler, 1990: 136), reflecting an individual’s active desire to project a particular image of himself or herself to others in a given context.

More recently, however, it has been recognised that a conception of identity as a social construct is perhaps not wholly adequate, as it can surely not be the case that an individual does not exist outside of social interaction. Additionally, during interaction there are constraints upon the identities that an individual is able to perform; we do not have an unlimited number of identities to choose from in any given setting, something Butler’s (1990) work on performativity recognises. Much research has therefore adopted a middle-ground approach, which recognises the dynamic, interactionally-achieved nature of identity, yet at the same time acknowledges that a person’s identity has an element of stability – enduring characteristics that constitute his or her self. As Bell (2000) puts it, in this approach identity is seen ‘both as product *and* process’ (2000: 186).

It is this conception of identity, as both a socially-constructed performance, but at the same time comprising stable attributes, that will be adopted in the present study. In 2.3, I introduced Charmaz’s (1983; 1991) notion of ‘self-concept’, the ‘relatively stable, coherent, organization of characteristics, attributes, attitudes, and sentiments that a person holds about him/herself’ (Charmaz, 1991: 279), which displays strong similarity with Cheshire and Ziebland’s (2005) concept of ‘personal identity’ (see 3.3). It is this more stable, enduring element of identity that is being referred to when Charmaz (1983) talks of chronic illness resulting in ‘loss of self’, as well as in Bury’s (1982) theory of ‘biographical disruption’ (2.3 and 2.4, respectively). Whilst being relatively stable, it is important to note that an individual’s self-concept is not entirely static, but may change over time.

Whilst, following Charmaz, I will use the term *self-concept* to refer to these stable aspects of identity, the term *identity* will be used to refer to the socially-constructed, performative aspects of identity achieved within the interviews. As discussed in 3.1, Riessman (1990; 2002; 2003) talks of how, within a given encounter, speakers can produce a 'multiplicity of selves' (2002: 13), thus allowing them to project a 'preferred identity' through their narrative at any given time. This is similar to the stance taken by Omoniyi (2006), who talks of a 'hierarchy of identities', in which 'the most salient identity option on the hierarchy fluctuates as the amount of salience associated with it fluctuates between moments' (2006: 19). This suggests a ranking of identities which is constantly shifting. This will be demonstrated in the present analysis, as it will be shown how respondents foreground different identities to varying degrees at different junctures within interviews, commonly attempting to construct an image of moral-appropriacy.

It is also important to note that, whilst speakers have different identity-options available to them in a given interaction, these are not wholly individual, but can be seen to 'reflect the language practices of groups in which the individual engages' (Thornborrow and Coates, 2005: 15), thus drawing upon some strands of essentialism. In looking at how individuals construct their individual identities, then, we must also look at the 'construction of one's social culture' (Brokmeier and Carbaugh, 2001: 16). Brock (2006) sums up this position nicely, proposing that identity takes place 'at the cross-roads of structure and agency' (2006: 38), as whilst an individual has agency in the identities he or she chooses to perform at any given point, these are to some degree 'constituted by the social environment' (2006: 38) in which the individual is situated.

Talking of identity-construction as influenced by the given social environment brings me back to the point made earlier (5.2.3), that interviews are 'active' pursuits, and therefore these identity choices are not made by the respondent alone, but are strongly influenced by my contributions as the interviewer. Georgakopoulou (2006) describes this in terms of interlocutors 'co-drafting or co-authoring identities' (2006: 84). It will therefore be shown in the present analysis that both the interviewees and myself are making choices from our hierarchy of identities throughout, on a moment to moment basis, regarding

which identity is seen as ‘preferred’, decisions dependent on the joint-construction of talk.

### 5.5 *Chapter Summary*

This chapter has detailed the methodological approach adopted in the present study, discussing the processes of data-collection, transcription and coding, and has outlined the analytical approach to be adopted. I will now move onto detailed discourse analysis of data-extracts, in line with each of the macro-themes identified: *Self*, *Other-orientation* and *Control*. Within the theme of *Control*, the final analytic chapter will focus on the micro-theme of *Social Drinking Practices* (initially labelled ‘Alcohol’ in Appendices J, K and L), issues related to which were found to be an especially salient concern of the respondents. The structure of each of the four analytic chapters will follow along similar lines. After an initial framing of each chapter, which will include outlining the concepts and theories relevant to the theme focused on, I will first examine extended data-extracts from interviews with respondents who have T1DM, and then from interviews with those who have IBD. The final section of each chapter will compare findings vis-à-vis the two conditions, exploring the cross-condition similarities and differences identified.

The next chapter will address the first predominant macro-theme identified in the preliminary analysis – representations of chronic illness relating to the construction of *self*.

## 6. Chronic Illness and the *Self*: How Young Adults Construct a Relationship between Illness and Selfhood

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This chapter will address the first macro-theme identified in the preliminary analysis – representations of chronic illness relating to the construction of the *self*. It will investigate how respondents draw on various discursive strategies to construct a relationship between their condition and selfhood, in terms of how they represent the role of illness within their present ‘self-concept’ (Charmaz, 1983), as well as its impact upon their previously held conceptions of self, either prior to illness, or at an earlier point in their illness trajectory.

In investigating these representations, I will draw upon theories of chronic illness resulting in ‘loss of self’ (Charmaz, 1983), and as ‘biographical disruption’ (Bury, 1982) or ‘biographical flow’ (Faircloth et al., 2004) (see 2.3 and 2.4, respectively); illness resulting in ‘alienation’ from former self-images (Brydolf and Segesten, 1996), and the notion of ‘transformation’ (Paterson, Thorne, Crawford and Tarko, 2001) (see 4.1.2 and 4.1.1, respectively). Drawing upon the insights of Cheshire and Ziebland (2005), Radley and Billig (1996), and Riessman (1990; 2002; 2003) (see Chapter 3), I will also demonstrate how respondents construct their illness-selfhood relationship in such a way as to create desired identities that align with cultural and ideological models of moral-appropriacy.

Analysis will demonstrate variation across data-extracts in the way that respondents with T1DM and with IBD construct their illness-selfhood relationship. In a few cases, the respondents will be shown to *distance* illness from self, through representing their condition as having a peripheral role within their self-concept; whereas others *integrate* illness to a greater degree within their conception of self, affording it a more central role.

The concepts of *integrating* and *distancing* illness vis-à-vis selfhood share similarities with the findings reported by others, for instance Charmaz's (1991) proposition that individuals can choose either to 'incorporate' or 'contain' an 'intrusive' illness (see 2.3). However, extending these findings, here it will be shown that the representation of illness in relation to self can be achieved in different ways, and in a few extracts there is a degree of tension present between respondents integrating *and* distancing their condition, which they attempt to discursively negotiate. These concepts are not observed as being diametrically opposed, and their boundaries are fuzzy and fluid; thus respondents will be shown to distance or integrate their condition vis-à-vis selfhood to differing degrees, as well as at different points within their accounts. These twin concepts of integrating and distancing can therefore most usefully be seen as *resources* for constructing the illness-selfhood relationship.

The notion of 'self-concept' (Charmaz, 1983) was discussed at length in 2.3, and in 5.4. As also previously discussed, the term 'identity' will be used to refer to the *performance* of different aspects of the self-concept, which Charmaz refers to as 'self-images'. One point that must be clarified in relation to the data, however, so as to avoid confusion during the analysis, is that at times in interviews, I explicitly asked respondents about the role of their condition vis-à-vis their 'identity'. I used the term 'identity' within the context of the interview, as I felt that from a lay perspective this would be more easily understandable than 'self-concept', and that respondents would likely consider 'identity' in terms of more stable, enduring attributes constituting their conception of self, which did in fact appear to be the case. There is therefore a disparity between the use of the term 'identity' in the interview data, and my use of the terms 'self' and 'identity' in the analysis.

As mentioned above, then, in many of the extracts (seven out of ten), I at some point explicitly introduce the term 'identity', asking respondents how they perceive the role of their condition in this regard. Whilst, in 5.2.3, I proposed intending my interviews to be somewhat participant-led, in the case of these extracts it is my contributions that elicit talk about illness in relation to self. This sometimes relates back to previous discussion of these issues at an earlier stage in interviews, but nevertheless, my introduction of this

theme must be taken into account when interpreting the data. Additionally, in asking the respondents how they perceive their condition, “it”, as fitting within their conception of self, in my questioning I am addressing illness as an entity which can be separated from selfhood, and thus *reifying* the two conditions. However, respondents’ orientation to my questions, and the representations of their condition that they produce, can be seen to align with this construction.

The *bodily experience* of illness will be shown to play an important role in the construction of the illness-selfhood relationship. The role of the body in illness experience has been discussed and debated by several researchers in the field (Frank, 1996; 1997b; Radley, 1989; 1997). Kelly and Field (1996: 251) propose that ‘the body is central to both the experience and feelings associated with illness...it is the point of immediate salience for self’. In the case of some of the extracts that will be presented in this chapter, it is not the direct bodily experience of symptoms and pain that is given salience, but the impact that bodily restrictions resulting from illness can have upon respondents’ lifestyle activities and self-presentation, and this will be shown, in some cases, to influence the construction of the illness-selfhood relationship. However, the body is commonly left implicit in the accounts that will be analysed here. Cross-condition disparities will be shown to be apparent vis-à-vis this indirect role that the body plays in the construction of self. Whilst across the analytic chapters there will inevitably be some overlap in places, in this chapter I will not address issues of respondents’ *control* over the bodily experience of illness and its subsequent effects on lifestyle activities, as this will be the focus of Chapter 8: ‘Negotiating Control’. Chapter 8 will also investigate representations of the body in terms of the bodily practices respondents engage in in their management of illness, principally drawing upon Balfe’s (2009) ‘body projects’ framework.

### **6.1 Representations of T1DM**

The first extract comes from an interview with Timothy, aged 23, who had been diagnosed with T1DM for nine years. At the time of the interview, he was working fulltime as a hospital pharmacist. Timothy (T) will be shown to represent T1DM as occupying a prominent role within his self-concept, a role which he constructs very

positively. Through this representation, he is able to foreground identities aligning with culturally-accepted models of moral-appropriacy. This extract is taken from the very beginning of the interview (see Appendix K; Interview 1: lines 1-28):

Extract 1:

1. BS: okay first of all I'll start with quite a broad question (.) how do
2. you feel the role of diabetes (.) um (.) fits within your overall life and
3. your overall sense of identity? (2.0)
4. T: uh (.) at the moment I'd say (.) yeah it is (.) yeah it's definitely part of my
5. identity now (.) um (.) I consider it part of me and I wouldn't have it uh any
6. other way now (.) because it's made me become a really healthy person (1.0)
7. BS: so you feel that it's had a positive (.) effect?
8. T: [very positive effect (.) yeah (.)
9. BS: oh right (.) how do you feel it's had a positive effect on you? (.)
10. T: uh (.) because it made me be aware of (.) uh be a bit more aware of my body
11. (.) um be aware to take care of myself more and to exercise more and to have
12. the correct diet (.) not only a good diet but the correct diet (.) uh (.) and that's
13. it (.) I've always been good at er (.) taking insulin and such (.) since I was
14. diagnosed when I was fourteen (.) but (1.0) over the years it was just as part of
15. a duty (.) but now it's more uh (.) less of a duty and more of doing it to look
16. after yourself (.) so yeah definitely a positive influence (.) and I find it (.) uh
17. (.) part of me (.) and I wouldn't have it any other way (1.0)
18. BS: have you always felt this way? (.)
19. T: no (.) no (.) only in the last couple of years (.) since um (.) uh (.) yeah only in
20. the last couple of years yeah (1.0)
21. BS: how did you feel it affected you previously? (1.0)
22. T: um (1.0) what do you mean? (.)
23. BS: in terms of did you view it more negatively previously?
24. T: [not really I just ignored it
25. (1.0) I just ignored it but uh took the uh took the doses but just ignored it (1.0)
26. and that's it really just ignored it and didn't think about any of the



27. consequences (.) didn't think about (.) uh I thought it would sort itself out (.)  
28. that type of thing (.) just an immature (.) [BS: mm mm] look on it (.)

In lines 1-3, I explicitly ask Timothy about the role of T1DM in relation to his conception of self, to which he emphatically responds that he presently views T1DM as being an important aspect of his self-concept (4-5). He represents this role as being very positive: 'I wouldn't have it uh any other way now' (5-6). This is unlikely to be intended as an outright rejection of a non-diabetic identity through Timothy proposing that he would prefer to have T1DM rather than not, because, as Frank (1995) notes, even in relation to the most positive representations of illness experience, 'any sane person' would rather *not* have a chronic condition (1995: 135). It is more likely, I would argue, that Timothy is proposing that, *within the context of living with T1DM*, he chooses to afford the condition a greater role within his self-concept, rather than a lesser role, or no role at all. The adverb 'now' (6) implies that, whilst being his present representation, Timothy has not always perceived his condition in this way.

The reason Timothy gives for this positive representation is that having T1DM has been beneficial to his overall health: 'it's made me become a really healthy person' (6). This appears quite counter-normative, as chronic illness is usually associated with deterioration in health, as opposed to health benefits. This self-description may therefore be quite unexpected, with the adverb 'really' perhaps suggesting a level of health *beyond* that of just a 'healthy person'. Timothy proposes that these beneficial health effects have resulted from him becoming 'aware to take care of myself more' (11) in relation to health issues such as diet and exercise (10-12). Whilst not explicitly stated, we can infer that this awareness has been gained as a result of Timothy paying closer attention to diet and exercise in order to manage his blood-sugar levels. It could be speculated that this kind of representation may be unique to T1DM, because of the emphasis that is placed on exercise and healthy eating in order to manage the condition. The adverb 'more' (11) suggests that, previous to the positive influence of T1DM, Timothy did not take care of himself to the same degree in relation to these areas of health. Whilst these positive health benefits are an *indirect* result of the influence of his condition, with Timothy's own actions being required to convert this greater awareness into improved health, his

construction of T1DM as having ‘made him’ (6) become really healthy, frames T1DM as having *directly* caused this positive benefit, thus heightening the positivity he attaches to the condition.

In line 10, Timothy explicitly addresses his body: ‘it made me...be a bit more aware of my body’, demonstrating an exception from the point I made above about the body remaining implicit in the accounts explored in this chapter. Timothy reifies his body here; however, again this functions to represent the *positive* influence of T1DM upon his general health, as opposed to the body being reified due to symptoms or treatments having adversely affected his body, or having heightened his awareness of his body in a negative way, as has been observed in previous research (see Bury, 1982; Cassell, 1976; Gwyn, 1996; Radley, 1993).

In Timothy’s construction of what Balfe (2009) would term his ‘healthy body’, then, he appears to be constructing his general health as being *separate* from his T1DM-related health, allowing him to represent himself as being ‘really healthy’, *in spite of* being chronically-ill by medical definition. Timothy is thus able, in this context, to foreground his T1DM-related identity as being a prominent aspect of his self-concept, but avoid performing an identity as somebody who is ill, thus negotiating identities which appear conflicting, and in fact representing these as being somewhat complementary.

These representations clearly show Timothy *integrating* T1DM within his self-concept, and through this he can be seen, in Charmaz’s (1991) terms, to ‘embrace’ his condition. This, she argues, goes beyond simply accepting the condition, but is where those with illness ‘welcome it...they take their images of self from it’ (1991: 65).

Timothy’s representation of the ‘preferred’ identity (Riessman, 2003: 8) as somebody who is healthy, and who takes good care of himself in relation to diet and exercise, aligns with cultural models of moral-appropriacy, appearing to draw upon ideological schemas that, within Western society, those who are pro-active and responsible with regard to personal health are looked upon positively. Through these representations, then, Timothy is ‘employing ideological themes which ‘naturalise’ the world’ (Radley and Billig, 1996:

223). I am not suggesting that Timothy's positive representation of the role of his condition within his self-concept is in anyway inauthentic, but that this identity-work is 'situated and accomplished' (Riessman, 2002: 27) within this particular interactional context, with his representation of integrating his condition within self functioning as a *resource* in this identity-construction.

Timothy's representation of moral-appropriacy is furthered through the construction of a 'contrast' structure, in lines 13-17, between the present role of T1DM within his self-concept, and the role he afforded the condition during adolescence. Timothy does not represent himself as having neglected his self-care practices at a younger age, assuring that he has always been proficient in 'taking insulin and such' (13). This suggests, then, that the physical-management of his T1DM has not changed during this time, at least in terms of administering insulin; however, his *perception* of these self-care practices *has* changed, from previously seeing these as being 'just...part of a duty' (14-15), to now viewing them as positive measures taken in order to stay healthy (15-16). This shift in perception towards self-care between adolescence and young adulthood is reported by several T1DM-respondents in the corpus (see for instance, Linda: Interview 5; Mitch: Interview 16). It could be that this is a predictable shift brought about by the transition into young adulthood (see 1.2), during which time individuals 'leave behind so-called youthful freedom and begin to take responsibility for different aspects of their lives' (Raymore, Barber and Eccles, 2001: 198), with this awareness regarding T1DM self-care being an example of such responsibility. Although not commented upon in Timothy's interview, it could be posited that his career as a hospital pharmacist is likely to also have influenced this shift in perception towards greater importance being afforded to health and medical treatments.

Timothy further elaborates upon the contrast between his present and former selves, in lines 24-28, proposing that, at a younger age, he 'didn't think about any of the consequences' of his T1DM (26-27). This suggests that Timothy did not associate adhering to his T1DM treatment-regimen with preventing future ill-health. Timothy represents his former, adolescent self as having *distanced* T1DM from his self-concept: 'I...took the doses but just ignored it' (25), marking a clear contrast with the close illness-

selfhood relationship constructed in the present. He represents his former self as having not fully understood the chronicity of the condition: ‘I thought it would sort itself out’ (27), a perspective which he now characterises negatively, as being ‘an immature...look on it’ (28).

The contrast Timothy constructs between his present and former selves can usefully be considered through the lens of Linde’s (1993) discussion of ‘life stories’ (see 3.3). Whilst Linde principally considers a life story as consisting of narratives recounting specific incidences or events from the past experiences of the narrator, Timothy’s construction can instead be considered to be a ‘habitual narrative’, which ‘tells of a general course of events over a period of time’ (Cheshire and Ziebland, 2005: 23). I would argue that a habitual narrative of this kind can certainly be considered as part of Timothy’s life story, clearly being used by Timothy to express his sense of self, and specifically to express the *temporal developments* in his self-concept.

Linde’s discussion of *reflexivity* in the life story is especially pertinent (see 3.3). Through contrasting the views of his present self with the ‘immature’ perspective (28) of his adolescent self, Timothy is able to separate himself from, and reflect upon, his former views, judging these as being morally-*inappropriate*. This allows him to project a positive identity as now holding a more morally-appropriate perspective towards his T1DM. Through this facet of his life story, then, Timothy is able to further support the construction of an identity as someone who has a mature, positive perspective towards his T1DM, and who takes good care of his T1DM-related health, and of his health more generally.

Extract 2 demonstrates similarities with Timothy’s account, with the respondent, Melanie, also largely representing her T1DM as *integrated* within her present self-concept. However, there will be shown to be differences between the two in how this role is constructed; thus, whilst Melanie’s representations also align with models of moral-appropriacy, these differ from the moral identities Timothy constructs.

Melanie (M), aged 28, had been diagnosed with T1DM for four years. At the time, she was studying for her undergraduate degree in dietetics at university (see Appendix K; Interview 21: 124-146):

Extract 2:

1. BS: the way you feel now [M: mm] (.) and when you think
2. about your life and your overall identity do you see it
3. [T1DM] as being quite prominent or playing quite a big
4. role? (1.0)
5. M: er yeah I do think it plays (.) I think it plays a big role but I
6. think (.) as much as anything (.) I think that's because of
7. what I've chosen to do like doing my nutrition and dietetics
8. degree (.) now because of (.) the fact that I have diabetes like
9. originally (.) I just wanted (.) well I sort of you know I got
10. quite obsessed with my diet (.) and that sort of led me to like
11. you know being interested in in diet (.) and then (1.0) but
12. also I've kind of well I thought you know if I could become a
13. dietician then I could help other people in the same situation
14. (.) as I was in (.) so um (.) so I think in that respect like it is a
15. huge part of my life (.) and also you know like I'd (.) I don't
16. do many things without thinking about it (.) without you
17. know having to (.) plan something around it like even if it's
18. just you know (.) I dunno making sure I've got my insulin on
19. me when I go out or making sure I've got something to eat
20. when I go out (1.0) so it's always in the back of my mind (.)
21. so I do think it is quite a big part of who I am (.)
22. BS: mm (1.0)
23. M: but it doesn't define me

When questioned about the role of T1DM within her life, and within her self-concept (1-4), Melanie proposes that she sees T1DM has having a 'big role' (5), this phrase

mirroring the construction in my initial question. She purports that one reason for this 'big role' is 'because of what I've chosen to do' (6-7), talking of how she is currently studying to become a dietician. The verb phrase 'I've chosen' emphasises *agency* on Melanie's part, that it is as a result of her active choice that she presently represents T1DM as big part of her self, rather than because of the direct influence of the condition upon her. In framing her initial response, the conjunction 'but' and subsequent statement 'I think (.) as much as anything' (5-6), perhaps suggest that Melanie more commonly associates T1DM having a 'big role' in one's self-concept with contributing factors *other* than its influence on one's career, or perhaps expects that I would hold this presupposition.

Whilst framing her decision to begin a dietetics degree as an active choice, she does indirectly attribute this decision to the influence of her condition. She proposes: 'because of (.) the fact that I have diabetes...I got quite obsessed with my diet' (8-10). The adverbial phrase, 'obsessed with', has negative connotations, being associated with taking something too far, perhaps suggesting that her condition 'originally' (9) had a *negative* influence upon her. Melanie proposes, however, that this 'obsessive' attitude towards *her own* diet resulted in an 'interest in' (11) diet more generally, which appears to have more positive connotations. Whilst citing this interest in diet as influencing her decision to study dietetics, she proposes that this choice was also prompted by her wish to help other people with T1DM to manage the dietary issues related to their condition (13).

Melanie therefore represents herself as having gained something positive from having T1DM by putting her experiences to good use, both in pursuing her interest in diet, and through helping others. This construction exemplifies Frank's (1995) 'quest narrative', representing Melanie as 'making significant vocational and personal changes in [her] life following illness' (Frank, 1995: 116), again taking the form of a habitual narrative. Similarly to Frank's observations, Melanie represents herself as gaining 'insight that can be passed on to others' (1995: 118); however, whereas Frank frames such insight as being 'given' to the ill person, Melanie represents herself as actively pursuing this insight through her dietetics degree, with her condition having only indirectly led her to this. This construction of illness as a 'quest' draws upon cultural and ideological schemas aligning

with models of moral-appropriacy, as here Melanie is able to perform a positive identity of altruism and unselfishness, through proposing her wish to help others with T1DM.

A comment from earlier in her interview, however, superficially appears to contradict my interpretation of this construction, as Melanie describes the motivation for pursuing her degree as 'pretty selfish reasons (laughs)' (Appendix K; Interview 21: 68). I would contend, however, that this is intended as humorous, and non-serious, as signalled by her subsequent laughter. She is perhaps attempting here to dispel the potential inference that she is *trying* to portray herself as altruistic, which could have the opposite effect of resulting in a negative identity-performance, as publicising one's good intentions is often regarded as *morally-inappropriate*.

Through constructing this association between her positive career choice and her T1DM, similarly to Timothy (Extract 1), Melanie represents herself as 'embracing' her condition (Charmaz, 1991: 65). She thus constructs a close relationship between illness and selfhood at this juncture, at least in respect to this lifestyle area: 'so I think in that respect like it is a huge part of my life' (14-15).

As well as representing her career choice as influencing the role she affords T1DM within her self-concept, Melanie cites the impact of her condition upon her daily life: 'I don't do many things without thinking about it (.) without...having to (.) plan something around it' (15-17). She exemplifies this planning by talking about how she must ensure she has insulin and food with her when she is out (17-20). The problematicity of these particular issues is mitigated, however, through the preceding phrase: 'even if it's just' (17-18). It could therefore be argued that Melanie's contention that her condition influences her daily life is not necessarily due to T1DM causing her to significantly change her lifestyle, but is due to the *constant* nature of its influence: 'so it's always in the back of my mind' (20). This representation aligns with Charmaz's (1991: 42) notion of illness as an 'intrusion' in that the condition requires consistent management and attention.

Whilst ‘intrusion’ appears adequate in describing Melanie’s latter construction (15-21), the negative connotations attached to this term are inconsistent with Melanie’s earlier, positive construction of T1DM in relation to her career choice, supporting the argument I put forward in 2.3, that this concept is too narrow to categorize someone’s entire account of illness, as Charmaz attempts to do.

The representation of the influence of T1DM upon Melanie’s daily life therefore demonstrates disparity with the first part of her extract (5-15). Although throughout, Melanie represents T1DM as having a prominent role within her self-concept, in representing the influence of T1DM upon her daily life she does not construct the same degree of choice and agency regarding her integration as in relation to her career choice. In reality, Melanie could choose to adhere less stringently to her T1DM treatment-regimen, and as a result these planning issues would not have as great an impact upon her daily life. However, other parts of Melanie’s interview represent this, not as being a choice, but something she *has* to do in order to stay healthy. One example is where Melanie is discussing how she has heard of some people with T1DM neglecting their self-care in order to lose weight: ‘I’m far too sensible for that (chuckles)...I feel like having my feet (.) you know...and both my kidneys’ (Appendix K; Interview 21: 803-805). In spite of the humorous adverbial phrase ‘I feel like’ implying agency, Melanie here displays clear recognition that, if she is to avoid the risk of experiencing serious future health consequences, she does not have a choice but to adhere to her treatment-regimen.

Having constructed T1DM throughout as having a prominent role within her self-concept, in line 23, Melanie mitigates this representation somewhat: ‘but it doesn’t define me’. This implies that T1DM does not constitute the *main* facet of her self-concept, but just one element constituting her selfhood. Melanie is therefore attempting to avoid representing her selfhood as being entirely entwined with her condition, thus rejecting an identity solely formed around T1DM, an identity which could be perceived as negative.

The findings vis-à-vis Timothy’s and Melanie’s respective accounts extend those of research which considers chronic illness experience principally in terms of ‘loss’. In these



accounts, illness has not caused 'a crumbling away of former self-images without the simultaneous development of equally valued new ones' (Charmaz, 1983: 168), which Charmaz (1983) terms 'loss of self', or a 'major kind of disruptive experience' (Bury, 1982: 169), as proposed by Bury's (1982) 'biographical disruption' (see 2.3 and 2.4, respectively). Instead, Timothy's and Melanie's accounts suggest *gains*, an improvement in their lives, at least in some respects, as a result of chronic illness. This finding is similar to that reported by Asbring (2001) vis-à-vis experiences of chronic fatigue syndrome, who talks of individuals experiencing intangible 'illness gains' such as changes in values, insights into self and increased understanding of illness. Here, however, the gains constructed by Timothy and Melanie *are* tangible. We can therefore talk of both respondents having *gained positive images of self*, in Timothy's case a better awareness of general health, and for Melanie, a positive career choice; however, it is important to note that Melanie does not talk entirely of gain.

However, these findings certainly do not conflict with notions of 'loss of self' or 'biographical disruption', but may reflect variation in experiences at different junctures within the overall illness trajectory. Timothy, for instance, proposes that he only discovered gains after several years of having lived with T1DM. It could therefore be the case that these two respondents initially experienced a degree of 'biographical disruption' or 'loss of self', but have moved past this disruption, and have been able to reconfigure their conceptions of self in learning to live with their condition. This is certainly the case vis-à-vis Melanie's reported experiences, as earlier in her interview she constructs a narrative about a holiday she went on shortly after being diagnosed (Interview 21: 107-121), during which the disruption caused by her T1DM resulted in her having 'the most miserable time' (112-113). Since her diagnosis, then, Melanie can be seen to have achieved the 'development of new images of self' (Charmaz, 1983: 170), and to have responded to the disruption caused by illness through the 'mobilisation of resources, in facing an altered situation' (Bury, 1982: 168).

These constructed gains can also be considered in relation to the theory of *transformation*, as discussed by Paterson, Thorne, Crawford and Tarko (1999) (4.1.1). Both Timothy and Melanie represent themselves as having 'restructure[d] the self and the

illness experience' (1999: 786) in a positive way, especially Timothy, who outlined an explicit transformation through the contrast between his present and former selves.<sup>9</sup>

For some respondents with T1DM, there is a greater tension in their construction of the relationship between illness and selfhood. In Extract 3, Polly will be shown to represent the role of T1DM within self in a more negative way than both Timothy and Melanie, leading her to both integrate *and* distance her condition vis-à-vis her self-concept. Polly will be shown to use various strategies to warrant her negative account, as a way of avoiding a negative identity-performance.

Polly (P), aged 20, had been diagnosed with T1DM for eight years. At the time, she was studying for a degree in nursing at university (see Appendix K; Interview 17: 41-136):

Extract 3:

1. BS: okay (.) so when you think about your diabetes now do you
2. see it as playing a big role in your life?
3. P: [yeah (.) a massive role it's
4. such a pain (chuckles) (.) I think it's changed since (.) when
5. I was in year thirteen I would've been (.) eighteen (.) I had (.)
6. after ((I fixed some dinner)) I came home and in the morning
7. (.) luckily I had a friend staying over but that was the only time
8. I had a really bad hypo (.) and like I didn't know I was hypo and
9. like luckily I set my alarm clock 'cause my friend was working
10. the next day (.) and I didn't turn it off 'cause I couldn't (.) and
11. she couldn't work out she just like thought that I was really
12. hung over (.) and she was going 'P I'm going now' ((and I said

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<sup>9</sup> Whilst in these extracts Timothy and Melanie present different 'rewarding outcomes' (Paterson et al., 1999: 786) resulting from this transformation, in another part of Melanie's interview, she too represents *gains* in relation to improvements in her general health as a result of T1DM. She discusses how, due to the health implications surrounding T1DM, she has stopped smoking and reduced her alcohol-intake, which she frames as positive changes (see Interview 21: 159-163).

13. 'oh I'm sleeping')) (.) so she went and my dad came in and he was  
14. like 'P turn off that alarm clock it's doing my head in' (.) and I  
15. was just like 'oh just leave it' I couldn't (.) and then like my  
16. parents were going to (place name omitted) and at the time we  
17. lived in (place name omitted) so it was like a two and a half hour  
18. drive away (.) and they got in the car and everything apparently  
19. and my dad said to my mum oh 'P seems a bit funny' but (.) I  
20. don't think he thought it 'cause I'd never had anything like that  
21. before (.)
22. BS: mm mm (.)
23. P: and I haven't since touch wood so (.) my mum just (.) she was  
24. probably a bit more on the ball being a GP and stuff so she  
25. came to check and I was just like (.) I can't really remember  
26. properly (.) but I can remember like (.) my dad was beside the  
27. bed and my mum was beside the bed and (.) my mum had a  
28. cup of like (.) Sprite and she was trying to get me to drink it  
29. I was just like 'urrghh' (.) I was trying to turn off this alarm clock  
30. it was annoying me so much and I was like (.) there was a little  
31. flick switch at the back (.) and I just couldn't do it and I  
32. remember squeezing it like that and going 'arrghh shut up' (.)  
33. and like (.) I'm quite a daddy's girl so I'm used to my dad being  
34. nice to me no matter what (.) and my mum was just nagging me  
35. going 'P drink this Sprite' and I was just like 'leave me alone' but  
36. then I remember my dad being like 'P (.) you've got to drink it'  
37. (.) and that's like I remember being like (putting on an upset  
38. voice) 'why are you being so horrible to me?' (chuckles)
39. BS: [(chuckles) (.)
40. P: and then for some reason something clicked in my brain I  
41. probably just wanted them to go away and so I just downed this  
42. Sprite and then like within ten seconds well I don't really know  
43. how long 'cause I didn't really know what was going on (.) I  
44. knew then that (.) and I had the duvet over my face and I was

45. crying and going ‘leave me alone’ (.) and I thought my friend was  
 46. still there (.) I didn’t remember her going or speaking to me  
 47. apparently she spoke to me (.) and that was my main thing I  
 48. was like (putting on upset voice) ‘don’t let (name omitted) see me  
 49. don’t let (name omitted) see me’ (chuckles)  
 50. BS: [(chuckles) (.)  
 51. P: and then (.) my mum was like ‘do you want me to stay I don’t  
 52. have to go to (place name omitted)’ and I was like ‘no go go  
 53. (.) but then after (.) the next day after I was it was such a shock  
 54. ‘cause I didn’t really know and then the next day I spoke to my  
 55. mum and I was like crying and stuff and like I dunno just  
 56. really (.) I was actually so frightened (.) it was really scary that  
 57. it could (.) if they hadn’t got out of the car what would’ve  
 58. happened (.)’cause you probably know like if you have a really  
 59. bad hypo it can cause like brain damage and stuff (.)

Polly initially expresses quite emphatically that she sees her T1DM as having ‘a massive role’ within her life (3), a role she represents as being quite negative: ‘it’s such a pain (chuckles)’ (3-4). Though this formulaic phrase could imply that the condition is more of an irritant or inconvenience than something Polly finds very troubling, I would contend that this phrase and the subsequent chuckle demonstrate ‘troubles-resistance’ (Jefferson, 1984: 360). This allows Polly to project that the ‘trouble is not getting the better’ of her, and that she is ‘in good spirits’ (1984: 360), in spite of the fact that her condition may in fact be quite troubling to her, an interpretation supported by Polly’s subsequent narrative.

Polly proposes that a temporal change has occurred vis-à-vis the role of T1DM within her life since a few years earlier (4-5). Before explicitly outlining the nature of this change, Polly produces a lengthy narrative (4-59), recounting an incident that occurred a few years previously, which she represents as directly resulting in her change in perception towards her T1DM. Polly uses several rhetorical devices in constructing the events within this narrative as being particularly grave and serious, in order to warrant her present, negative construction of her T1DM which follows (60-81, presented below).

In this narrative, which includes all of the elements of Labov and Waletzky's (1967) classic structural model, Polly recounts experiencing a serious episode of hypoglycaemia (see Appendix A), during which she was unable to communicate or function properly; but thankfully her mother, being a GP, noticed the signs, and her parents managed to get her to consume a sugary drink in order to raise her blood-sugar levels to within the safe-range.

It is the evaluative elements of this narrative which constitute the rhetorical force behind Polly's representation. This includes 'simple external evaluation' (Labov and Waletzky, 1967): 'I was actually so frightened (.) it was really scary that it could (.) if they hadn't got out of the car what would've happened (.)'cause you probably know like if you have a really bad hypo it can cause like brain damage and stuff' (56-59). These evaluative elements function as a 'comparator' (Gwyn, 1996: 132, see 3.4), enhancing the gravity of the recounted scenario, through proposing that the incident could have had a far more serious result. Polly's evaluation of her reaction to the incident the following day: 'I was actually so frightened (.) it was 'really scary' (56), emphasises her distress regarding the potential scenario that she could have suffered brain damage.

Polly further enhances the drama and gravity of her narrative through other linguistic choices made in the telling. She uses direct reported speech on several occasions, for instance, in lines 34-38: 'and my mum was just nagging me going 'P drink this Sprite' and I was just like 'leave me alone' but then I remember my dad being like 'P (.) you've got to drink it' (.) and that's like I remember being like (putting on an upset voice) 'why are you being so horrible to me?'''. This appears to be presented as a directly reported exchange, as the use of 'like', used here on four occasions, has been found to be a conventional way of framing direct reported speech, especially in the case of younger speakers (Dailey-O'Cain, 2000). Polly uses direct reported speech on three occasions during this sequence, allowing her to 'offer the audience a feeling of direct experience' (Hamilton, 1998: 63). This makes the narrative appear more real, heightening the drama. Additionally, presenting her parents' speech functions to convince me, as her fellow interlocutor, that Polly's representation of this event, as very serious and potentially

dangerous, was shared by her parents at the time of the incident. She is thus able to ‘recruit voices and authenticate different versions of events’ (Arribas-Ayllon et al., 2008: 1524). I would argue that constructing her narrative in this dramatic way enables Polly to account for what could be viewed as a negative or ‘regressive’ (Kelly and Dickinson, 1997: 261) shift in her perception of her condition, a shift marked by ‘deterioration...which does not reach a satisfactory solution’ (Kelly and Dickinson, 1997: 261). In Scott and Lyman’s (1968) terms, this can be viewed as an ‘excuse’, as Polly is ‘denying full responsibility’ (1968: 47) for this regressive shift, enabling her to guard against the potential negative identity-performance that could be associated with such a representation, though at this point she is yet to explain the nature of this change in perception.

For the next fourteen lines, which continues from Extract 3 above, Polly discusses having recounted this experience to her school teacher, and then continues:

Extract 3 (contd):

60.           yeah so since that (.) to go back to your original question (.) it (.) does  
 61.           (.) I think about it all the time (.) for about six months after that I used  
 62.           to wake myself up about twice in the night and do a BM<sup>10</sup> just to check  
 63.           that it wasn’t going low or anything (.) but (.) I don’t do that  
 64.           anymore and I do wake up if I go hypo (.) I decided it was just  
 65.           ‘cause I’d been drinking and stuff and I hadn’t had a snack when  
 66.           I’d come in (.) ‘cause you should always have snack when you  
 67.           come in (.) and um I was so ((     )) and there was no bread in  
 68.           the breadbin and I thought oh (.) fuck it I’ll just go to bed (.) and  
 69.           (chuckling) I don’t do that now (.)  
 70.    BS:   (chuckles) (.)  
 71.    P:    I’ve learnt my lesson (.) but yeah since then (.) I don’t know how  
 72.           to explain but I always (.) if I feel a bit funny but I don’t  
 73.           necessarily feel like I’m having a hypo I’ll be like right do a BM

<sup>10</sup>‘BM’ refers to carrying out a blood-monitoring test (see Appendix A).

74. do a BM (.) I do loads more BMs than I used to (.) everyday I do  
75. (.) every time before I eat and if I remember I'll do one  
76. afterwards as well everyday (.) and like when people ask me  
77. about it I'm more like (.) I used to be like 'oh it's life isn't it'  
78. (chuckling) you know (.) now I'm kind of like (.) 'yeah it's quite  
79. hard sometimes' (laughs) (.) but it is quite hard sometimes (.)  
80. BS: yeah (.)  
81. P: and I do get a bit depressed about it sometimes

Polly makes an explicit causal link between this reconstructed event and the shift in her perception of T1DM: 'so since that (.) to go back to your original question (.) it (.) does [have a big role within her life] (.) I think about it all the time' (60-61). It could be argued that, at this juncture, Polly's representation is moving towards Charmaz's (1991: 76) concept of 'immersion' in illness; as whilst there is no suggestion of Polly's life being entirely determined by illness, her condition *is* represented as having a significant, negative impact upon her. This is evidenced through a habitual narrative, in which Polly represents this experience as having resulted not only in a psychological change, but a change in her illness-behaviour, as she reports presently testing her blood-sugar levels far more frequently than she did in the past: 'I do loads more BMs than I used to (.) everyday I do (.) every time before I eat and if I remember I'll do one afterwards as well everyday' (74-76). The adverb 'loads', as well as the repetition of 'every', in 'every time' and 'everyday', signals consistent, frequent repetition of this routine. Whilst, in many instances, reporting consistent adherence to T1DM self-care practices would function to perform a morally-appropriate identity associated with responsible condition management, in the context of Polly's overall account it appears that she is constructing this as *over*-adherence, almost obsessive observance of these self-care practices. This habitual narrative thus functions to further highlight the profound effect that Polly's experience of hypoglycaemia has had upon her.

Polly further emphasises the shift in her perception of T1DM through meta-talk regarding how her self-presentation to others has changed: 'when people ask me about it...I used to be like 'oh it's life isn't it' (chuckling) you know (.) now I'm kind of like (.) 'yeah it's

quite hard sometimes' (laughs)' (76-79). The formulaic phrase 'it's life' implies that Polly previously presented her condition to others as just one of life's hardships, and not something that caused her any significant psychological strain, markedly contrasting with her current, more negative presentation. Her subsequent laughter again signals 'troubles-resistance' (Jefferson, 1984: 36), as a way of mitigating any potential 'face-threat' (Goffman, 1955: 215) that may arise from this admission that she now at times finds her T1DM hard to deal with. The orientation to interactions with others was something not found in Timothy's and Melanie's respective accounts. It is unclear why Polly chooses to report her self-presentation at this point, but this could perhaps reflect the salience Polly affords to her self-presentation to others in the formation of her illness-selfhood relationship.

Polly does also proceed to voice her perceptions directly: 'it is quite hard sometimes...and I do get a bit depressed about it' (79-81). This displays Polly's most explicit representation of the negative psychological effect of her T1DM upon her, though this is still slightly mitigated through 'quite', and 'a bit', again perhaps alleviating the potential face-threat of explicitly voicing negative emotions of this kind.

Analysis of this extract reveals a tension present, as through representing T1DM as having a 'massive role' (3) within her life, and significantly impacting upon her psychologically, Polly can be seen to *integrate* her condition within her self-concept, albeit constructing T1DM as having a negative role. However, through her expression of being 'frightened' (56) following her experience of hypoglycaemia, an emotion which she represents as influencing her present perceptions and behaviours, she constructs herself as being fearful of her condition, which could be seen as a form of *distancing* of her condition from selfhood. Polly can therefore be classified amongst what Kelleher (1988) terms 'worriers and agonizers' (1988: 150), individuals who have 'difficulty giving a stable meaning to their diabetes, and thus get depressed about their condition' (1988: 150).

Slightly later in her interview, discussing the same topic, Polly explicitly states that she is no longer 'scared' of her condition, contradicting the representations shown above



(Interview 17: 199). This proposition could, however, be intended to dispel the potential negative identity-performance associated with representing herself as fearful, with those who display fear commonly being perceived less positively than those who display courage and bravery.

It could be argued that, in Polly's case, the theories of 'loss of self' (Charmaz, 1983) and 'biographical disruption' (Bury, 1982) are relevant to representations of her present self. Polly constructs the loss of the self-image of somebody who performs a relaxed, easy-going identity to others, and who represents T1DM as not significantly affecting her: 'it's life' (77); and she has instead become somebody who is fearful, and who gets 'depressed...sometimes' (81). Whereas Charmaz (1991) would describe the distressing incident reconstructed in Polly's narrative as a 'turning point' causing a shift in self-perception, I would argue that this can also be conceptualised as biographical disruption. This is because, earlier in her interview Polly reports that although she was upset upon first being diagnosed, because of her young age she did not fully understand the implications of her condition (Interview 17: 13-30). Therefore, whereas Bury talks of biographical disruption occurring upon diagnosis, in Polly's case this disruption has been delayed, triggered by this distressing incident, which has led her to a realisation regarding the severity of her condition. Polly's account clearly demonstrates 'disruption in the structures of everyday life and the forms of knowledge which underpin them' (Bury, 1982: 169). Polly has not yet, however, been able to fully achieve what Bury characterises as a response to this disruption, which is the 'mobilisation of resources, in facing an altered situation' (1982: 168).

Polly's account demonstrates significant disparity with the account produced by Steve in Extract 4. Steve *distances* T1DM from self, proposing that his condition has *not* impacted upon the conception of self he held prior to the onset of illness, and in doing so he constructs a heroic identity.

Steve (S), aged 22, had been diagnosed with T1DM for just over six years. At the time of the interview, he was living in a house with two friends, and studying for a PhD at university (see Appendix K; Interview 2: 456-491):

## Extract 4:

1. BS: okay (.) um you talked a little bit (.) about your views a few years ago when  
2. you were first diagnosed [S: mm] (.) and (.) obviously yourself now (1.0) can  
3. you sort of elaborate a little bit about the way that that your view (.) towards  
4. your diabetes might have changed and how maybe you viewed it differently (.)  
5. in terms of fitting into your identity in the past to now and how your management  
6. has changed? (.)
7. S: hmm (.) identity is a word that doesn't (.) doesn't automatically spring to mind  
8. (.) I have to say and that's (.) um (2.0) I mean that whole I mean like at the  
9. start (.) when I first had it (2.0) I was probably the first person (.) in the family  
10. just as (.) everyone else around is (.) panicking a bit wondering what on earth  
11. all this means (.) I just ((sort of)) shrug it off get on with it (.) if you like and  
12. um (1.0) at the start (2.0) particularly because of the insulin I was on I'd been  
13. really (.) really careful (.) and I was extremely strict with myself about  
14. monitoring blood sugar as often as possible (.) and so on and (2.0) now I  
15. guess (1.0) it's no one great sort of then and now but it's been a gradual  
16. transition to (.) being (1.0) a lot (.) I wouldn't say less strict with myself I do  
17. (.) very very little blood testing (.) I know when I'm beginning to go a bit high  
18. on blood sugar and I certainly know about it if it's going low (1.0) um (.) I've  
19. relaxed my eating (.) plans and probably (.) that was the one instantaneous  
20. thing with changing the insulin I suddenly realised ah I can now (.) I'm at free  
21. will to do this (.) um (3.0) I struggle with this identity thing though (.) um (.)  
22. 'cause (.) like if (1.0) somebody was to go up to you and say (.) describe  
23. yourself (.) or whatever (.) the word diabetic wouldn't come to mind very  
24. quickly (.) um (.) it would be a secondary issue (.) really (.) I don't think (2.0)  
25. I don't think I myself have particularly changed (( )) or outlook or (1.0) the  
26. way I would want people to perceive me has changed as a result of being  
27. diabetic (.) cert- (.) certainly there are people (.) who would have a condition  
28. (1.0) and it would become a sort of controlling factor they'd want everybody  
29. to know about it (1.0) not (.) from a sort of care point of view but just from a

30. (.) wow look how well I'm doing (1.0) point of view (.) look how careful I (.)  
31. have to be (.) or (.) worse still (.) look how bad I've got it (.) um and they use it  
32. as a sort of bargaining tool if you like just to get you know a bit of sympathy (.)  
33. none of that comes to mind it doesn't bother me I don't mention diabetes  
34. unless I think it's to the advantage of (1.0) if I pass out (.) basically (.) that's  
35. the only that's the only reason I'd mention it really (.) it's not a (.) it's not that  
36. sort of thing it's not an identity thing at all

This extract begins with a complex question construction, where I pick up on a temporal shift Steve introduced earlier in the interview regarding his perception of his condition (1-6). In his response, Steve orients to my use of the term 'identity': 'identity is a word that doesn't...automatically spring to mind' (7). This opening exchange exemplifies my 'active' role, as my use of this term presupposes that Steve will perceive T1DM as forming some facet of his self-concept. Steve's response challenges this presupposition, highlighting a mismatch in our joint-construction of reality (Holstein and Gubrium, 1997), as it appears that, in Steve's representation, T1DM does not have great significance in relation to issues of self.

Steve draws on several discursive resources to *distance* T1DM from his self-concept. He uses a 'contrast' structure, in lines 8-11, to draw a distinction between his reaction to being diagnosed with T1DM and that of his family, describing them as 'panicking a bit' (10), whereas his reaction was less pronounced, and he was able to just 'shrug it off get on with it' (11). Steve thus demonstrates that, since the very beginning of his illness experience, his T1DM has not had a major impact upon his selfhood. Through this other-oriented contrast, Steve performs a positive moral identity as being calm and unflustered, and therefore could be interpreted as drawing upon ideological schemas that those who carry on with their lives as best they can, in spite of any hardships, are seen as behaving in a morally-appropriate manner. Through being described as 'panicking', however, Steve's family are represented as 'behaving in a less competent, or less morally-appropriate manner' (Cheshire and Ziebland, 2005: 25). It can be argued that Steve's experiences are here being 'presented through a lens of what to [him] are integral aspects of [his] personal identity' (Cheshire and Ziebland, 2005: 26). Steve is thus able to

perform a 'preferred' identity aligning with his desired self-concept, one which challenges, and marks the rejection of, an illness-identity.

Steve proposes that a 'gradual transition' (15-16) has occurred in his T1DM-management, from when he was first diagnosed and was 'extremely strict...about monitoring blood sugar as often as possible' (13-14) to the present, in which he does 'very very little blood testing' (17). This representation again allows Steve to *distance* T1DM from his conception of self, through constructing his treatment-regimen as having a minimal role within his life. At the same time, however, he attempts to avoid charges of being irresponsible in his T1DM-management. He does this firstly through avoiding framing his past and present behaviours as being diametrically opposed, stating in relation to his present behaviour: 'I wouldn't say less strict' (16). Also, he proposes that he is aware of when his blood sugars are going either above, or below, the recommended range (17-18). Through this, he implies that it is unnecessary for him to test his blood more frequently, and therefore his 'very very little blood testing' is *not* irresponsible, allowing him to avoid a potentially negative identity-performance.

Another argument Steve constructs in support of his representation of T1DM is that he does not feel he has 'changed', or his 'outlook' has changed, as a result of him having T1DM (25-27). Therefore, whilst previously Steve constructed a contrast between his present behaviour and that at any earlier point in his illness trajectory (12-21), here he compares his present self with his *pre-illness* self, constructing *similarity* between these selves. Whilst in relation to Extracts 1-3, I talked of chronic illness resulting either in 'loss of self', or the *gaining* of self, here Steve proposes neither has taken place, and thus he has not experienced the need to adapt his conception of self as a result of living with his condition. This reported consistency in self suggests that, in Steve's case, biographical disruption has *not* occurred, and instead his account aligns with Faircloth et al.'s (2004) concept of 'biographical flow' (see 2.4), whereby chronic illness is incorporated within the general 'flow' of events and experiences in a person's life. I would argue that, through representing his reaction to illness in this way, Steve provides further support for his morally-appropriate identity-performance as just getting on with life in an unflustered manner.

Steve also constructs his orientation to others: 'I don't think...the way I would want people to perceive me has changed as a result of being diabetic' (25-27). He is thus proposing that, not only has his conception of self not changed, but that the identities he wishes to project to others has also remained consistent with those prior to illness, suggesting he does not wish for others to view him *in relation to* his T1DM. This explicit orientation to the identities projected to others is not present in Extracts 1-3, with the exception of Polly's meta-talk vis-à-vis presenting her condition to others.

Steve emphasises this consistency both in his selfhood, and in his identity-projection to others, through again constructing a contrast, this time with hypothetical others who may have experienced a change in self as a result of having 'a condition' (27), but not specifying these as necessarily being people with T1DM. He proposes that these others may allow illness to become a 'controlling factor' (28), using it either to gain praise (30), or to elicit sympathy (32). This is distinguished markedly from Steve's own perceptions and identity-projections: 'it doesn't bother me' (33). Again here, Steve is constructing his *distancing* of illness from selfhood as being a morally-appropriate representation, and one which is 'in harmony with what [he] believes to be salient aspects of [his] personal identity' (Cheshire and Ziebland, 2005: 24).

His subsequent statement extends his argument further still: 'it's not an identity thing at all' (36), demonstrating some inconsistency with his earlier proposition that his T1DM is a 'secondary issue' (24), by suggesting that rather than T1DM having a peripheral role in his self-concept, it in fact has *no* significance in this regard.

Analysis of Extracts 1-4 has shown variation in T1DM-respondents' constructions of their illness-selfhood relationship. Timothy (Extract 1) and Melanie (Extract 2) largely *integrate* their condition within selfhood, constructing themselves as *gaining* positive images of self. Polly (Extract 3) predominantly constructs 'loss of self', through which she presents a tension between integrating and distancing, whilst Steve distances T1DM from self, representing consistency between his pre-illness, and present self-concepts. The ways in which these different representations are framed allows the four respondents

to respectively align with differing models of moral-appropriacy, and thus to construct largely positive identities.

## 6.2 *Representations of IBD*

Extracts from interviews with IBD-respondents will similarly be shown to display variation in the constructed illness-selfhood relationship, evidencing both integrating and distancing of IBD to varying degrees. The performance of morally-appropriate identities will again be shown to be salient.

Extract 5 is from an interview with Tara, aged 28, who had been diagnosed with Crohn's disease for seven years. At the time, she was living with her husband, and was working as a dental nurse.

Tara (T) will be shown to construct a close relationship between illness and selfhood, explicitly foregrounding her illness-identity as a prominent aspect of her self-concept. She performs a positive identity through representing this constructed-relationship as an aspect of her developed maturity (see Appendix K; Interview 27: 520-544):

Extract 5:

1. BS: so would you say that there's been a change (.) over the time
2. that you've had the Crohn's over the years (.) the way you've
3. viewed it and the way you manage it? (.) do you think the role
4. it plays in your life has changed at all? (.)
5. T: yeah I think so the older I've got as well because (.) yeah the
6. older I've got the better it's got (.) 'cause I don't know it's
7. almost as if I've matured into it (.) and I can deal with it now
8. (.) 'cause I've got over all my kind of (.) you know find out
9. who you are (.) I've managed to find out who I am with
10. Crohn's now (.) I'm a happily married lady who's got Crohn's
11. (.) and that's who I am (.) I deal I deal with it everyday (.) but

12.           yeah I think I have changed I was (.) I dunno I almost rebelled  
13.           against it when I first had it (.)  
14.    BS:     right (.)  
15.    T:     and (.) 'cause when they first got me settled down after I'd  
16.           first been on the steroids I didn't really watch what I was  
17.           eating and I did literally just eat what I fancied and didn't take  
18.           any notice of it and then I think that's why I used to go round  
19.           in circles (.) sometimes I was fine and then I was really ill (.)  
20.           it wasn't 'cause I just didn't take any notice (.) and I almost did  
21.           just ignore it (.) and then the older I get I think (.) when I was  
22.           in hospital I realised quite how ill I was and the fact that I  
23.           didn't wanna be that ill again even though I know that at some  
24.           point in the future I'm gonna be (.) 'cause that's just the way it  
25.           goes (.) I just didn't wanna be (chuckling) quite that sick again

The opening question here differs from those in the extracts in section 6.1, in that the term 'identity' is not explicitly introduced. Instead, I ask Tara whether her perception and management of her Crohn's disease has changed in any way during the course of her illness trajectory (1-4). Tara proposes that a temporal shift has occurred: 'the older I've got the better it's got...it's almost as if I've matured into it (.) and I can deal with it now' (5-7). This suggests that greater emotional maturity achieved through ageing has allowed Tara to become better equipped to 'deal with' the condition, the adverbial 'now' implying that previously she could *not* deal with it. Though left implicit here *what* she must deal with, this is discussed at earlier points in the interview as relating both to disease symptoms and treatment side-effects (see 1.3). This representation allows Tara to perform a positive identity, as maturity, and being able to 'deal with' one's hardships, is commonly considered as being morally-appropriate.

Tara subsequently explicitly orients to the theme of *self*: 'I've managed to find out who I am with Crohn's now (.) I'm a happily married lady who's got Crohn's (.) and that's who I am' (9-11). This demonstrates very overt construction of the relationship between illness and selfhood, with Tara foregrounding her illness-identity as a prominent aspect of

self, positioned only as secondary here to ‘happily married lady’. That her IBD-identity is part of the same phrase as this very positive identity: ‘happily married lady’, when considered alongside her positive proposition that she is now able to ‘deal with’ the demands of her IBD, suggests that Tara is not, at this point, representing the role of IBD within self as being particularly negative.

Tara displays explicit awareness of the *process* she has gone through in forming this close relationship between IBD and selfhood: ‘I’ve got over all my kind of...find out who you are...I’ve managed to find out who I am with Crohn’s now’ (8-10). Bury’s (1982) ‘biographical disruption’ is again very relevant, as Tara represents herself as having undergone a ‘fundamental re-thinking of...biography and self-concept’ (1982: 168), and ‘re-evaluation of the relationship between...disease and selfhood’ (1982: 172), which Bury argues is vital in adapting to living with a chronic condition. Tara contends that she has been able to form a new conception of self within which she has integrated her condition. The following statement: ‘I deal with it everyday’ (11), suggests, however, that this relationship is not entirely harmonious – ‘deal with’ appearing here to have negative connotations, especially when followed by ‘everyday’, which signals a continuous influence of IBD upon her life, framing IBD as an ‘intrusion’ (Charmaz, 1991: 42). This appears to demonstrate subtle contrast, then, with Tara’s earlier, more positive use of the same phrase, ‘deal with’ (7).

Tara discusses how this ‘fundamental re-thinking of...self-concept’ (Bury, 1982: 168) has come about, through contrasting her present perceptions of IBD, and subsequent illness-behaviour, with that of her self when first diagnosed. She displays reflexivity (Linde, 1993), condemning her previous self as having behaved in a morally-inappropriate manner, by not being careful regarding what she ate, and she proposes that she ‘didn’t take any notice...almost just ignored it’ (20-21). This claim, however, is mitigated slightly through ‘almost’, suggesting she did not, or was perhaps not able to, *completely* ignore it. Tara frames these behaviours as having been detrimental to her IBD-related health: ‘I think that’s why I used to go round in circles (.) sometimes I was fine and then I was really ill’ (18-19). She implies a shift in perception and behaviour vis-à-vis her present self, through proposing that, following a period of hospitalisation, she has come



to a realisation of the severity of her illness, and that she 'didn't wanna be that ill again' (23). Although Tara does not outline *how* her illness-behaviour is different in the present as a result of this realisation, it is implied that she now does *not* 'ignore' her IBD. Tara appears, then, to equate her change in perception of her IBD, and the closer relationship she now constructs between illness and selfhood, with a positive change in illness-behaviour, thus constructing her present self as being moral (Linde, 1993: 123) both in the way she now perceives, and behaves towards, her condition.

Tara's representation of IBD as having a prominent role within her self-concept is generally reflective of her interview as a whole. With this said, there is some variation in her representations, as in certain parts of the interview she *distances* her condition from her self, as a way of expressing frustration over the impact that IBD can, at times, have upon her lifestyle.

This can be seen in the following extract from near the end of the interview, just prior to which, Tara had been discussing the impact of her IBD on social activities, such as day trips with friends (see Appendix K; Interview 27: 703-711):

Extract 6:

1. T: you can guarantee pretty much that if you organise anything
2. you're gonna be ill on that day (.) (chuckling) you can pretty
3. much guarantee it [BS: (chuckles)] (.) without a doubt (.) you
4. can be fine for weeks and you'll be like yeah I can go out on
5. Friday (.) and then you're like oh my (( )) I can't go (.)
6. BS: yeah (.) I mean is that something that really frustrates you
7. then when that sort of thing happens?=  
8. T: =yeah (.) it does (.) it
9. gets (.) I almost feel like it's picking on me

Here, Tara's frustration at IBD preventing her from participating in desired social activities is expressed through a metaphorical representation: 'I almost feel like it's

picking on me' (9). Whilst demonstrating her recognition of the metaphorical nature of this construction through 'almost', she personifies her IBD, characterising it as a bully and tormentor that intrudes upon her lifestyle at the most inconvenient times. This representation of IBD, as an adversary of sorts, shows similarity with the findings of Gwyn (1996, see 3.4), aligning with the metaphorical representation of *illness is war*, whereby illness is represented as a hostile invader, something to be fought against. The metaphor Tara constructs is perhaps more akin to a schoolyard bully than the military metaphors Gwyn discusses; however, I would contend that this representation certainly resides within the same metaphorical domain. Tara's use of the second person pronoun 'you' on seven occasions, in lines 1-5, could be intended to represent her as part of an 'in-group' of those with IBD who share similar experiences, perhaps implying that others would construct similar representations of IBD as 'picking on' on them (metaphorical representations of illness as an oppressive enemy will be further explored in Chapter 8: 'Negotiating Control').

Though left implicit in this extract, it can be inferred that the reason IBD prevents Tara from participating in desired social activities at certain times is due to the *bodily limitations* arising as a result of disease symptoms.<sup>11</sup> This highlights the centrality of the body in Tara's experience of illness, and its influence upon her constructed illness-selfhood relationship. As Kelly and Field (1996) propose, 'when bodily demands conflict with desired self-presentation the individual becomes acutely aware of the divergence between body and self' (1996: 245). In Tara's account, it is the divergence between her body and self, as *caused by* her IBD symptoms, that leads her to represent illness as an adversary in relation to self.

Comparison of Extracts 5 and 6 therefore reveals a tension in Tara's constructed illness-selfhood relationship, demonstrating how, at times, she represents IBD as an integral aspect of her self-concept, and at others places her condition in opposition to self, thus shifting, at different junctures, between *integrating* and *distancing* her IBD from selfhood. However, the distancing observed in Extract 6 is not straightforward, as

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<sup>11</sup> Tara's experience of IBD symptoms is discussed explicitly during other parts of her interview. See for instance: Appendix K; Interview 27: 676-692.

although through representing her IBD as an adversary Tara can be seen to separate her condition from her selfhood, this does *not* in fact *conflict* with her construction in Extract 5 of IBD as being an integral aspect of self. It could be said, then, that Tara's account in Extract 6 represents IBD as being both *part of* her selfhood, and also as *acting upon* her self from outside. This tension shows similarity with that observed by Bury (1982), who proposes that 'a strict separation of disease and self...is precarious' (1982: 173), and that respondents in his study experienced an 'uneasy balance' between seeing their illness as an 'outside force', yet also as part of who they are (1982: 173).

In analysing Tara's account, I have 'strayed' somewhat into issues regarding *control*, as it is the *lack of control* Tara represents herself as having over her 'healthy body' (Balfe, 2009) and subsequently over her lifestyle, at certain times, that leads to the variation observed in her constructed illness-selfhood relationship. Whilst I earlier proposed keeping the themes of *self* and *control* separate for analytic purposes (see 5.3.3), the introduction of control issues was necessary here to support my argument vis-à-vis the construction of self, thus demonstrating the closely related nature of these themes. I will further explore issues surrounding condition control and lifestyle control in Chapter 8: 'Negotiating Control'.

Extract 7 demonstrates the respondent, Sally, aged 18, also representing IBD as occupying a significant role within her self-concept, displaying similarity with Tara's account in Extract 5. Sally does not represent herself as having a great deal of choice regarding this representation, thus demonstrating a lack of agency vis-à-vis her constructed illness-selfhood relationship.

Sally (S) had been diagnosed with Ulcerative Colitis (UC) for six years. At the time of the interview, she was living at home with her parents, having recently left college on medical grounds. Sally explained to me that she has struggled considerably with ill-health resulting from her IBD, and throughout her interview she represents IBD symptoms as having significantly impacted upon her lifestyle (see Appendix K; Interview 28: 844-857):

## Extract 7:

1. BS: okay (.) I mean when you think about (.) yourself as a
2. person (.) and your overall identity (.) where do you
3. see it [IBD] fitting? do you think it's (.) quite a big part of
4. who you are or?=  
5. S: =yeah it is (.)
6. BS: yeah=  
7. S: =yeah (1.0) and not always because I want it to be
8. BS: (.) mm=  
9. S: =but it just is it is (.) a part of who I am (1.0) and
10. like (.) like I said when I go to college it's something (.)
11. you know (.) you ((arrive)) at the college and you say (.)
12. you know I'm S and (.) I enjoy this I enjoy this and then
13. afterwards I've got to go and tell the teacher what I've got
14. so it's as much part of me as my hobbies are or (.)
15. anything like that so yeah

Though proposing that IBD forms a significant part of her self-concept (5), Sally constructs this role quite negatively: 'not always because I want it to be' (7). This suggests a *lack* of agency, whereby if Sally had the choice, IBD would occupy a lesser role, although the adverbial phrase 'not always' could suggest that there are some occasions when she may choose to afford IBD a significant role within selfhood; however, this is not elaborated upon.

In exemplifying the prominent role of IBD, Sally constructs meta-talk regarding how she self-presents to others upon first meeting them, within the context of introducing herself at college: 'at the college...you say (.) you know I'm S and (.) I enjoy this I enjoy this and then afterwards I've got to go and tell the teacher what I've got' (11-13). Presumably referring here to her self-presentation to peers or classmates, Sally proposes foregrounding aspects of her identity related to her interests, the things she enjoys doing. She states, however, that subsequently, away from this frontstage (Goffman, 1969: 109)

area, she will disclose to her teacher that she has IBD. The adverbial 'got to' (13) implies she does not have any choice regarding this disclosure. Sally explains in another part of her interview that this necessity to disclose her condition to her teachers is because of the possibility that she may have to take time away from college due to her IBD, or leave class without warning to use the toilet. This shows similarity with Tara's account (Extracts 5 and 6) in exemplifying the salience of bodily experiences in the construction of the illness-selfhood relationship. Whilst the representation of IBD-disclosure as 'backstage' (Goffman, 1969: 116) information, only revealed at this point to a responsible adult, and not to her peers, could be seen to position her IBD-identity as being of lesser importance than the frontstage presentation of her interests, in fact Sally represents this backstage disclosure of IBD as having *equal* significance in relation to her conception of self: 'so it's as much a part of me as my hobbies are' (14). The conjunction 'so' represents this statement of self-concept as, to some extent, *resulting* from this self-presentation to others. Sally therefore represents this self-presentation as being a significant influence upon her own conception of self; and because she does not have agency over her IBD disclosure in this context, a lack of agency is thus implied vis-à-vis her view of self. Sally's discussion of her disclosure of illness-information to others will be further explored in Chapter 7: 'Chronic illness and Other-orientation'.

In Bury's (1982) terms, Sally represents herself as having undergone a 're-evaluation of the relationship between...disease and selfhood' (1982: 172), forming a new conception of self to that before illness, within which she integrates her condition. However, this is a conception of self with which she does not appear entirely satisfied; and her constructed relationship between IBD and selfhood could therefore be described, in Hillege's terms, as an 'uneasy truce' (2005: 116).

Whereas Extracts 5-7 have shown respondents affording IBD a prominent position within their self-concept, though not always out of choice, Extract 8 shows the respondent, Nancy, *distancing* IBD from self, and through this, performing a morally-appropriate identity as somebody who just gets on with things, and does not moan or complain about her illness.

Nancy (N) was aged 27, and had been diagnosed with Crohn's disease for two years. At the time of the interview, she was studying for her PhD at university (see Appendix K; Interview 11: 102-126):

Extract 8:

1. BS: so the way you (.) view yourself now I mean do you do you think of
2. your Crohn's as (.) having quite a large part in your identity like when
3. you you think of the sort of person you are does it you know (.) do you
4. do you think of it as being quite prominent or?=  
5. N: =um (1.0) no I don't know if I
6. do really I think because I'm not really that ill with it much of the time it's
7. kind of just (.) you know (.) something that (.) I don't really think about that
8. often and I just my tablets seem to keep everything under control (.) um I
9. think I did but in the last year or so I've been I (.) pretty much felt back to normal
10. before that I was having problems with drinking and stuff and I really couldn't
11. drink so I think then it was (.) more of an issue because you know (.) when I
12. went out with my friends and stuff not being able to drink (.) obviously it
13. makes a huge difference compared to when you're like (.) you know (.)
14. knocking back shots and stuff (.) and it really really made me quite ill to drink
15. so I think (.) whereas now (.) and because I'm a bit older like I don't really go
16. out so much 'cause I'm boring (.) um I think it doesn't make such a difference
17. to me so I don't I I dunno (.) I suppose I think of it as part of my identity but
18. not (.) it's not one of the first things that would come to mind I don't think
19. (.) I just kind of (.) get (.) I don't I wouldn't I don't wouldn't like to define
20. myself as someone who's ill as well (.) which I suppose (.) I dunno I know
21. so many people who just go on about their health all the time so I try not to (.)
22. you know (.) moan about it and talk about it that much (.)
23. BS: mm mm (.)
24. N: so (.) I dunno I wouldn't say it's uh you know an important part of my
25. identity but I suppose (.) it is there (.)

Nancy states that she does not see IBD as having a prominent role within her self-concept (5-6). Her reasoning for this suggests that disease severity is a significant mediating factor in Nancy's case: 'because I'm not really that ill with it much of the time' (6). Nancy therefore, to some degree, represents her condition as an 'interruption' (Charmaz, 1991: 14), through signalling the periodic nature of disease symptoms; and it is due to her present state of remission that she is able to *distance* her condition from selfhood, by proposing that IBD is 'something that (.) I don't really think about that often' (7-8). For Nancy, then, the negligible impact of IBD upon her life is equated with the condition having only a minor role within self.

Nancy further supports this representation through making a 'contrast' between this present perspective, and that of her self a few years earlier, at which time she proposes that her condition had a more prominent role in her conception of self: 'I think it did but in the last year or so I've been...pretty much felt back to normal' (8-9). This statement implies that, from Nancy's perspective, having IBD is *not* 'normal', presumably when compared with the absence of illness, and she thus constructs the absence of IBD symptoms as signalling a return to 'normal' health.

Nancy's implicit representation of IBD as abnormal appears to be associated with symptoms having previously prevented her from partaking in what she considers to be 'normal', age-appropriate behaviours, such as drinking alcohol with her friends (10-14). Nancy proposes, however, that going out drinking with friends is an element of her self-concept that is no longer as salient to her, as she is now 'a bit older' (15) and therefore does not partake in this activity as frequently. This reference to being older implies that for somebody in their later twenties, there is not the same cultural expectation associated with social drinking as for somebody a few years younger. Nancy's humorous description of herself as 'boring' (16) could signal her recognition that I am a few years younger than her, and she may therefore presume that I would participate in these activities. It could be argued, then, that it is not only the diminished influence that IBD presently has upon Nancy's life, in terms of her feeling 'back to normal', that leads her to distance the condition from her self-concept, but that this is also a result of changing priorities due to

ageing, meaning that certain self-images that can be affected by IBD are no longer as salient to her: 'it doesn't make such a difference to me' (16-17).

Nancy does not represent herself here as experiencing disruption to her life in the present, in the way that Tara (Extracts 5 and 6) and Sally (Extract 7) do; however, it could be argued that Nancy did experience a degree of both 'loss of self' (Charmaz, 1983) and 'biographical disruption' (Bury, 1982) during the period when she was not able to drink alcohol. This is signalled by her description of the 'huge difference' (13) with her pre-illness behaviour in relation to this activity, which may suggest that drinking with her friends was a self-image that was lost at this time, and that she therefore experienced a 'disruption of taken-for-granted assumptions and behaviours' (Bury, 1982: 168) with regard to this activity. However, it is not suggested that this caused any kind of major shift in self-concept, and in any case this is represented as temporary, an 'interruption' (Charmaz, 1991: 14).

Whilst distancing IBD somewhat from her present self-concept, Nancy does represent her condition as constituting a *part* of her self: 'I suppose I think of it as part of my identity' (17). This integration of IBD is mitigated, however, through the verb 'suppose'. Also, her subsequent statement: 'but not...one of the first things that would come to mind' (17-18), represents IBD as secondary to other aspects of her self-concept, similar to Steve's account in Extract 4.

Nancy constructs further distance between illness and selfhood through proposing that she does not *want* IBD to be the defining characteristic of her self: 'I...wouldn't like to define myself as someone who's ill' (19-20). It can therefore be argued that Nancy's representation of IBD does not just result from its diminished influence upon her life, and her shifting priorities, but is also due to her wish not to label herself as 'ill'. She emphasises this point through another 'contrast' structure, this time drawing a distinction between others who 'go on about their health all the time' (21) and her own behaviour: 'I try not to...moan about it and talk about it that much' (21-22). Nancy is therefore 'outgrouping' those who talk frequently about, and moan about, their ill-health, constructing this as being a morally-*inappropriate* characteristic. For Nancy, then,



distancing her condition from her conception of self is represented as being morally-appropriate, as this aligns with the positive identity she is constructing as somebody who does *not* moan or complain about her health. Nancy thus constructs her condition 'through a lens' (Cheshire and Ziebland, 2005: 26) of what she wishes to present as stable personality traits, which align with her desired self-concept.

Analysis of Extracts 5-8 has demonstrated respondents with IBD drawing upon various resources in constructing a relationship between illness and selfhood, evidencing both integrating and distancing of their condition from their conception of self at different points. Extract 9, however, demonstrates the respondent, Eve, having yet to form a stable illness-selfhood relationship. Eve is an exceptional case, as whereas all other respondents in the study had been diagnosed for at least six months, Eve had been diagnosed for only three months, and had yet to experience any remission of her symptoms. She will be shown to construct significant 'loss of self' (Charmaz, 1983), representing herself as having yet to form a coherent conception of self which takes account of her condition. Eve was aged 21, and was studying for her medical degree at university.

Prior to this extract, Eve discussed how she had recently started taking steroids daily to control her IBD symptoms. She had explained that it is unsafe for her to take this medication on a long-term basis due to its side-effects (see 1.3). She expressed strong concerns that reducing her steroid-dosage will lead to her symptoms returning (see Appendix K; Interview 23: 171-199):

Extract 9:

1. BS: okay (.) so when you mentioned about (.) um (1.0) being
2. worried about reducing the steroids and the fact that you
3. think that the symptoms will (.) come back again I mean
4. how do you feel about the fact that you feel like you're
5. dependent on the steroids? is that something that (.)
6. really annoys you?=  
7. E: =yeah (.)

8. BS: yeah (.)
9. E: like (.) it really does like (2.0) (( )) at the start when I
10. was told that I was gonna be on steroids there was a part
11. of me that was like oh how exciting you know ‘cause we
12. learn about all these drugs and stuff=
13. BS: =mm (.)
14. E: and then (.) and then like (1.0) they make me excitable and
15. stuff and I just (.) kind of (.) (( )) I was having a good
16. time (.) but then (.) it’s (.) it just like (.) like I say yesterday
17. was really shit ‘cause it’s just suddenly hit me that like (.)
18. this is a chronic thing and I’m gonna be having it for (.)
19. ages or forever whatever (.) and um (1.0) yeah I (.) and it’s
20. really bizarre to think that (.) two months ago I was (.) you
21. know (1.0) normal and not on all these drugs and stuff (.)
22. BS: mm (.)
23. E: and the thought of (.) like being dependent on (.) drugs is
24. just not something I even want to think about (.) but it’s
25. like (.) there in the back of my mind and it’s sort of like I
26. said to my flatmates yesterday like (.) like I (.) I know it
27. sounds like (1.0) extreme ((but it’s kind of like)) I was in
28. denial like I didn’t wanna admit to myself that I’m actually
29. gonna be (.) stuck on these damn things forever

When asked about her feelings regarding the dependency she has on medication to maintain her present state of health, and whether this ‘annoys’ (6) her, Eve responds emphatically: ‘yeah...it really does’ (7-9). She constructs a ‘contrast’ between her present views, and those when she was first prescribed steroids, at which time she says she found it ‘exciting’ (11), and that she was ‘having a good time’ (15-16). This is an unusual reaction, as most respondents in the data-corpus who had been prescribed this medication report having been fearful or unhappy as a result. Eve’s reaction appears to relate to her having a professional interest in medication and treatments: ‘‘cause we learn about all these drugs and stuff’ (11-12). Here, she can be seen to foreground the ‘preferred’ identity

of medical student, which is represented as influencing her identity-performance as somebody with a chronic illness.

Her present perception of the condition is constructed far more negatively, however. Eve talks of how, coincidentally, the day before the interview she had come to a stark realisation which signalled a significant reconfiguration in her perception of IBD: 'yesterday was really shit 'cause it's just suddenly hit me that like (.) this is a chronic thing and I'm gonna be having it for (.) ages or forever' (16-19). This signals a tension between Eve's self-image of 'medical student' and the newly-acquired self-image of 'person with IBD'. Whereas Eve represents herself as initially having viewed her condition 'through a lens' of her interest in medicine, here she represents herself as viewing the condition from the perspective of somebody who *must live with* illness. Thus, despite the fact that, as a medical student, she would have understood the medical implications of chronic illness, her proposition that 'it's just suddenly hit me', perhaps refers to the need to arrive at an *acceptance*, in addition to an understanding, of this chronicity.

Eve proposes that because she has IBD she no longer considers herself to be *normal*: 'it's really bizarre to think that (.) two months ago I was...normal and not on these drugs and stuff' (19-21). I would argue that Eve's account portrays somebody who is *in the process* of experiencing 'biographical disruption' (Bury, 1982), as well as a profound 'loss of self' (Charmaz, 1983). Throughout her interview, Eve represents herself as having predominantly experienced 'loss', when compared with her pre-illness self, in Charmaz's terms, 'the crumbling away of former self-images without simultaneous development of equally valued new ones' (1983: 168). This loss appears to principally arise from the development of 'discrediting definitions of self' (Charmaz, 1983: 181), based around the representation of herself as no longer 'normal'.

In relation to 'biographical disruption', it can be argued that Eve has experienced a 'disruption of taken-for-granted assumptions and behaviours', but she has yet to reach the next two stages Bury proposes; firstly, a 'fundamental re-thinking of the person's biography and self-concept' (1982: 168); and then, a response to this disruption involving

‘mobilisation of resources, in facing an altered situation’ (1982: 168). This is evidenced through Eve’s very explicit recognition that she has been ‘in denial’ about her IBD (28), as well as her proposition that being dependent on medication, described in very negative terms as ‘these damn things’ (29), is ‘just not something I even want to think about’ (24). By Eve’s own admission, then, she is not yet ready to form a new conception of self which integrates her IBD, as this would mean facing up to its permanency. However, it could be the case that the sudden realisation she arrived at the day before *could* mark the beginning of Eve moving through this disruption.

Particularly apt in relation to Eve’s present representation of her struggle to come to terms with the chronicity of her condition is a quote from Defenbaugh (2008), who, in her auto-ethnographic account of the early stages of living with UC, professes: ‘I cry for the loss of my former self, for the health I once knew. I cry because I know that I will never be clinically ‘healthy’ again’ (2008: 1420).

Schur, Gamsu and Barley (1999) argue that ‘loss of self’ as a result of chronic illness may be especially difficult to deal with for young adults, who are still trying to develop a sense of who they are; thus the onset of chronic illness may be ‘especially undermining’ (1999: 227). I would contend that Eve’s projected-identity as a medical student adds a further layer of complexity to this, as her future, aspired-to self-image of ‘doctor’ has the extra potential for lack of fit with a chronic illness-identity, due to the diametrical opposition of the roles of healthcare professional and patient, within the clinical setting.

Having moved in a different direction, the discussion comes back to the theme of the role of illness within selfhood slightly later in the interview (see Appendix K; Interview 23: 520-543):

Extract 9 (contd):

30. BS: when you think about it [IBD] now I mean do you generally  
31. see it as playing a big role in your life? (.) or (.) maybe  
32. your identity? (.) when you think about who you are

33.           (.) do you think of it as being part of you or do you  
34.           think it's maybe still too early (.) for that because you  
35.           haven't had it for very long or? (.)  
36.    E:     I think like (.) I I actually think (.) because it's early (.) it is  
37.           a huge part of (.) it's more of a huge part of my life like (.)  
38.           all of a sudden I'm I'm (.) an Ulcerative Colitis patient (.)  
39.           and that's what I am (.) do you know what I mean (.)  
40.           whereas I think like (.) give it a year or so and it'll just be  
41.           kind of in the background and that'll be the case because  
42.           like at the moment my life is dominated by (.) by taking  
43.           pills and eating (.) like you know (.) worrying that I'm  
44.           gonna put on a load of weight because I'm on the steroids  
45.           and stuff (.) and um (.) and I'm obviously still like (.) not in  
46.           remission yet so like (.) I tried to go out running the other  
47.           day with my flatmates and I just couldn't do it (.) because  
48.           of the Colitis (.) um (.) that does it does seem to be the  
49.           answer to everything like (.) why can't you do that? why  
50.           can't you do that? because I've got Colitis and I can't [BS:  
51.           mm] (.) I'm not saying that to people I'm saying it to  
52.           myself

Whereas up until this point (1-29), Eve represents herself as having not yet reconfigured her self-concept in order to address her newly-acquired self-image of ill person, here there is a degree of contradiction, as she explicitly constructs the role of IBD within her selfhood: 'all of a sudden I'm...an Ulcerative Colitis patient' (38), with the following statement: 'and that's what I am' (39) appearing to mark this as *the* defining facet of her selfhood. Eve's description of herself as a 'patient' may be due to the fact that she has not yet fully experienced living with the condition as a person, and has instead mainly experienced the condition from a clinical/treatment perspective. Alternatively, the fact that she is a medical student could lead her to describe all those with illnesses as 'patients', even when referring to herself. Either way, here Eve can be seen to adopt the 'voice of medicine', which she interweaves with the 'voice of the lifeworld' (Mishler,

1984), as a way of negotiating the tension between her medical student-identity and her illness-identity.

Eve attributes this identity-statement to the significant influence that IBD presently has upon her life: ‘because like at the moment my life is dominated by...taking pills...and worrying that I’m gonna put on loads of weight because I’m on the steroids’ (41-44). In addition to issues surrounding medication and psychological concerns, Eve represents IBD as restricting her lifestyle activities: ‘it does seem to be the answer to everything...why can’t you do that? because I’ve got Colitis and I can’t’ (48-50). This shows evidence of another theme Charmaz (1983) identifies that can contribute to ‘loss of self’: ‘living a restricted life’ (1983: 172). Charmaz contends that living a narrowed, restricted life, whereby ‘sufferers’ cannot participate in normal, everyday activities because of the symptoms of illness, can lead them to feel a distance between their present self-concept and that which they held before the onset of illness. Eve’s construction also demonstrates similarities with Brydolf and Segesten’s (1996: 40) theory that young adults with IBD can experience ‘alienation from their former selves’ (see 4.1.2), which includes ‘no longer recognising themselves in terms of their physical capabilities’ (1996: 40), something clearly witnessed in Eve’s account. Again, then, as was observed in Tara’s account (Extract 6), the bodily experience of disease symptoms is at least partially influencing the construction of Eve’s illness-selfhood relationship, although again the details of symptoms are left implicit here.

Whilst not lacking narrative structure, Eve’s construction of this loss and alienation has echoes of Frank’s (1995: 97) chaos narrative (see 2.2), with Eve appearing to be struggling amidst the chaos of her reported experiences, representing herself as to some extent ‘immersed’ (Charmaz, 1991: 76) within her illness.

Eve stresses, however, that this representation that IBD restricts her lifestyle is a perception she holds herself, but is not something that she voices to others: ‘I’m not saying that to people I’m saying it to myself’ (51-52). Therefore, as was similarly observed in Nancy’s account in Extract 8, Eve avoids performing a negative identity as

somebody who moans and complains to others about her hardships, a trait commonly considered to be morally-*inappropriate*, regardless of the severity of these hardships.

Similarly to the findings vis-à-vis T1DM-respondents in 6.1, analysis of Extracts 5-9 has demonstrated variation in respondents' accounts of the relationship between their illness and self. Representations were also similarly found to be framed in such a way as to create positive identities, aligning with various different models of moral-appropriacy. The next section will compare and contrast the interpretations made in relation to accounts of the respective conditions.

### **6.3 Cross-condition comparisons**

Analysis has revealed variation in the ways in which respondents with T1DM and IBD discursively construct the relationship between illness and their selfhood. Whilst common trends have emerged, there has been shown to be variation both across the two conditions, and across the accounts of those with the same condition, as well as within the representations produced by individual respondents.

Timothy and Melanie (Extracts 1 and 2, respectively) were both shown to construct a close relationship between illness and selfhood, affording T1DM a prominent position within their respective self-concepts. Both represent the influence of T1DM as having resulted in them *gaining positive elements* of self – in Timothy's case an improvement in his general health; and for Melanie, a positive influence on her career choices. I proposed that these constructed-experiences can be viewed as being 'transformational' (Paterson et al., 1999); and I would also contend that these representations exemplify Feste and Anderson's (1995) conceptualisation of 'empowerment', which they talk of in terms of individuals with chronic illness being able to 'define and achieve their own goals' (1995: 140), and to discover 'how they can become the authors of their own life stories' (1995: 142). This is the case for both Timothy and Melanie, who construct themselves as actively using their experiences of illness in order to improve their lives, and to achieve certain goals. Their respective representations therefore display that, through transformation of illness experience, they have gained greater control over a particular area of their lifestyle,

which has influenced them into affording T1DM a prominent role within their self-concept. This again demonstrates the interrelationship between issues of *self* and *control*, the latter of which will be further explored in Chapter 8: ‘Negotiating Control’.

Whilst, in 6.1, I proposed that both Timothy and Melanie are able to construct morally-appropriate identities, through drawing upon different ideological schemas – Timothy constructing a positive identity as mature and taking care of his health, and Melanie as altruistic – I would contend that *the transformation process itself* can be seen to align with ideological models of moral-appropriacy. Within Western society, those who are able to discover the positives in their hardships, and to ‘find strength in the face of adversity’ (Rittman, Northsea, Hausauer, Green, and Swanson, 1993), are generally looked upon favourably. Timothy and Melanie therefore both employ ideological themes, which they interweave with personal, subjective experience, in order to represent themselves as constructing a positive, morally-appropriate illness-selfhood relationship. This moral-potential of transformation is not something explored by Paterson et al. (1999), but is important when considering talk about illness as a socially-constructed performance.

Transformation, and the *gaining* of positive self-images, is generally not evidenced in the representations of IBD-respondents in the data-extracts explored. It could be argued that Tara’s account in Extract 5 does show evidence of her ‘altering [her] cognitive and affective response to [her illness]’ (Paterson et al., 1999: 799), and coming to a greater acceptance of its role in her life: ‘I’ve matured into it (.) and I can deal with it now’ (7). Whilst this may suggest that she has experienced transformation, she does *not*, however, represent herself as having experienced ‘positive and rewarding outcomes’ (Paterson et al., 1999: 786), which Paterson et al. propose is a key element of the transformational experience. Instead, Tara generally represents her condition as impacting negatively upon her life, especially in Extract 6.

This greater prominence of transformation in the accounts of T1DM-respondents could be due to the respective nature of the two conditions. For those in young adulthood, T1DM is commonly associated with *future* health complications (although not always *only* future, as was shown in Polly’s case, in Extract 3); whereas the symptoms of IBD are



generally a *present*, or immediate future concern for those with the condition. It could therefore be argued that there is greater scope for IBD to impact negatively upon the lives of those with the condition in the present, and thus for representations of the illness-selfhood relationship also to be more negative, with less likelihood of gains being constructed. With this said, there are some examples of IBD-respondents constructing transformational experiences in spite of having experienced great pain and suffering. For instance, Joanna talks of having reframed the restrictions presented by her condition as challenges, and she reports that, because of the extra effort required on her part to complete everyday tasks, she feels a greater level of achievement (see Appendix K; Interview 30: 851-878).

It is important to note, however, that in relation to representations of both conditions, when gains are constructed this is commonly only in relation to *certain* facets of illness experience; and even those who could be said to have undergone transformation do not represent their illness experiences as being wholly positive by any means. This is explicitly exemplified by Melanie slightly later in her interview: 'I'm definitely not one of those people who like oh you know I'd I'd never (.) turn back the clock I'd never want to be without it that's absolute rubbish...I'd love to if I in a second I would get rid of it' (Appendix K; Interview 21: 155-158).

It can be argued that, through constructing illness as at least partially resulting in gains, Timothy and Melanie display a degree of *agency* and *choice* in their integration of T1DM within their self-concept. This agency is not so apparent in relation to the accounts of IBD-respondents. Sally (Extract 7), for instance, proposes that the prominent role that she affords IBD within her selfhood is not out of choice, but rather it is the *influence of the condition upon her* which leads her to construct this representation, which she exemplifies through proposing a lack of agency over the disclosure of her condition in a certain context. This cross-condition disparity is reflective of the data-corpus as a whole. This may suggest that, for those with IBD, the direct influence of the condition upon respondents' lives is a greater *mediating factor* in influencing the construction of self than it is for those with T1DM. For T1DM-respondents, the impact of the condition upon their daily lives appears to be less important in determining whether they integrate or distance

their condition vis-à-vis their selfhood, again because the condition is generally represented as having a less restrictive impact upon their lives in the immediate present. With this said, however, some T1DM-respondents do represent their condition as having a large role in their selfhood *because of* the consistent influence of their treatment-regimen upon their daily lives, as was found in the second part of Melanie's extract: 'I don't do many things without thinking about it' (Extract 2: 15-16), thus displaying *less* agency in this construction. In these cases, then, the impact of the condition *does* play a mediating role in the construction of the illness-selfhood relationship; however, this mediating role appears to be less pronounced than in the case of IBD-respondents' representations.

Linked to this finding, it could be argued that the indirect role of *bodily experience* is more salient in the construction of the illness-selfhood relationship vis-à-vis IBD-respondents' accounts, than is the case in the accounts of T1DM-respondents. This is because, in the case of IBD, bodily restrictions are more likely to affect the individuals' leisure activities and self-presentation in the present; although, as mentioned in relation to Tara's, Sally's and Eve's accounts, the bodily experience of symptoms is left implicit in the accounts investigated in this chapter.

The nature of IBD as often characterised by flare-up/remission cycles may also be a factor in this cross-condition disparity. Whilst T1DM is generally represented as having a more consistent influence on respondents' lives (although some report variation regarding how much attention they pay to their self-care at different points in reported-time; see for example: Polly: Interview 17: 456-467; Mitch: Interview 16: 241-281), the influence of IBD upon individuals' lives can differ significantly depending on whether disease symptoms are active or in remission. This can lead IBD to have a greater mediating impact upon the role illness is afforded in self, as highlighted for instance in Nancy's account: 'I'm not really that ill with it much of the time' (Extract 8: 6).

Tara's account in Extract 5 *appears* to demonstrate disparity with this trend vis-à-vis agency, as she represents herself as making the active decision to change her perception of, and behaviour towards, her IBD. However, this choice is framed as having been

prompted by a period of hospitalisation due to IBD; thus the influence of illness upon her *was* an indirect mediating factor in her reconfiguration of the illness-selfhood relationship. Through positioning herself in this way, then, as somebody able to make the active choice to reconfigure the relationship between illness and self, Tara can be seen to discursively construct her experiences in a way that allows for the 'healing [of] some of the discontinuities and contradictions' (Riessman, 1990: 1199) between the 'reality' of the restrictions imposed by her illness and her *desired* self, the person she wishes to be seen as.

The example of Tara shows, then, that this notion of (lack of) *agency* vis-à-vis the constructed illness-selfhood relationship does not in any way contradict Riessman's claims (1990; 2002; 2003: see 3.1) that the discursive presentation of illness can function to repair the gap between the ideal self, and the restrictions imposed by illness – what Goffman (1963) would term the disparity between an individual's *virtual* identity and his or her *actual* identity. The representations here have certainly shown throughout respondents projecting 'preferred' identities (Riessman, 2003: 8) in line with their desired-selves. What I am arguing here, however, is that the greater the influence of illness upon individuals' lives, and the more entwined their daily activities are with their condition, the lesser agency they have to distance the condition from their conception of self, and to make claims that the condition does not constitute a significant part of who they are; even if a self-concept within which illness is prominent does not align with the desired-self they wish to project. This was shown most notably in relation to Eve (Extract 9), who attributes the central role that she presently affords to illness within her selfhood to the fact that her life is 'dominated by' (Extract 9: 42) her IBD. The significant impact of IBD therefore makes it difficult for her to present her condition as *anything but* a salient part of her self.

In Eve's account, not only is there no evidence of transformation, or gaining elements of self, but she constructs significant 'loss of self' (Charmaz, 1983), and 'biographical disruption' (Bury, 1982). She represents herself as being radically altered by the onset of her condition, and is still mourning the loss of her former self. Whilst 'loss of self' is quite prominent across the accounts of IBD-respondents in the data-corpus, most commonly

those who have experienced the most severe forms of the disease (see for instance, Lewis: Interview 25; Mary: Interview 26; Sally: Interview 28; Joanna: Interview 30), such representations are less salient in the accounts of those with T1DM. This may again be because few T1DM-respondents have reportedly experienced significant ill-health<sup>12</sup>, whereas it is more common for those with IBD to experience lifestyle restrictions due to illness, leading them, in the same way as Eve, to see themselves as being radically altered from their pre-illness selves. Experiencing ‘loss of self’ is not, however, exclusive to those with IBD, as evidenced in Polly’s account (Extract 3). Polly represents herself as having experienced a negative psychological change in her perception of her condition, constructing ‘loss’ in relation to the view of her condition she presents to others: ‘when people ask me about it...I’m kind of like (.) yeah it’s quite hard sometimes’ (Extract 3: 76-79). Polly’s account is somewhat of an exception, however, as within the data-corpus as whole, there is little evidence of respondents constructing themselves as being *fearful* about the short-term health implications of their T1DM, in the way that Polly’s account suggests.

Notable in relation to Polly’s account is her meta-talk regarding how she presents her T1DM to others. This demonstrates similarity with Sally, who also discusses her self-presentation of illness. This orientation to self-presentation is not present in the other seven extracts, and could exemplify the salience that both Polly and Sally afford to their self-presentation to others in the formation of their own self-concepts. This again demonstrates an overlapping of macro-themes, with issues surrounding *self* and *others* closely related. Disclosure of illness-information to others will be further explored in Chapter 7: ‘Chronic Illness and Other-orientation’.

Unlike Tara, Sally or Eve, Nancy was shown to *distance* IBD from her selfhood. Similarly to Timothy and Melanie in relation to T1DM, Nancy is able to represent herself as being healthy, due to her symptoms presently being in remission: ‘I’m not really that ill with it much of the time’ (Extract 8: 6). However, rather than representing herself as transformed by her illness experience, *because* of the negligible impact of IBD, Nancy

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<sup>12</sup> There are some exceptions, as a few T1DM-respondents do report having experienced serious ill-health in the present, for instance Helena (Interview 6: 212-229) and Mark (Interview 12: 101-208).

*distances* her IBD from her conception of self, affording it only a peripheral role. In Nancy's case, then, the mediating impact of IBD has influenced the construction of the illness-selfhood relationship in a different direction to Tara's and Sally's respective representations.

Steve (Extract 4) was shown to distance T1DM from his conception of self, at certain points affording the condition a peripheral, 'secondary' (24) role in his self-concept, and at others representing it as not having a role of any kind: 'not an identity thing at all' (36). He does this through the construction of consistency in selfhood between his present, and pre-illness selves, thus representing himself as not having undergone loss of self *or* as having gained elements of self, and instead constructing 'biographical flow' (Faircloth et al., 2004). Comparison of Steve's and Nancy's extracts demonstrates a similarity across accounts vis-à-vis T1DM and IBD; in distancing their condition from their self-concept, both construct a morally-appropriate, almost heroic identity, of somebody who does not make a fuss, and just gets on with things: 'I just ((sort of)) shrug it off get on with it' (Steve: Extract 4: 11); 'I try not to...moan about it and talk about it that much' (Nancy: Extract 9: 21-22).

It can therefore be seen that *both* the construction of a close relationship between illness and selfhood, *and* distancing illness from self, *can* be constructed in such a way as to perform a morally-appropriate identity – either as somebody who has a positive attitude towards gaining something beneficial and worthwhile from illness (Timothy and Melanie); or as somebody who does not moan or making a fuss, and heroically carries on with life (Steve and Nancy). As proposed in the above analysis, the creation of both of these types of moral identity demonstrates respondents constructing their condition 'through a lens' of what they wish to present as stable personality traits.

In spite of the variations in these moral identities, respondents were shown to draw on similar discursive devices in their construction. Most notable perhaps is respondents' use of 'contrast' structures. This includes making contrasts between their own perceptions and behaviour, and that of others: either others who have an illness (Steve, Extract 4; Nancy, Extract 8), or family members (Steve); who they represent as behaving in a less capable,

or less morally-appropriate manner, than themselves. This, Sarangi (2007: 37) refers to as ‘self-vs.-other’ representations, whereby individuals distance themselves from the ‘undesirable’ behaviour or perceptions of others. Respondents also commonly made contrasts which were temporal in nature, contrasting their present selves with their former selves, either pre-illness, or at an earlier stage in their illness trajectory. This reflexivity is mostly used to demonstrate a shift from the morally-*inappropriate* views and behaviour of their former selves, to the morally-appropriate views and behaviour of their present selves. As Radley and Billig (1996) argue, in using such resources, respondents are ‘making claims about themselves as worthy individuals, as more or less ‘fit’ individuals in the activities of the social world’ (1996: 221). Here, then, respondents can be seen to be drawing upon culturally-accepted models regarding how people ‘should’ behave, represented within the context of their personal, subjective experiences.

These constructions of temporal changes demonstrate the fluid, changeable nature of the illness-selfhood relationship. This data merely represents a snapshot of this constructed relationship at this particular moment, *in this particular context*. Hillege (2005), in looking at adolescents’ experiences of living with T1DM, proposes that ‘T1DM is not a condition that individuals accept and manage once and for all, but the process is continuous...people continuously have to renegotiate the relationship between T1DM and the self’ (2005: 245).

Whilst I have proposed commonality amongst extracts in this construction of moral identities, Eve’s extract is a notable exception in that there is very little alignment to issues of morality, the only evidence of this being Eve’s proposition that she does not voice to others the restrictions imposed by her condition (51-52). Throughout the extract, she constructs an identity as somebody struggling to come to terms with her condition. This is perhaps not a morally-*inappropriate* identity, as given her current circumstances, most would sympathise with her plight; however, this is still a somewhat negative identity performance. The same could perhaps be said of Polly’s account (Extract 3); however, Polly was shown to go to great lengths to ‘excuse’ (Scott and Lyman, 1968) the negative construction of her condition.

This does not reflect the whole of Eve's interview, as there are occasions when she *does* orient to issues of morality. For instance, in the following utterances, when discussing her immediate reaction to diagnosis, she constructs a morally-appropriate identity as just getting on with things and not making a fuss (see Appendix K; Interview 23: 353-356): 'I'm not the sort of person to...let it get to me that much I was just like okay fine (.) diagnosis Ulcerative Colitis (.) let's (.) go and treat it'.

I would argue, then, that the reason for Eve's lack of attention to issues of morality in Extract 9 is that, *at this particular juncture*, the seriousness and gravity of Eve's constructed-experiences may supersede the desire to construct a morally-appropriate self. Therefore, in spite of constructing multiple identities at various points throughout her interview, it can be argued that, *at certain points*, the acuteness of the pain and suffering being expressed and the need to just get this out into the open take precedence over concerns about performing for others.

The reason for this phenomenon being observed in relation to Eve's account, and not in the other extracts examined in this chapter, could be because she is newly diagnosed. Her desire to express this suffering is thus reflective of her struggle to come to terms with her new self as somebody with a chronic condition. This is in spite of the fact that the extract presented above shows this not to be the case when she was *first told* of her diagnosis, thus the 'biographical disruption' she is experiencing appears to have been slightly delayed from the diagnosis of her IBD. I argued in the analysis that Eve's account has echoes of Frank's 'chaos narrative' (1995: 97). It could therefore be argued that, in the midst of this chaos, issues of morality are given less salience, or are less easily performed.

Finally, it is important to reiterate that these representations are not only temporally changeable, but are contextually-contingent. With this in mind, I must relate back to a point made at the beginning of this chapter, that in many instances it is I who initially elicit talk about self, at times in a very direct manner, and this must be taken into account in interpreting respondents' accounts. We do not know if such issues would have been discussed in the same way by respondents had I not elicited such talk, or if I had framed my questions in different ways. As was emphasised in 5.2.3, however, taking account of

such considerations does not diminish the value of respondents' constructions, but simply recognises that they are 'situated and accomplished in social interaction' (Riessman, 2002: 27).

Having investigated representations of chronic illness in relation to the construction of *self*, the next chapter will explore the second predominant macro-theme identified in the preliminary analysis – young adults' representations of their *orientation to others*.



## 7. Chronic Illness and *Other-Orientation*: How Young Adults Construct the Perceptions and Behaviours of Others vis-à-vis their condition, and their own Self-Presentation of Illness

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This chapter addresses the second macro-theme identified in the preliminary analysis – young adults' *other-orientation*, that is, representations of their orientation to others, and of the ways in which others orient to them. It will investigate how respondents construct others' perceptions about their condition, as well as others' behaviours resulting from these perceptions, and will also explore the comparisons respondents make between themselves and others. Through these representations, respondents will be shown to construct varying degrees of *normalcy*, or lack thereof, regarding their condition, which they represent as having implications for how they present their condition to others.

The notion of *others* first needs unpacking. In the extracts selected, others can be grouped firstly into those who are *unknown* to respondents, strangers. It is usually not the case that specific examples of unknown others are recalled, but more commonly representations of the possible perceptions and reactions of *hypothetical* unknown others, those Sarangi (forthcoming: 3) terms 'the generalized other'. The second group are those who are *known* to respondents. These are most commonly friends, or in one case (Extract 13) romantic partners. Whilst the discussion of friends is also at times generalized, in some instances 'specific others' (Sarangi, forthcoming: 3) are introduced. Whilst here I am grouping others into known and unknown (both of whom can be either generalized or specified, and possibly hypothetical), it is perhaps important to note that this distinction is not entirely clear-cut – it may be possible to *know of* somebody without knowing them *per se*, and it could also be argued that once an individual is discussed specifically, they are no longer 'unknown'. However, for the purposes of my analysis, this known/unknown distinction will be shown to be suitable.

In the case of both known and unknown others, these are people who do *not* have the same chronic condition as the respondent. Notably, family are not mentioned in any of the extracts selected. This may be because it is treated as given by respondents that family are fully aware of their condition, and that there are not the same complexities of issues when compared to those arising vis-à-vis social interactions outside of the family setting. There are instances within the data-corpus where family *are* the focus of discussion, as was shown in Steve's account vis-à-vis *self* in Chapter 6 (Extract 4), but across the data-corpus as a whole, orientation to friends and peers is more common.

It is again important to note that, in a few cases, *I* introduce the topic of others, and in Extract 13, I specify social and romantic relationships, prompting the respondent to orient to *these particular* others, which must be considered when interpreting the data. In all other extracts, respondents either initiate other-orientation, or I initially ask about *generalized* others, from which respondents orient to a particular group of others. The discussion of this theme *is* therefore largely respondent-led.

### **7.1 Studies and concepts relevant to analysis**

Analysis will be informed by a range of concepts regarding other-orientation, normalcy, stigma, deviance and disclosure of illness-information.

In terms of *how* respondents construct their other-orientation, I will draw upon the conceptual framework developed by Sarangi (2007) in the context of genetic counselling interactions. He talks of three perspectives taken towards the 'other': 'self-vs.-other'; 'self-as-other'; and 'self-and-other'. Self-vs.-other (as already briefly mentioned in 6.3) involves an *us-vs.-them* dichotomy, whereby individuals distance themselves from those who behave differently from themselves: 'the principles of dichotomization and opposition are at the heart of such characterisation...the 'other' is regarded as undesirable' (Sarangi, 2007: 37). This concept will be used to explore how respondents employ 'othering', through distancing themselves from those who do not have the same

condition as them, often constructing these others as behaving in a morally-*inappropriate* manner, thus allowing them to construct positive identities for themselves.

The concept of 'self-as-other' draws on the work of Mead (1967). As Sarangi summarizes:

Mead's argument is based on the complex characterisation of the 'I-me' distinction. The 'me' is the objectification of 'I', i.e., the 'I' is the active agent while the 'me' is the retrospective experience...the 'I' conceives itself as another would conceive it by "taking the attitude of the other".

(Sarangi, 2007: 37)

This idea, then, essentially involves the perceptions of the generalized other; how the self is constructed by respondents *through* how it is perceived by others. In the present analysis, this type of construction will be shown to be drawn upon both in relation to 'generalized others' *and* 'specific others' (Sarangi, forthcoming: 3).

In Sarangi's work, 'self-and-other' is used to refer to how partners and specific family members are invoked within the context of genetic counselling interactions, and thus involved in the patient's experiences. In the context of my data, however, I will extend this concept to refer to how respondents, at times, represent both themselves *and* friends as *jointly* constructing the (lack of) normalcy of their condition, and subsequently their illness-identities, and also instances where respondents construct *similarity* between themselves and others.

This conceptual framework is a useful lens through which to view the accounts in this chapter. It could be argued that, in relation to chronic illness experience, issues surrounding *self* and *other* are difficult to separate, even for analytic purposes as I have done; this overlapping of themes has already been shown in the other-orientation present in a few places in Chapter 6. However, I would contend that this framework can provide a bridge between these two themes, in showing how the self can be constructed by making comparisons with others, drawing on the perceptions of others, and in representing collaborative meaning-making between the individual and specific others.

It will be shown that, through this other-orientation, respondents with T1DM and IBD construct differing degrees of *normalcy* in relation to their respective conditions – both in terms of whether they represent themselves as normal relative to others, and in the perceptions of others. This construction of (lack of) normalcy commonly centres on the degree of *stigma* they represent as being attached to their condition. In examining this, I will draw firstly upon Goffman's (1963) classic conceptual model of stigma (introduced in 4.2). Goffman defines stigma as 'an attribute that is deeply discrediting' (1969: 13), which, he argues, arises from an 'undesired differentness' (1963: 14), in this case chronic illness. It is how this differentness is constructed in relation to others which is at issue: whether respondents construct their condition, and subsequently themselves, as being normal or otherwise.

Both IBD and T1DM will be shown to be largely constructed by respondents as not being immediately 'evident' or 'perceptible' (1963: 65); thus positioning themselves as 'discreditable', in Goffman's terms. The issue at hand might therefore be seen to be 'managing information about [their] failing' (1963: 57): whether to disclose their condition to others, or whether, and in which circumstances, to 'pass' (Goffman, 1963: 58), meaning to conceal their condition from others. It will be shown, however, that it is not always the case that both conditions remain imperceptible to others. With T1DM, there is the potential for self-care practices to become visible; and in the case of IBD, symptoms can, at times, become evident. In such contexts, the individual becomes 'discredited'; therefore focus must shift to managing *impressions*, rather than information. This potential change in the perceptibility of the same stigma is something Goffman does not fully consider.

What is more, I will demonstrate that, rather than talking of stigma simply as 'discredited' or 'discreditable', we could talk of a *continuum of discredibility*, on which different stigmas are attributed greater or lesser degrees of discredibility. This is something alluded to by Weitz (1991) in her research into the experiences of living with HIV/AIDS, as she proposes that certain illnesses provoke greater levels of stigma, such as those where 'the blame and dread they evoke are strongest' (Weitz, 1991: 45). Something Weitz does

not consider, however, is the way in which the same stigma can be constructed as having greater or lesser levels of discredibility by different groups or individuals. Therefore whilst, due to cultural predispositions or prejudices, a condition like HIV/AIDS may be afforded a high degree of discredibility by many people, conditions such as T1DM and IBD may be afforded varying levels of discredibility by different individuals, something which will be explored in the present analysis.

The concept of stigma is further developed by Scambler and Hopkins (1986). In exploring the experiences of 94 respondents with epilepsy, of a non-specific age-range, they developed the dual concepts of 'enacted stigma' and 'felt stigma' (introduced in 4.2). The former refers to 'instances of discrimination...on the grounds of perceived unacceptability or inferiority' (1986: 33), and the latter refers to 'fear of enacted stigma, but also encompasses a feeling of shame' (1986: 33). Scambler and Hopkins propose that 'felt stigma' often leads individuals to 'pass', in Goffman's terms, as a way of avoiding 'enacted stigma'. These concepts will be shown to be very relevant to respondents' accounts in the present analysis, in relation to both T1DM and IBD.

Following Scambler (2004; 2006; 2009), I will also make a distinction between the terms 'stigma' and 'deviance', which have often been used synonymously in past research, including Goffman (1963). Scambler proposes that both 'stigma' and 'deviance' are in opposition to normalcy, but that stigma denotes 'an ontological deficit', whereas 'deviance refers to a *moral deficit*'. Stigma thus 'invokes 'shame', and deviance 'blame'' (Scambler, 2009: 450). So where Weitz (1991) talks of stigma being most prominent when blame is attached, such as with HIV/AIDS, Scambler would in fact conceptualise this in terms of it having greater *deviancy*. Scambler and Hopkins' conceptualisation of stigma is mirrored in relation to deviance, as Scambler talks of both 'enacted deviance' and 'felt deviance'.

Scambler and Paoli (2008) add a further concept, termed 'project' (2008: 1851). This is where individuals respond to discreditable or discredited illnesses, 'without either internalizing cultural norms of shame or blame or becoming fearful, defensive or subdued by prospects of discrimination', and instead they 'formulate positive strategies and tactics

that acknowledge the risks of enacted stigma and deviance whilst trying to avoid the pitfalls of felt stigma and deviance' (2008: 1851), i.e., strategies which constitute their 'projects'. These concepts will also be shown to be very relevant with regard to the accounts in the present analysis. For clarity, below I have reproduced a summary table of these concepts, taken from Scambler and Paoli (2008: 1851):

<b>Conceptual distinctions for stigma and deviance</b>	
<i>Stigma</i> : an ontological deficit, reflecting infringements against norms of shame	<i>Deviance</i> : a moral deficit, reflecting infringements against norms of blame
<i>Enacted</i> : discrimination by others on the grounds of 'being imperfect'	<i>Enacted</i> : discrimination by others on the grounds of immoral behaviour
<i>Felt</i> : internalised sense of shame and immobilising anticipation of enacted stigma	<i>Felt</i> : internalised sense of blame and immobilising anticipation of enacted deviance
<i>Project</i> : strategies and tactics devised to avoid or combat enacted stigma without falling prey to felt stigma	<i>Project</i> : strategies and tactics devised to avoid or combat enacted deviance without falling prey to felt deviance

Respondents' accounts of (lack of) normalcy in relation to stigma and deviance will be shown to influence their reported disclosure of illness-information, and whether or not they decide to 'pass'. Related to this will be shown to be issues of (*dis*)trust. As Sarangi (2008: 174) proposes, in relation to HIV/AIDS in the context of India: 'trust and fear of disclosure are two sides of the same coin: one discloses information to someone trusted; trust is built upon shared information. Distrust and non-disclosure likewise go hand-in-hand'. The notion of disclosure must be unpacked, however. Firstly, there will be shown to be variation regarding whether respondents employ 'selective disclosure' (Schneider and Conrad, 1980), in terms of *who* they choose to disclose to, and in which contexts. Schneider and Conrad contend that the metaphor 'coming out of the closet' can be usefully applied to disclosure of chronic illness. They argue that individuals do not just 'come out of' or 'stay in the closet', but they extend this metaphor to suggest that this closet has a 'revolving door' (1980: 37); thus individuals can choose to come out of, or

stay in the closet, at different times, and in different contexts, as a way of managing their 'discrepant identities' (1980: 32). However, another facet of illness disclosure that I will look at, which is not considered by Schneider and Conrad, is the potential for *partial* disclosure, relating to the *amount* of information revealed, and the framing of disclosures. To extend the 'closet' metaphor, this would suggest that it is possible not only for individuals to be either in, or out of the closet, but that they can come out only partially, and at the same time partially remain in the closet, through disclosing only some details of their condition.

I will also make a further distinction between what I will term *verbal* disclosure, and *physical* disclosure, a distinction not fully explored in previous research literature. By verbal disclosure, I refer to respondents actually telling others about their condition, which it would be imagined is the most common form of disclosure. However, whether respondents choose to allow others to witness self-care practices related to their condition can also, I would argue, be seen as a form of (non-) disclosure.

## **7.2 Analytical Frameworks**

These issues surrounding (lack of) normalcy, stigma, deviance and disclosure will be integrated within a focus on identity-performance, a central tenet of the thesis throughout. Scott and Lyman's (1968) 'accounts' framework (see 3.2) will be drawn up in showing how respondents, at times, 'excuse' or 'justify' their reported-behaviour regarding illness-disclosure, in order to construct themselves as behaving in a morally-appropriate manner (Radley and Billig, 1996). This focus on issues of morality demonstrates coherence with the accounts analysed in Chapter 6. Narratives and habitual narratives will also be identified in some instances, the rhetorical function of which will be explored.

Respondents' attempts to perform moral identities will also be demonstrated through their use of various other discursive resources, such as 'contrasts', as mentioned above in relation to the concept of 'self-vs.-other' (Sarangi, 2007), reported speech, as well as their pronominal use.

### 7.3 Representations of T1DM

Extract 10 shows the respondent, Linda, representing T1DM as being removed from normalcy in the view of others, and thus constructs her identity as someone who is different from everyone else, and potentially susceptible to stigmatization as a result. She is able in spite of this, however, to perform a positive, morally-appropriate identity.

Linda (L) was aged 20, and had been diagnosed with T1DM for eleven years. At the time of the interview, she was studying for her undergraduate degree at university (see Appendix K; Interview 5: 477-516):

Extract 10:

1. BS: you've mentioned a little bit about telling people about your diabetes and stuff
2. I mean do you ever worry about what people might think about it? (.)
3. L: um (2.0) sometimes (.) but then (.) to be honest I think if they've got an issue
4. with it then it's their loss (.) like (2.0) obviously it is a bit sometimes I do get
5. paranoid about it and I know that people think it's a bit weird and that (.) you
6. know I'm not like normal (1.0) but (1.0) it's kind of something that I've got to
7. live with and if I can live with it they don't have to do the injections they don't
8. have to eat or count what they eat (.) so they should like (.) really get over it
9. I know (.) there's been times (.) where like (.) some (.) like friends have said
10. 'oh yeah I'm feeling really rubbish' or (.) you know 'I've got a cold' and I think
11. well (.) you've got a cold yeah big deal (laughing) are you doing anything
12. about it like? (.) one of my (.) um housemates recently (.) didn't do a (.) class
13. test because she had a cold (.) and I just sat there thinking like (.) that's really
14. a rubbish reason while I've still got on with everything (.) in my life like (.) I
15. don't want to make an issue out of it (.) and I didn't say anything to her about
16. it but I'm sat there thinking well (.) I've still got on with everything I still do
17. all my work on time and you've got a common cold (laughs) (.) it's not really
18. a big deal but (1.0) yeah I mean if people (.) did have an issue then I'd just
19. well (.) it's their problem more than mine really (1.0) like I'd rather not worry



20. about that as well as everything else (chuckles) (2.0)
21. BS: so would you never try and actively sort of conceal it? or would there be times
22. when you might think oh
23. L: [um (1.0) oh yeah definitely like (1.0) when (.) I ha-
24. kind of hadn't really realised even that I had concealed it (.) but then this year
25. there's been a lot of people that have said 'oh yeah I had no idea that you were
26. diabetic' and I suppose last year I did try and conceal it I mean it's not exactly
27. a normal (.) like common thing to have (.) um (.) and I (.) I don't like the
28. attention that I get (.) when people say (.) 'oh god that must be really hard to
29. deal with' or whatever (.) um (.) and so I think (.) I (.) had probably
30. subconsciously concealed it last year without even thinking about it obviously
31. like (.) my junior school sort of fed on to my senior school (.) and so when I
32. was diagnosed at junior school everybody knew about it 'cause I was off
33. school for a while and they did a big assembly and everything like that on
34. it (.) which I (.) hate (1.0) um (.) and so everyone knew then without me even
35. saying anything (.) and it just like (.) it was just one of those things you just
36. get on with it but yeah I suppose I did probably conceal it without (.) not
37. without meaning to just without even thinking (1.0) but (.) I kind of think the
38. people (.) the people who (.) need to know (.) I tell (.) and if they don't need to
39. know then I just there's just no point really (.) what's the point in having them
40. think I'm a bit weird (chuckles)

Linda responds to my initial question, regarding whether she worries about what others may think about her T1DM (1-2), with a degree of contradiction. However, it must be noted that, not only do I introduce the theme of others' perceptions here, but my use of the term 'worry' (2) has negative connotations, potentially influencing Linda's response. This orientation to others had, however, already been introduced by Linda previously in the interview (see Interview 5: 121-164).

Linda initially constructs a positive identity by proposing that she tries to take the attitude that if someone were to hypothetically adopt a negative view towards her because of her condition, then that is the other person's problem and not her own (3-4), thus aligning

with ideological models of moral-appropriacy, through representing herself as a confident, strong-willed person, who rejects others' negative perceptions. This exemplifies Scambler and Paoli's (2008) 'project' stigma, the 'conscious rejection of attributions of shame' (2008: 1853), though in this case the construction of stigma is hypothetical.

This construction is somewhat contradicted, however, as Linda proposes that she at times feels 'paranoid' (5) about others forming negative perceptions of her as a result of her condition. The intensifier 'obviously' (4) frames this reported felt paranoia as somewhat inevitable; and the verb phrase 'I know' (5) projects certainty on Linda's part that these others see her T1DM as 'a bit weird' (5), and as a result see her as 'not...normal' (6). She does not, however, specify who these others are, and whether she is referring generally to those who do not have T1DM. Linda's orientation here demonstrates 'self-as-other' (Sarangi, 2007); she is constructing herself as not 'normal' *through the eyes of others*. Linda does not, however, report actual experiences of stigma, thus this 'self-as-other' construction reflects 'felt stigma', rather than 'enacted stigma' (Scambler and Hopkins, 1986); although rejecting feelings of shame (3-4), her construction of negative perceptions may suggest an anticipation of experiencing stigma as a result of her differentness. Linda therefore represents T1DM as being a potentially stigmatized condition, discreditable in the eyes of others, thus affording it a relatively high position on the continuum of discreditability.

Despite representing herself as removed from the normalcy of others, Linda again constructs a positive identity, through use of a 'contrast' structure. Linda differentiates her behaviour favourably with that of friends, and specifically her housemate. She presents a short narrative (12-17), in which she tells of how this housemate did not do a university test, because of having 'a common cold' (17). Through this narrative, she represents her housemate negatively, as making a fuss about minor ailments; whereas Linda is positioned in opposition to this, as just getting on with her university work, in spite of what is implied as being the extra demands she faces because of T1DM: 'I've still got on with everything I still do all my work on time' (16-17). Linda therefore constructs 'self-vs.-other' (Sarangi, 2007) orientation, distancing herself from the undesirable qualities displayed by others. She thus again *foregrounds* her illness-identity (Riessman, 1990), but

at this juncture in a very positive way, not representing herself as abnormal, but constructs a heroic identity as getting on with things in a more morally-appropriate manner than others.

In spite of again proposing that she does not care what others think of her (18-20), in relation to her disclosure practices Linda states emphatically that she has 'definitely' (23) concealed her T1DM at times. She therefore represents T1DM as 'discreditable', rather than 'discredited' (Goffman, 1963: 14), allowing her to 'pass' if she so chooses. She provides both an 'excuse' *and* a 'justification' (Scott and Lyman, 1968) for her 'passing', thus framing this behaviour as potentially being deemed morally-inappropriate, perhaps because concealing one's condition could be equated with self-shame, which may be looked upon unfavourably.

She 'excuses' her non-disclosure, firstly by framing this as having not been a conscious decision (23-26), thus 'denying full responsibility' (Scott and Lyman, 1968: 47). This excuse is furthered through the proposition that she does not like the 'attention' (28, and see also 30-34) that she receives as a result of her T1DM, or when others express sympathy towards her because of her condition (28-29). This aligns with Linda's earlier identity-construction as somebody who does not like to make a fuss about her condition: 'you just get on with it' (35-36), or in this case does not wish for others to make a fuss over her. Through this representation, then, she implies moral reasoning for her non-disclosure.

Linda later proposes practising 'selective disclosure' (Schneider and Conrad, 1980): 'the people who (.) need to know (.) I tell (.) and if they don't need to know then...there's just no point really' (37-39). She does not elaborate on the circumstances under which she feels certain people would 'need to know' about her condition; but we could speculate that this refers to Linda disclosing to people she is close to, around whom it would be difficult to conceal her condition. This could be inferred as being not only proximal closeness, but also those with whom she shares a greater level of trust (Sarangi, 2007). It is thus implied that Linda only 'comes out of the closet' (Schneider and Conrad, 1980), to certain people, and/or in certain contexts. This reasoning functions as 'justification',

‘den[ying] the pejorative quality associated’ (Scott and Lyman, 1968: 47) with her passing, by proposing that it is *unnecessary* for her to disclose to everyone.

However, again in contradiction to her earlier assertions that she does not care what others think of her, Linda constructs another ‘excuse’ for her passing, this time based around her concerns about the stigma attached to T1DM: ‘it’s not exactly a normal...common thing to have’ (26-27), and later: ‘what’s the point in having them [generalized others] think I’m a bit weird’ (39-40). These findings problematize Scott and Lyman’s (1968) separation of ‘excuses’ and ‘justifications’, as whilst I have identified separate instances of these two types of construction, it can be seen that and these constructions are by no means mutually exclusive, here being interwoven at different junctures within the same account. This excuse (26-27 and 39-40) again demonstrates ‘self-as-other’ (Sarangi, 2007) orientation, with Linda constructing herself as not being ‘normal’. Again it is ‘felt’ rather than ‘enacted’ stigma (Scambler and Hopkins, 1986) that is constructed as influencing this passing. However, Linda’s concern appears to be that others will ‘think’ (40) badly of her, as opposed to necessarily *acting* upon this stigma. Whilst Linda’s account primarily addresses ‘generalized’ others, with only one instance of a ‘specific’ other (Sarangi, 2011) being introduced (12), we can assume that these are *known* others. Even in cases where hypothetical scenarios are constructed (3-4 and 39-40), these appear to be the *hypothetical reactions* of known others, rather than hypothetical *unknown* others, as these issues of disclosure would likely not be relevant in the case of strangers.

Through her self-as-other constructions, Linda appears to challenge the arguments of the sociologist Guggenbühl-Craig (1980), who contends that ‘total health’ is merely a ‘fantasy’ (1980: 14), and that everyone has some form of ailment or deficiency. Rather than ascribing to the views that no one is truly healthy, and thus having an illness of some kind is the norm, Linda constructs her T1DM as *abnormal*, and herself as different, from those who do not have the condition.

It must be reiterated that my ‘loaded’ question (1-2) may have influenced Linda into discussing her reaction to *negative* perceptions of her T1DM. However, Linda’s representations *are* reflective of her interview as a whole, as she commonly constructs

contradictions between her concerns over others' possible negative views, and the performance of 'project' stigma (Scambler and Paoli, 2008) in the form of strong-willed heroism.

Extract 11 shows some disparity with Linda's account, as the respondent, Robert represents T1DM as being 'normal', and *not* highly stigmatized in the eyes of others, thus *backgrounding* his illness-identity in this context. Robert will be shown to shift at different points in his account between addressing generalized *unknown* others, and alluding to generalized *known* others.

Robert (R) was aged 20, and had been diagnosed with T1DM for five years. At the time of the interview, he was studying for his undergraduate degree at university (see Appendix K; Interview 24: 895-943):

Extract 11:

1. BS: when you think about the sort of person that you are (.) how
2. prominent is [R: um] (.) diabetes do you think within that? (1.0)
3. R: I don't I don't think it's a big thing you know (.) you know
4. the other person on the street isn't gonna go 'oh look he's
5. got diabetes' or anything (.) um (.) I think it's entitled to the
6. individual whether they want to say (.) look I'm diabetic (.)
7. um (1.0) and that's that's what I do I just say to them 'look I
8. am a diabetic' so if anything does go (.) pear shaped then
9. there's (.) you can always fall back on (.)
10. BS: mm=
11. R: =they can sort of help you (1.0) but I don't think it
12. affects me like I don't get singled out saying 'oh there's
13. a diabetic over there stay away from him' or anything=

.

. For the next 15 turns, Robert continues to talk about the imperceptibility  
. of his T1DM.

- 
14. R: not everybody has to know
15. BS: (.) mm (.)
16. R: um (1.0) yeah they just (.) you don't you don't go round
17. telling everybody in the street 'oh look I'm diabetic' so they
18. don't know anyway (.)
19. BS: mm mm=
20. R: =um (.) and like other people have got things
21. wrong with them and it all you know (.) uh I think I I don't
22. know many people who haven't who are perfectly well (.)
23. BS: mm=
24. R: =they've there's always something 'oh I've got a bad
25. hip' or 'I've got a (.) I've got a bit of asthma coming on' or
26. something [BS: mm] they there there's things like that (.)
27. BS: mm mm (1.0)
28. R: so just (.) if you wanna keep quiet about it then keep quiet
29. about it but just (.) no impact at all on uh (.)
30. BS: mm (.)
31. R: your identity or anything like that (.)

When asked how he sees his condition as fitting within his 'self-concept' (Charmaz, 1983) (1-2), Robert minimises the role of T1DM (3). He explains this view through 'self-as-other' (Sarangi, 2007) orientation, in terms of how he feels he appears to generalized unknown others: 'the other person on the street isn't gonna go 'oh look he's got diabetes' or anything' (4-5). Here then, it is through Robert's contention that unknown others will not likely be aware of his T1DM that he is able to represent his condition as occupying only a peripheral role within self.

This construction of T1DM as 'discreditable' (Goffman, 1963) is reflected in Robert's discussion of illness disclosure: 'it's entitled to the individual whether they want to say (.) look I'm diabetic' (5-6), which suggests that Robert is able to 'pass' (Goffman, 1963) if he so wishes. Robert appears here to be shifting to reference to generalized *known* others,

as we can assume that he is not referring to the choice over whether to disclose to strangers. For Robert, then, it appears to be his *outward* physical appearance which is the most salient identity-marker, and it is based on the normalcy of his outer-appearance that he is able to play down his differentness from others, and to construct 'normification' (Goffman, 1963: 44), that is, 'present himself as an ordinary person' (Goffman, 1963: 44).

Despite proposing that he has agency not to disclose his T1DM, Robert reveals that he *does* disclose his condition (7-11), though he does not specify the circumstances in which he discloses, or whether this is context-specific. Robert implicitly suggests that the primary motivation behind his disclosure is the issue of safety, as it can be inferred that 'if anything does go (.) pear shaped' (8) refers to the possibility of Robert experiencing short-term T1DM-related health problems, such as hypoglycaemia (see Appendix A), an interpretation further supported by Robert's proposal that, in these circumstances, the others he tells 'can sort of help you' (11). This is referred to by Schur, Gamsu and Barley (1999: 232) as 'safety telling'. However, Robert only *implies* telling these others how to help him in these circumstances. He indicates dispreference for outlining the details of this disclosure, signalled through hesitations and disfluency, 'sort of' (11), as well as the light-hearted idiom (8), perhaps avoiding the discussion of hypoglycaemia symptoms with me in this context. This could imply that Robert views these aspects of the condition as being potentially discreditable, at least in relation to explicit discussion of them.

Robert implies, however, that when he discloses illness-information, he is *not* stigmatized or marked out from others in a negative way: 'I don't get singled out saying 'oh there's a diabetic over there stay away from him' or anything' (12-13). Therefore, whilst adopting Goffman's terminology in classifying T1DM as 'discreditable' suggests that Robert faces being discredited if his condition were known about, here it is in fact suggested that Robert does not feel he is discredited by others. Robert can therefore be seen, through 'self-as-other' (Sarangi, 2007) orientation, to place T1DM very low down on the continuum of discredibility. This supports Schneider and Conrad's (1980) argument that 'stigma is by no means an automatic result of possessing a discreditable

attribute...[this] becomes relevant to self only if the individual perceives it as discreditable' (1980: 35).

Robert further constructs T1DM as 'normal' through 'self-and-other' (Sarangi, 2007) orientation, constructing similarity between himself and others: 'other people have got things wrong with them...I don't know many people who haven't who are perfectly well...there's always something 'oh I've got a bad hip' or...'I've got a bit of asthma coming on' (21-25). Through placing T1DM in the same bracket as other ailments, such as a 'bad hip' (24-25), Robert constructs the condition as common and mundane, rather than in any way stigmatized. This type of 'normification' (Goffman, 1963: 44) could be termed *generalization*, as Robert appears to be constructing normalcy through generalizing his illness-identity, positioning himself within a wider group of people who have illnesses. By proposing that those without an illness or ailment of some kind are in the minority, Robert aligns with Guggenbühl-Craig's (1980) contention that it is the absence of illness that is removed from normalcy.

Through this construction of his 'normal' outward appearance, and T1DM as not highly stigmatized by others, or as being markedly different from other ailments or illnesses, Robert is able to *background* his illness-identity (Riessman, 1990), explicitly stating that *because* of these factors, he does not consider his T1DM in relation to issues of self: 'no impact at all on...your identity' (29-31). Robert's pronominal use here, the second person 'your' (31), and 'you' (28), as well as the earlier third person reference to 'the individual' (5-6) and 'they' (6), could be seen as an ingrouping strategy, whereby Robert is presenting these views as similar to those of others with T1DM, adding further rhetorical weight to his representations.

Extract 12 demonstrates the respondent, Mitch, also drawing upon others' perceptions in order to construct 'normification' (Goffman, 1963: 44) in relation to his T1DM; however, he orients only to the perceptions and reactions of *friends*, both specific and generalized. Whilst, similarly to Robert, he represents T1DM as not being highly stigmatized or discreditable, unlike Robert, Mitch *foregrounds* his illness-identity.



Mitch (M) was aged 24, and had been diagnosed with T1DM for eight years. At the time of the interview, he was studying for his medical degree at university (see Appendix K; Interview 16: 77-97):

Extract 12:

1. BS: so the way you feel now (.) with it [T1DM] (.) if you think about your overall  
2. identity as a person and who you are (.) I mean do you think it plays  
3. a big role? (.) do you see it as being quite prominent within your life or?  
4. (.) or not?

5. M: (1.0) uh yeah (.) I do (.) I don't not necessarily in a bad way...one of my  
6. friends actually you know ((only something stupid)) but she introduces me (.)  
7. to everyone that she knows she's (.) was one of the social reps one year and (.)  
8. got to know everybody and then whenever she introduced me to someone I  
9. don't know there's always 'this is M (.) he's got diabetes' (.) uh just as a jokey  
10. thing and it doesn't bother me (.)

11. BS: mm=

12. M: =but (.) in that way it is quite uh and lots of my friends (.) joke and we  
13. have a good laugh about it (.) at certain times I can't eat chocolate or (.) I I  
14. love chocolate actually that's my big weakness so (.) um (.) and that's  
15. obviously quite bad (.)

16. BS: mm

17. M: [but um (1.0) but otherwise in general I think it could be (1.0) I don't think it  
18. defines me (.) I think it is a very important (.) aspect and I'm quite open about  
19. it with my friends and everyone talks about it and we have a laugh

.

. For the next 6 lines, Mitch continues to talk about discussing his T1DM with friends.

.

20. so as I said now everyone (.) jokes and laughs at me and tells me I'm gonna  
21. get fat and (.) overweight and you know (.) end up having to take (.) tablets as  
22. well as the (.) insulin and all this sort of thing and introduce me as being the  
23. diabetic one (.) um and I like it actually it's really (.) it's just funny something

24. to add to my character I suppose (.)

In response to my prompting (1-4), Mitch confirms that he sees T1DM as having a ‘prominent’ (3) role within his life and within his self-concept (5). He constructs this prominence firstly through ‘self-as-other’ (Sarangi, 2007) orientation. He talks of how his friend introduces him to new people as ‘the diabetic one’ (22-23), demonstrating a form of mediated-disclosure. This kind of introduction foregrounds T1DM as *the* main aspect of Mitch’s identity, which marks the condition as something that separates him from others to the degree that it is worthy of comment, thus implicitly constructing T1DM as removed from normalcy. This construction takes the form of a habitual narrative, suggesting that this identity-foregrounding is a consistent occurrence. However, Mitch proposes that he does not view being marked out in this way as being negative: ‘just as a jokey thing and it doesn’t bother me’ (9-10). The prominent role that Mitch represents T1DM as having within his self appears, then, to derive partially from *others* framing the condition in this way, a framing which Mitch appears to happily accept.

In interpreting this construction, Mitch’s student-doctor identity must also be taken into consideration. We can perhaps infer from the description, ‘one of the social reps’ (7), that the friend Mitch is referring to is a fellow medical student. Introducing Mitch as ‘the diabetic one’ could therefore be viewed within the frame of doctor-banter, with the intention of creating humour through the dissonance between the identity of doctor and that of person with a medical condition. Considering the data within this frame does not necessarily diminish the interpretation that Mitch’s differentness (Goffman, 1963: 14) is being explicitly marked; however, this shared medical-orientation will probably influence this mediated-disclosure, with such explicit foregrounding of Mitch’s T1DM less likely in interactions involving non-doctor friends.

In terms of Mitch’s own disclosure of illness-information, he proposes being ‘quite open’ (18) in disclosing his condition to friends, though he does not elaborate as to whether he would disclose as readily to those with whom he is not so well acquainted. Again through a habitual narrative, Mitch reveals that within his friendship groups, his T1DM is, at times, explicitly discussed: ‘lots of my friends (.) joke and we have a good laugh about it’

(12-13). Whilst open, jovial discussion of Mitch's T1DM amongst him and his friends could, in some cases, be seen to be quite counter-normative, and potentially face-threatening (Goffman, 1955), if we infer that Mitch is referring to fellow medical-student friends, this kind of discussion could be seen as more socially acceptable within this group. Additionally, Mitch's use of the inclusive first person plural pronoun 'we' frames this behaviour as 'laughing with', rather than 'laughing at' (Glenn, 2003: 114); thus Mitch's complicity in such jokes frames this not only as being socially acceptable, but in fact as quite positive, collaborative behaviour. Here, Mitch's representation of combined-action between himself and others could be conceptualised as 'self-*and*-other' orientation, marking a joint-construction of his T1DM.

It could be argued that Mitch's activity of laughing and joking with friends about his T1DM simultaneously constructs it as both abnormal, and as normal. Openly discussing T1DM in this way marks Mitch out from others in his friendship group who do not have T1DM, thus constructing him as different from them. However, mutually agreeing with friends that this is a topic that it is acceptable to joke about de-mystifies the condition, separating it from other topics deemed inappropriate to joke about, perhaps situating T1DM amongst other 'normal' joked-about topics. This can therefore be seen as an example both of 'normification' *and* 'normalization' (Goffman, 1963: 44); as whilst the former refers to Mitch's attempts to construct his own normalcy, the latter is others' construction of the individual with differentness as normal. This construction also exemplifies what Schneider and Conrad (1980) term 'telling as therapy' (1980: 39), where, through disclosure, the individual is able to 'define [his or her] condition as a non-remarkable and neutral facet of the self, perhaps even an "interesting" one' (1980: 39). Through proposing that he joins in with his friends' jokes, and takes no offense, Mitch implicitly constructs a positive, morally-appropriate identity as somebody who is a good sport, able to laugh at himself and make light of his problems, qualities usually looked upon favourably.

Whilst I proposed above that the use of the inclusive 'we' (12) suggests 'laughing with', Mitch later talks of his friends laughing 'at' (20) (Glenn, 2003: 114) him about his T1DM. However, rather than representing himself as being stigmatized or singled out by this

laughter, Mitch instead proposes that ‘it’s just funny something to add to my character’ (23-24). This again functions to implicitly construct normalcy in relation to the condition by placing it alongside other ‘normal’ character traits. The adjectival use of ‘funny’ (23) can also be seen to mitigate the severity of the condition. This allows Mitch to further play down the stigma-potential attached to T1DM, positioning it relatively low down on the continuum of discreditability.

Whilst Extracts 10-12 address issues surrounding verbal disclosure of illness-information to others, in Extract 13, the respondent, Timothy, addresses the issue of physical (non-) disclosure, in addition to verbal disclosure. These two types of disclosure will be shown to be framed quite differently. Additionally, whereas Extracts 10-12 address issues of stigma, or lack thereof, Timothy will also be shown to attend to issues of *deviancy*, thus making relevant Scambler’s (2004; 2006; 2009) distinction outlined in 7.1.

Timothy (T), who we also came across in Chapter 6 (Extract 1), was aged 23, and had been diagnosed with T1DM for nine years. At the time, he was working fulltime as a hospital pharmacist (see Appendix K; Interview 1: 101-121):

Extract 13:

1. BS: do you feel as if it [T1DM] has any impact in terms of social or romantic
2. relationships or anything like that?=  
3. T: =no (.)
4. BS: not at all?=  
5. T: =not at all (.) no (.) not at all (.) because socially I mean I only tell
6. my nearest and dearest (.) uh (.) friends best friends you know my best (.)
7. good friends who I know will be my friends for a long time I only (.) they’re
8. the only ones who know (.) um (.) girlfriends inevitably find out (.) and they
9. don’t mind (.) um (.) I mean if I was in a restaurant (.) and I was with a whole
10. group of people I would go to the to the loo to shoot up I’m not gonna go
11. inject myself in front of a bunch of strangers I mean in an ideal world (.)
12. perhaps that would be the thing to do but I (.) I would find it a bit unpleasant if

13. I was someone (1.0) if I was someone else watching from a table across across  
14. the restaurant I wouldn't wanna see someone doing that (.) it would lead to  
15. confusion (.) or they might just think oh what's that guy doing? well they  
16. might know full well and they might think god why's he doing that (.) in front  
17. of us you know is he trying to prove something? (.) so I wouldn't do it you  
18. know I would never do that so only my nearest and dearest know (.) [BS: mm]  
19. and that's it you know (.) but socially romantically nah no problems at all (.)  
20. because if I ever need to inject in front in public (.) I'll just pop off to a rest  
21. room and do it

When asked if his T1DM has any impact on his social and romantic relationships (1-2), Timothy is adamant that this is not the case (5). The reason he gives for this is that, 'socially' (5), he only discloses his condition to his 'nearest and dearest...best friends' (6). This may imply that Timothy feels that there could be the potential for T1DM to affect his social relationships if he were to disclose to those who are not 'best' friends, or who he does not know as well, perhaps implying Timothy sees T1DM as being potentially discreditable. Issues of (dis)trust therefore appear to be important, Timothy suggesting that he would only trust his 'best' friends with such information. This construction of agency in terms of selective disclosure again underlines the initially non-perceptible nature of the condition, and exemplifies Schneider and Conrad's (1980) 'closet' metaphor, with Timothy reportedly only 'coming out' to a select few. Timothy's contention that he only discloses to those he shares a close relationship with frames these others as 'the wise', in Goffman's (1963: 41) terms, that is, 'persons who are 'normal' but their special situation has made them privy to the secret life of the stigmatized individual'. Schneider and Conrad (1980) refer to these individuals as 'safe others' (1980: 38).

In terms of romantic relationships, rather than talking of actively disclosing illness-information, as in the case of friends, Timothy proposes that 'girlfriends inevitably find out' (8), suggesting a lack of agency over disclosure, perhaps because romantic partners are in a position to witness many of the 'backstage' (Goffman, 1969: 114) behaviours that others do not see. As Goffman comments: 'relationships can necessitate time spent together, and the more time the individual spends with another, the more chance the other

will acquire discrediting information about him' (1963: 108). However, Timothy proposes that when girlfriends do find out they do not react negatively (8-9).

Having proposed that he will only 'tell' his best friends about his condition (5-7), Timothy creates a distinction between verbal disclosure and physical disclosure, by stating that he would not carry out self-care practices, such as injecting insulin, in front of others, in a context such as a restaurant, and would instead excuse himself to do this in the bathroom (9-17). He therefore represents such self-care practices as primarily 'backstage' (Goffman, 1969) behaviours. He shifts here from orienting to others who are close to him, to generalized *unknown* others, as Timothy suggests that the primary reason for his concealment of self-care practices is that he would not want 'strangers' (11) to witness these practices, though he does not reveal whether or not he would be comfortable carrying out these practices in front of the group in his social company. It is implied, then, that whilst Timothy does not see himself as being discreditable in the eyes of best friends and girlfriends, presumably because they will view other aspects of his self as being more salient than T1DM, disclosing to unknown others, through physical disclosure at least, is potentially higher on the continuum of discredibility.

Timothy attributes his concealing of self-care practices not to his own self-consciousness about others witnessing these behaviours, but to how he thinks others would perceive this, thus adopting a 'self-as-other' (Sarangi, 2007) orientation at this point. Timothy places himself in the position of these hypothetical strangers, proposing that if he were in their place, he would 'find it a bit unpleasant' (12) to witness somebody injecting insulin. Timothy therefore constructs a positive identity as being considerate towards others, putting their concerns above his own convenience. He speculates that these unknown others may also experience 'confusion' (15). He does not elaborate on this, but it could be that Timothy is implying that strangers may mistake his injecting insulin for others behaviours, such as illegal drug-taking, an interpretation supported by his description of injecting insulin as excusing himself to 'shoot up' (10), a phrase commonly used to refer to the injecting of illegal drugs. Here, then, it is suggested that physical disclosure, when left unexplained or not clarified, could lead to misconceptions that Timothy is engaging in 'deviant' (Scambler, 2004), morally-*inappropriate* activities.

Timothy further speculates that unknown others witnessing these behaviours may well be aware that this is treatment for T1DM, but that this could also lead to negative reactions, not necessarily due to *stigma* attached to T1DM, but because these strangers may feel that it is inappropriate for him to carry out such practices on the 'frontstage' (Goffman, 1969: 109): 'they might think god why's he doing that (.) in front of us you know is he trying to prove something?' (16-17). Through the reported thoughts of hypothetical unknown others, then, Timothy projects a concern that they may feel he would actually be doing this purposefully in front of them in order to make a point, perhaps that he does not care what others think of him, and thus they may perceive him as explicitly rejecting social norms. Here, then, it is issues of *deviance* being addressed through this 'self-as-other' representation, and specifically 'felt deviance' (Scambler, 2004), that is, anticipation of experiencing 'enacted deviance' on the grounds that injecting his insulin in public could be deemed a morally-inappropriate practice, thus evoking moral judgements against him. Timothy's insistence that he instead excuses himself to inject in the bathroom can therefore be seen to display 'project deviance' (Scamber and Paoli, 2008): 'strategies and tactics devised to avoid or combat enacted deviance without falling prey to felt deviance' (2008: 1851).

Extracts 10-13 have shown similarity in that all four respondents adopt 'self-as-other' (Sarangi, 2007) orientations, drawing on the perceptions of others to represent the (lack of) normalcy of T1DM in relation to those who do not have the condition, and subsequently to construct their own illness-identities. There was, however, shown to be variation in their accounts. Linda represents her T1DM as abnormal, and herself as *different* from others, thus foregrounding her illness-identity (Riessman, 1990), and constructing 'felt stigma' (Scambler and Hopkins, 1986); however, through 'self-vs.-other' orientation, she also performs a positive, heroic identity. In contrast, both Robert and Mitch construct T1DM as *not* being highly discreditable or stigmatized; however, they do this in differing ways. Robert represents similarity between himself and others ('self-and-other' orientation) through constructing a 'normal' outward appearance, allowing him to *background* his illness-identity. Mitch *foregrounds* his illness-identity, marking his differentness from his friends through both 'self-as-other' and 'self-and-

other' orientations. However, through constructing T1DM as an acceptable topic to be discussed and joked about, Mitch 'normifies' (Goffman, 1963: 44) the condition. Timothy makes the most marked distinction between known and unknown others, constructing T1DM as not highly discreditable vis-à-vis close friends and romantic partners, but potentially discreditable in the eyes of unknown others. However, unlike in Extracts 10-12, he addresses issues of *deviancy* regarding physical disclosure, rather than the (lack of) stigma attached to the condition itself.

#### 7.4 *Representations of IBD*

Having analysed extracts from interviews with T1DM-respondents, I will now examine extracts from those with IBD-respondents.

Extract 14 shows Sally constructing 'felt stigma' (Scambler and Hopkins, 1986) through representing IBD as somewhat taboo and socially unacceptable, and thus potentially discreditable. As a result she reports feelings of embarrassment regarding disclosure of illness-information to generalized known others, leading to both *partial* and *selective* disclosure on her part.

We came across Sally (S), aged 18, in Chapter 6 (Extract 7). She had been diagnosed with Ulcerative Colitis (UC) for six years, and at the time of the interview was living at home with her parents (see Appendix K; Interview 28: 211-270):

Extract 14:

1. BS: okay so (.) when you said about not knowing (.)
2. whether to tell people (.) what do you do? I mean are
3. there lots of people that know or (.) do you generally not
4. tell people?
5. S: [um (.) I don't tell people (.) the full extent (.) I
6. tell people that (.) um (.) I've got a disease (.) I tell them
7. what it's called (.) mainly because people usually don't



8. know what it is (.)  
9. BS: yeah yeah  
10. S: [I tell them what it's called (.) and they kind of know  
11. I still have pain I go back and forth to the toilet but we  
12. don't discuss it (.) but I always tell my teachers (.)  
13. BS: okay (.)  
14. S: so my lecturers and stuff in college (.) they all know (.)  
15. because (1.0) well (.) you keep going (.) to the (.) toilet and  
16. stuff and it can get a bit (.) weird but I usually only tell  
17. (.) my teachers (.) I've (.) my friends not so much (.)  
18. BS: yeah (.)  
19. S: I'll I'll tell them if they ask me (.)  
20. BS: okay (.)  
21. S: but they kind of (.) they're happy to know (.) what I've  
22. got and (.) that's about it really

Sally proposes that she practises *partial* verbal disclosure of her IBD to others: 'I don't tell people (.) the full extent (.) I tell people that...I've got a disease (.) I tell them what it's called' (5-7). Thus, whilst Sally does not 'pass' (Goffman, 1963), she reports disclosing very little information to others, withholding details of symptoms or treatments. Her 'coming out of the closet' (Schneider and Conrad, 1980) can therefore be considered minimal.

Through 'self-as-other' (Sarangi, 2007) orientation, Sally reveals that others are aware of her IBD symptoms, due to them witnessing her going 'back and forth to the toilet' (11), though she mitigates their level of awareness: 'they kind of know' (10). In Sally's account, then, IBD is not entirely imperceptible, as her *behaviours resulting from symptoms* are, at times, outwardly apparent. These can thus be considered 'stigma cues' (Scambler and Hopkins, 1986: 36): 'events and happenings...which are...noticed and ultimately 'give them [the individual with differentness] away' (1986: 36), though Sally implies that these stigma cues alone do not *necessarily* reveal to others that she has IBD.

Sally reports preferring to leave such behaviours unexplained, rather than disclosing that they are symptoms of IBD (11-12), perhaps perceiving the ‘felt stigma’ (Scambler and Hopkins, 1986), the fear of experiencing stigma if she were to disclose her condition, as outweighing ‘felt deviance’ (Scambler, 2004), the fear that others will perceive her as deviant because of these unexplained behaviours.

It is unclear at this point exactly who Sally is referring to, as she talks only very generally of ‘people’ (7), though we can infer these to be *known* others. She does, however, make a distinction between those to whom she does disclose her condition, and those she does not. She reports ‘passing’ in relation to friends, but disclosing to college lecturers, giving the reason that otherwise it would ‘get a bit...weird’ (16) if she were constantly excusing herself to use the toilet. Whilst not explicitly stated, it can be assumed that Sally is referring to excusing herself during lectures or classes, which she may view as being more noticeable, and thus have greater potential to seem ‘weird’, than would be the case in other social contexts. Whilst having observed above, then, that Sally displays a general preference for leaving ‘stigma cues’ (Scambler and Hopkins, 1986: 36) unexplained, in opposition to this, in the context of college lectures she represents the ‘felt deviance’ of leaving these behaviours unexplained as outweighing the ‘felt stigma’ attached to revealing that they are a result of her IBD. Sally’s disclosure of illness-information, and whether she leaves stigma cues unexplained, or attributes these to her IBD, appears therefore to be context-dependent. This may also be dependent upon who she is interacting with, as she may feel more fear of experiencing stigma from friends than in relation to responsible adults in a position of care.

Sally’s constructions, in lines 5-22, can also be viewed through the lens of Scott and Lyman’s (1968) ‘accounts’ framework. She proposes that her friends do not actually wish to know details of the condition: ‘they’re happy to know (.) what I’ve got and (.) that’s about it really’ (21-22). This functions as a ‘justification’ for her *partial* disclosure, as through proposing that she is not in fact concealing her condition from friends, and that this level of disclosure is mutually-desired between herself and others, she ‘denies the pejorative quality associated with [the act in question]’ (Scott and Lyman, 1968: 47).

Following this, the interaction immediately continues:

Extract 14 (contd):

23. BS: [yeah yeah (1.0) okay (.) so are  
24. there issues over it (.) being embarrassing to tell them [S: mm] (.)  
25. what it's all about? I mean is that  
26. S: [yeah (.) very]  
27. BS: is that the main thing?  
28. S: [yeah (.)  
29. BS: yeah=  
30. S: =yeah I wouldn't (.) I would only tell (.) close  
31. friends I wouldn't tell people (.) if they were just  
32. wondering why I keep going back and forth (1.0) um it  
33. is very embarrassing (.) to tell people (.) you know things  
34. like that (.)  
35. BS: mm mm (.)  
36. S: and then (1.0) I don't tell that many people it's hard just  
37. to tell teachers that 'cause that's (.) you know (.) um (.)  
38. with my friends ((there's no)) but I always think well  
39. they probably do know (.) you know they guess (.)  
40. BS: mm (.)  
41. S: but I couldn't actually discuss it with them I couldn't  
42. (.) say (.) this is these are the actual symptoms (.) that  
43. kind of thing (.)  
44. BS: mm (.)  
45. S: I'd rather them (.) I'd rather know that (.) okay they  
46. might know but then again they might not (.) I'd rather  
47. just leave it at that (.)  
48. BS: right okay [S: chuckles] (.) okay (.) I mean are you  
49. worried that if people knew the full extent of it are you  
50. worried what they'd think of

51. S: [yeah]  
52. BS: you and things like that? yeah  
53. S: [yeah (1.0) because (.) especially  
54. it was (.) more in school 'cause people are just (.) so  
55. childish in school (.)  
56. BS: right yeah  
57. S: [you know (.) giggle about it and things like that (.)  
58. when I got to college my friends were a lot more mature  
59. but still (.) you're still quite young and you're still (.)  
60. finding it quite embarrassing

Sally here reports feelings of embarrassment about the condition symptoms as being the main reason for her partial disclosure, therefore constructing the condition as taboo and socially unacceptable (32-34), and affording it a high position on the continuum of discredibility. Though the term 'embarrassing' is introduced by me (24), it is a word used by Sally twice in the interview prior to this extract (see Appendix K; Interview 28: 70 and 72). The term appears to connote *shame*, as opposed to *blame*, thus here it is clearly issues of 'felt stigma' (Scambler and Hopkins, 1986) influencing this partial disclosure. For Sally, the source of this embarrassment appears to be both the possibility that friends may actually *know* about the details her condition (48-60), but also the act of disclosure itself, as she proposes being too embarrassed to actually explain the symptoms to them (41-42). The euphemistic phrase 'things like that' (33-34), and the indexical 'it' (41), used to refer to the more discreditable details of the condition, also display a dispreference towards explicitly outlining these details to me in the interview context. In spite of this construction of 'felt stigma', Sally reports disclosing her illness to 'close friends' (30-31), thus in similarity with Timothy's account (Extract 13) this underlines the importance of (dis)trust vis-à-vis disclosure; close friends are considered 'safe others' (Schneider and Conrad, 1980: 38), those Sally is willing to trust with this discreditable information.

Whilst Sally reports having experienced 'enacted stigma' (Scambler and Hopkins, 1986) to a more significant degree at a younger age (53-57) than in the present, as her current

friends are 'more mature' (58), she proposes still finding the condition 'embarrassing', *because* of her young age (59-60). This suggests, then, that from Sally's perspective, symptoms are *especially* embarrassing for younger people. This could be seen to function as an 'excuse' for her reported embarrassment, and subsequent partial and selective disclosure, as by suggesting that her youth influences her behaviour, she is able to 'den[y] full responsibility' (Scott and Lyman, 1968: 47). Sally's pronominal use also contributes to this accounting. Her use of the second person pronoun 'you're' (59) functions as an ingrouping device, implying that others with IBD would behave in a similar way in their disclosure practices, thus further excusing her own behaviour.

In Extract 15, Rosie similarly reports either non-disclosure of her IBD, or only partial disclosure to generalized known others, as result of 'felt stigma', and also at times 'enacted stigma' (Scambler and Hopkins, 1986), related to what she constructs as the taboo nature of IBD-symptoms. However, whilst Sally represents the problematic nature of behaviours linked to disease symptoms becoming outwardly perceptible, in contrast to this, Rosie constructs problemat�city regarding the *non*-outwardly apparent nature of the condition leading to 'enacted deviance' (Scambler, 2004).

Rosie (R) was aged 22, and had been diagnosed with Ulcerative Colitis (UC) for six months; although she reported having experienced disease symptoms for a significant period before being diagnosed. At the time of the interview, she was in the final year of her undergraduate degree at university. Just prior to the beginning of this extract, I asked Rosie about the role of IBD within her life. Having briefly discussed the impact of symptoms on her lifestyle activities, she orients to her presentation of the condition to others (see Appendix K; Interview 4: 131-135):

Extract 15:

1. R: um it's quite difficult to (.) explain to people (.) what it
2. involves 'cause as soon as you say (.) 'poo' they go 'ahh
3. no' (chuckling) 'don't talk to me' [BS: (slight chuckle)] and
4. you say 'blood' and they go 'nooo don't say anything' (.)

5. so um (.) it's quite difficult

. The discussion moves onto the effect of IBD on social activities, until  
. a few minutes later when Rosie orients to her social relationships  
. (Interview 4: 391-428):

6. and my friends (.) um (.) I didn't (.) I mentioned it because  
7. obviously I'd been in hospital in the summer and I hadn't  
8. (.) been in contact for a little while and (.) they wanted to  
9. know how China was and then when I came back I was  
10. in hospital and things (.) but um (.) I'm not sure that they  
11. really understand (.) I don't think (.) oh well I haven't really  
12. explained it properly I suppose you kind of (.) say 'I've got (.)  
13. Ulcerative Colitis and (.) that's why I was in hospital and  
14. it means this' and they go 'oh okay' (.) and then they it's  
15. like back of the mind and they forget about it so next  
16. time you say (.) 'yeah I'm feeling ill' (.) they don't (.)  
17. they don't put them both together they think oh (.) you  
18. know she's just (.) got a cold or something (.) and um  
19. (.) they get a bit annoyed when I don't go out and  
20. things and I (.) do try and explain (1.0) I don't try and  
21. explain I don't (.) I just say that I'm not feeling well I'll  
22. stay in (.) I don't really feel like I should have to justify  
23. (.) have to use the Ulcerative Colitis card to not want to  
24. go out or to not feel like going out (.) and um (.) I know  
25. they get annoyed with me because I can't always go out  
26. with them (.) and I can't drink (.) a lot (.) and (.) um  
27. (chuckling) I get tired and I have to go home (.) and  
28. you know (.) I do I try put putting in my time in other  
29. ways you know I'll I'll go round for cups of tea and  
30. 'cause I don't live with them I live with my boyfriend  
31. (.) um and I lived with these girls last year and (.) I try

32. and you know (.) pop round for tea and (.) dinner and  
33. stuff and (.) but you know at uni the bonding's all done  
34. (.) on nights out so (.) people get annoyed and think  
35. you're not putting in your friend time if you don't go  
36. out as much and (.) I can't do it so and I don't feel like  
37. I should have to make excuses for it almost I feel I just  
38. (.) just accept it it's fine it's just the way it is (.) but (.)  
39. I don't think they (.) people really understand but at the  
40. same time I'm sure they've got their own problems that  
41. (.) I don't really understand so (.) can't expect them to  
42. be aware of it all the time

Rosie proposes finding it 'difficult to...explain to people' (1) the symptoms of her condition, due to previous experiences of 'enacted stigma' (Scambler and Hopkins, 1986), whereby others have reacted squeamishly to the description of these symptoms. These others are not specified, though we can assume them to be *known* others. Rosie thus constructs implicit 'self-as-other' (Sarangi, 2007) orientation, framing the condition symptoms as taboo and socially unacceptable in the eyes of others, positioning IBD relatively high on the continuum of discreditability. This construction takes the form of a habitual narrative, perhaps demonstrating this to be a common reaction to Rosie's description of symptoms. Rosie constructs these reactions in quite a humorous way, however (2-4), and her chuckling, which whilst in some contexts may indicate 'troubles-resistance' (Jefferson, 1984: 350), here appears to suggest that she does not find these reactions upsetting. Additionally, proposing that others react in this squeamish manner does not necessarily imply that they treat her any differently as a result. It is likely that such reactions demonstrate fellow interlocutors' discomfort in discussing issues relating to bowel functions, as opposed to them necessarily forming a negative attitude towards Rosie. Nevertheless, this reaction still marks the condition as having a degree of stigma attached to it.

Rosie later constructs 'self-as-other' (Sarangi, 2007) orientation in relation to the reaction of friends to whom she has disclosed her condition. She displays frustration regarding her

friends' lack of understanding of issues surrounding her condition; however, she does accept some accountability for this: 'I haven't really explained it properly' (11-12). She proposes that when she feels unwell as a result of her IBD, she does not reveal to her friends that this is caused by her IBD, therefore her friends do not associate this with their prior knowledge of her having been hospitalised because of the condition, and instead assume that her feeling unwell is due to less serious illness, such as a cold (16-18). This implies a different kind of partial disclosure to that addressed by Sally (Extract 14), Rosie not necessarily withholding details about symptoms, but rather not explaining to friends the *chronic nature* of the illness. This means they do not understand that symptoms are liable to return, and thus 'forget about it' (15), resulting in them becoming 'annoyed' (19) with her for not partaking in activities such as 'nights out' (34).

Whilst Rosie could be held accountable for her friends' lack of understanding, due to her admission of not having explained the condition properly: 'I just say that I'm not feeling well' (21), she mitigates this self-responsibility by arguing that she does not feel she should 'have to use the Ulcerative Colitis card to not want to go out' (23-24), or 'make excuses for it' (37). Here then, Rosie constructs an 'excuse' (Scott and Lyman, 1968) for only partially disclosing her condition, by attributing blameworthiness to her friends for their annoyed reactions, proposing that they should just accept a generalised illness account for abstaining from sociable activities, and she should therefore *not have to* remind them of her condition. Rosie clearly does not wish to *do* repeated disclosure, perhaps signalling a reluctance to be labelled as somebody with UC, thus her account displays a tension between her wanting her friends to be understanding about her condition, yet not wanting them to view her *in relation* to her condition.

Rosie also attempts to construct a positive identity as a good friend, by proposing that, whilst her condition prevents her from staying out late at night and drinking alcohol, she does make an effort to see her friends in other sociable ways in which she is not restricted by her IBD (31-33). She claims, however, that these types of activity are, in her friends' views, not equivalent to nights out, to which they afford greater salience: 'the bonding's all done (.) on nights out so (.) people get annoyed and think you're not putting in your friend time if you don't go out as much' (33-36).



Here, then, rather than disclosure of IBD resulting in 'enacted stigma' (Scambler and Hopkins, 1986), or unexplained 'stigma cues' (Scambler and Hopkins, 1986: 36) prompting 'enacted deviance' (Scambler, 2004), conversely, it is the *absence* of visible signs or symptoms, the imperceptibility of the condition, that leads to 'enacted deviance' of a different kind. The fact that Rosie's friends think she has a less serious, acute illness means that they do not see a justifiable reason for her abstaining from sociable activities. In this case, then, the appearance of normalcy, which partially results from Rosie's desire not to explicitly mention her IBD, is in fact problematic, as opposed to desirable, as Rosie faces charges of 'deviance' for not partaking in culturally-expected social activities. This leads to moral judgements of *blame* towards Rosie, because her friends are unaware that this abstinence is not Rosie's fault.

Rosie does mitigate the criticism of her friends to some degree: 'I'm sure they've got their own problems that (.) I don't really understand so (.) can't expect them to be aware of it all the time' (40-42). Through this, she constructs a morally-appropriate identity as being thoughtful and understanding, and avoids potential charges of egocentricity. Additionally, through situating IBD as one of life's problems which everybody has to deal with, Rosie implicitly 'normifies' (Goffman, 1963: 44) her IBD, constructing it as no different from other people's hardships, which could serve to further legitimate her decision to only partially disclose her condition.

Later in the interview, the discussion returns to the issue of disclosure of illness-information (Interview 4: 721-738):

Extract 15 (contd):

43. BS: so do you ever think that you would try and hide it or  
44. conceal it from someone when you first met or would  
45. you not want them to know or [R: um] anything like  
46. that?=  
47. R: =on first meeting I don't think that I would ever

- 
48. (.) tell anybody (.) and I think (.) I dunno (.) I  
 49. wondered about telling (.) I suppose (.) it's easier to say  
 50. I've got a tummy ache or I've got a bug or something if  
 51. you're not (.) feeling well that kind of thing (.) if you  
 52. didn't know someone I think (.) also 'cause you've  
 53. got to gauge how they're gonna react you know (.) if  
 54. you just suddenly blurt out 'I've got Ulcerative Colitis'  
 55. they might go 'urghh' you know 'what's that is it  
 56. infectious?' and you know (.) not want to (.) know you  
 57. but (.) um (.) yeah or (.) they might be really  
 58. understanding about it which you hope for obviously (.)  
 59. I wouldn't tell someone straightaway (.) definitely not  
 60. (.) I'd wait (.) 'til I knew them a bit better

Having been asked whether she would ever 'conceal' her IBD (43-46), Rosie responds quite adamantly that she *would* always actively conceal her condition when first meeting somebody (47-48). It must be noted, however, that my framing of this question sets up the expectation that there will be orientation towards *non*-disclosure. Rosie proposes that her decision to 'pass' (Goffman, 1963) is due to 'felt stigma' (Scambler and Hopkins, 1986) in relation to people she does not know well. One of these reported fears is that recently acquainted others may display *ignorance* in thinking that the condition is infectious, which itself is a form of stigma (Green, 1995: 557). The modal verb 'might' (55) signals that these are the hypothetical views of others about which Rosie is speculating, as opposed to 'enacted stigma'. She in fact speculates that she could be stigmatized to the extent that others may 'not want (.) to know you' (56). She does, however, also propose an alternative possible reaction whereby others 'might be really understanding' (57-58). Rosie thus constructs two 'extreme-case formulations' (Pomerantz, 1986) regarding others' possible reactions, which occupy polar opposites in their levels of positivity/negativity. Rosie suggests that her lack of certainty regarding which of these opposing reactions she would receive means that she is not willing to take the risk of disclosing. In describing her hypothetical disclosure, Rosie uses the phrase 'suddenly blurt out' (54), which has negative connotations of being hasty and not well

considered, suggesting she views disclosure of illness-information as something which requires careful thought and planning. Rosie's pronominal use here is also noteworthy, as throughout this particular passage (43-60) she switches several times between the first person singular pronoun 'I' and the second person 'you', perhaps constructing herself as part of an 'ingroup' of those who have IBD, suggesting that others would have similar concerns regarding disclosure, thus 'excusing' (Scott and Lyman, 1968) her non-disclosure practices.

Rosie implies that at times the symptoms of her IBD can become outwardly apparent when she is feeling unwell, and in these circumstances she conceals her condition by attributing such symptoms to a less serious, more common illness: 'it's easier to say I've got a tummy ache or I've got a bug or something if you're not (.) feeling well' (49-51). Whilst framing this as 'easier' presumably because it would require no further explanation, it is also likely that Rosie sees attributing symptoms to a more common illness as having less stigma-potential. This demonstrates 'stigma-management' (Goffman, 1963: 69) on Rosie's part, 'presenting signs of a stigmatized failing as signs of another attribute, one that is less significantly a stigma' (1963: 117). Again, her use of the second person 'you' (51) legitimates these actions by framing this behaviour as that which anybody in her position would do.

Extract 16 demonstrates Lewis also orienting to the reactions of friends to his IBD. Lewis constructs a very conflicted, problems-ridden account of his ability to manage his IBD in relation to others. He represents friends as responding negatively to his IBD, both when he has disclosed his condition *and* when he has chosen to 'pass' (Goffman, 1963). Lewis constructs two narratives recounting specific past events, with the rhetorical function of emphasising the difficulties he has faced when interacting with others.

Lewis (L) was aged 19, and had been diagnosed with IBD for ten years, which was initially thought to be Ulcerative Colitis (UC), but was later re-diagnosed as Crohn's disease (see 1.3). At the time of the interview, he was living at home with his parents, and had just finished college. This extract follows discussion about the impact of IBD on a

recent holiday Lewis went on with a group of friends (see Appendix K; Interview 25: 53-101):

Extract 16:

1. BS: so I mean did it [the symptoms related to IBD] cause you (.) a lot
2. of problems when you were away on holiday in terms of what
3. you were able to do with your mates and stuff? (.)
4. L: um (1.0) it caused me problems (3.0) because (1.0) as soon as
5. I got through the door (.) I had to use the toilet (.) and I made
6. one hell of a stink that was terrible (.) but the lads they said
7. ‘right L you’re not ever gonna use our toilet again’ (.) and the
8. only toilet next was the one the next floor up (.) and we
9. didn’t know where the stairs were (.)
10. BS: right right (.)
11. L: so one day when I was bursting I had to run down the
12. corridor and out into the (.) place where they had all the lifts
13. and I had to wait about (.) three or four minutes (.) for a lift to
14. come (.) to go up one flight of stairs (.) and (4.0) it was a
15. mess when I got back (1.0) because I (.) I just bled (.) it it was
16. (.) it could have been helped (.) if they’d just let me go but
17. they didn’t know (.)
18. BS: mm mm (.)
19. L: and I didn’t (.) I’ve only ever told some of my friends (.)
20. ‘cause it’s hard for me to tell everyone about it (.)
21. BS: oh right so you obviously went on holiday with your mates
22. but they didn’t know anything about it then?
23. L: [yeah]
24. BS: then so obviously
25. L: [only one of them did (.) and he kept saying
26. ‘leave him alone leave him alone’ (.) but no nobody else
27. understood (.)

When asked whether his IBD affected his participation in activities whilst on holiday (1-3), Lewis instead constructs 'self-as-other' (Sarangi, 2007) orientation vis-à-vis the reaction of his friends to the presence of his IBD-symptoms. Lewis highlights the problematicity caused by his IBD through constructing a very negative narrative of a specific event. He explains how his urgent need for toilet access, and the fact that when he did use the toilet he 'made one hell of a stink' (5-6), caused his friends to forbid him from using the same toilet as them, meaning he had to use a toilet on a different floor, which he was unable to reach in time before defecating. Differently to Sally, in Extract 14, then, it was not only the actions Lewis had to take as a result of IBD-symptoms which became perceptible, i.e., rushing to the toilet, but the *symptoms themselves* became evident, leading Lewis to become 'discredited' (Goffman, 1963). Scambler and Hopkins (1986) refer to this 'clinical manifestation of people's conditions' as 'stigmata' (1986: 36). However, whilst they propose that such signs 'are noticed and lead to exposure' (1986: 33), in this context stigmata did *not* lead to the exposure of IBD.

Lewis reports that he had *not* previously disclosed to his friends that he has IBD (17), thus we could speculate that Lewis' friends perhaps had no prior knowledge of IBD generally, or if they did know of the condition, the symptoms Lewis displayed were not enough on their own to lead them to infer that Lewis has IBD. Their reactions therefore display 'enacted deviance' (Scambler, 2004), rather than 'enacted stigma' (Scambler and Hopkins, 1986), as Lewis implies having experienced *blame* for these behaviours, due to his friends' lack of awareness that he was not in control of his actions. In Goffman's (1963) terms, then, Lewis' 'effort to conceal incapacities [his IBD] caused him to display other ones' (1963: 104), in this case the appearance of 'deviance' relating to his bowel habits.

To some extent, Lewis constructs himself as a sympathetic hero, forced to struggle on in spite of the inconsiderateness of his friends, who are represented as blunt and 'face-threatening' (Goffman, 1955) in their forbidding of Lewis, as displayed through their direct reported speech: 'right L you're not ever gonna use our toilet again' (7). However, there is ambiguity in this construction, because Lewis does emphasise that the reason for

his friends' behaviour was their lack of awareness of his condition, which implies that had he disclosed, they may have been more understanding. This possibility is further supported by Lewis revealing that the one friend present who *was* aware of his condition was far more understanding and supportive, again displayed through direct reported speech: 'he kept saying 'leave him alone leave him alone'' (25-26). A degree of blameworthiness could therefore be attributed to Lewis for this scenario, as it could be speculated that had he disclosed his condition these negative consequences may not have occurred, a view Lewis himself puts forward: 'it could have been helped...but they didn't know' (16-17).

Lewis proceeds to 'excuse' (Scott and Lyman, 1968) this non-disclosure, however, through the interaction which immediately follows:

Extract 16 (contd):

28. BS: oh ok so do you (.) you say that there's only a few of your  
29. friends that you tell about it then is that? (.)  
30. L: well I (.) in the second year I tried to tell the group (.) and it  
31. was a group of um (.) twenty odd people (.) and truthfully it  
32. didn't (.) nobody really took it in (.) and when I said (.) you  
33. know 'I told you about my Crohn's' (.) everybody looked up  
34. and said 'no' (.) so nobody really cares that much (.)  
35. BS: mm mm (.)  
36. L: mainly people keep quiet if they got an illness (.) in our  
37. groups (.)  
38. BS: right so is that (.) do you think the reason that you don't like  
39. to tell people is that just because you don't want people  
40. thinking of you as being ill or do you think it's actually the  
41. nature of the illness itself and the fact that it's a bowel  
42. disease? (.)  
43. L: yeah it's probably the nature of the illness itself (1.0) I've  
44. got no problem with people knowing that I've got an illness

45.           (.) 'cause I've lived with it for so long (.) and if they've got a  
46.           problem with that then they can stick it (.)  
47.    BS:    mm (.)  
48.    L:     I choose my friends carefully (.) and they're lucky to be my  
49.           friend (chuckles) (.)

Lewis presents a short narrative (30-34) in which he outlines a previous context in which he *did* choose to disclose his condition, to a large group of friends. Whilst the formulation 'the group' (30) suggests this to be a group of friends already mentioned, it is not entirely clear whether this larger group included the holiday friends. Lewis again constructs 'self-as-other' (Sarangi, 2007) orientation, reporting that the result of this disclosure was that 'nobody really took it in' (32), and had forgotten about it by the time he next mentioned it. Therefore, whilst Lewis said that the holiday friends had no prior knowledge of his condition, this larger group may have included the holiday friends, whose reported lack of knowledge of his IBD during the holiday incident could be a result of them having forgotten about his disclosure. Here, then, disclosure of illness-information reportedly resulted not in stigmatization or charges of deviance, but *apathy* on the part of others towards Lewis' troubles. Lewis produces a 'simple external evaluation' (Labov and Waletzky, 1967: 28) of this narrative: 'so nobody really cares that much' (34). The use of the present tense here suggests that Lewis is generalizing from this experience, proposing that everyone else would also respond in this uncaring manner. This can therefore be seen to function to 'excuse' his decision to 'stay in the closet' (Schneider and Conrad, 1980) in relation to most, and disclose only to a select few friends (19), presumably those he feels that he can *trust* with this information.

When questioned further, Lewis proposes that it is primarily the *nature* of the condition itself that prompts his non-disclosure, as opposed to just the fact that he has a chronic condition (43-44). Though he does not elaborate on this, it can be assumed that he is referring to the taboo nature of the condition symptoms, as alluded to in his initial narrative (4-17). Lewis proposes that if, hypothetically, anyone did react negatively to finding out that he has a chronic condition, his response would be that 'they can stick it' (45-46). Thus, in spite of reportedly finding it difficult to disclose to others (20), and in

conflict with the secrecy reported in his initial narrative, Lewis here constructs a positive identity as a strong-willed person who would emphatically reject others' negative perceptions of him, demonstrating 'project stigma' – the conscious rejection of attributions of shame (Scambler and Paoli, 2008).

Extract 17 sees the respondent, Joanna, also constructing 'self-as-other' (Sarangi, 2007) orientation. Unlike Lewis, she does not report any negative issues in relation to friends who are aware of her condition, but does construct 'enacted stigma' (Scambler and Hopkins, 1986) in relation to people first finding out about her IBD. Predominantly through the use of reported speech, she displays these others as pitying her, and thus implicitly constructing IBD as being abnormal.

Joanna (J) was aged 25, and had been diagnosed with Crohn's disease for five years. She had explained to me that upon first being diagnosed she experienced very severe disease symptoms, which had caused significant disruption to her life, as she was forced to leave university and move back home with her mother for several months. At the time of the interview, however, she had moved into her own flat, and was working fulltime as a receptionist (see Appendix K; Interview 30: 513-548):

Extract 17:

1. BS: you mentioned about your friends being really supportive
2. and stuff [about her IBD] I mean do they all know about it?
3. J: everyone knows (.)
4. BS: everyone knows? (.)
5. J: everyone (.)
6. BS: oh right=
7. J: =there's pretty much no one that doesn't know (.) apart
8. from the people who just haven't naturally found out (.) I tell
9. you they'd be so shocked if they did find out 'cause that's
10. people's reaction generally (.) my friends have all generally
11. accepted it and then you get new random people who find out



12. and they're really shocked that's weird (.) 'cause I just expect  
13. everyone to accept it (.)  
14. BS: right so are they shocked because you look well on the (.) outside?  
15. J: [yeah]  
16. BS: or like (.)  
17. J: and how sad and desperate it really is (.)  
18. BS: okay (.)  
19. J: so that's quite weird (.)  
20. BS: so what do you mean by sad and desperate?=  
21. J: =(laughing) as in  
22. the symptoms are really horrendous (.) it's not just something that  
23. you're putting up with now and again it's horrendous (.) people  
24. are just so shocked by the extent of what you've got to go  
25. through and 'you look so normal how can you look so normal  
26. on the outside?' and it's like 'yeah but you're disabled (.) you  
27. could be on benefits for life if you wanted to be'<sup>13</sup> they don't  
28. understand it (.) so it's new people's reactions that are the  
29. weirdest (.) it's like oh my god (.) at work and stuff they just  
30. don't get it the comment I had yesterday was 'isn't it really sad  
31. you're so young' and it's like 'so young what?' and they're like  
32. 'so young to be like this' and I don't think like that (.) and their  
33. reactions really get me down 'cause it's like (.) don't talk like  
34. that I don't talk like that (.) (chuckling) you don't talk like that  
35. you know (.) it annoys me when people don't know how to  
36. handle it (.)

In contrast to the selective disclosure proposed in Schneider and Conrad's (1980) 'closet metaphor', Joanna states that 'everyone knows' (3) about her condition. However, she qualifies this: 'apart from the people who just haven't found out naturally' (7-8). It is

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<sup>13</sup> In a few previous places in her interview, Joanna had mentioned her eligibility for receiving benefits as a result of her IBD. Individuals with severe forms of IBD may be eligible for a range of benefits, including Disability Living Allowance (DLA) (see: [www.crohnsandcolitis.org.uk/content/services/dla.asp](http://www.crohnsandcolitis.org.uk/content/services/dla.asp)).

unclear whether by this she means that rather than her actively choosing to disclose, people ‘naturally’ find out because her symptoms become outwardly apparent, or whether there are naturally-arising circumstances or contexts where it is more suitable or appropriate for her to disclose.

Through ‘self-as-other’ (Sarangi, 2007) orientation, Joanna constructs her condition as not being particularly discreditable in the perceptions of her friends, who she proposes have ‘generally accepted’ (10-11) her IBD. However, she creates a distinction between her friends and the reactions of ‘new random people’ (11), presumably referring to people she has just met, but who she does not yet know. Through indirectly reported speech of these unspecified new people, she constructs her IBD as *abnormal*, emphasising her ‘differentness’ (Goffman, 1963) from those who do not have the condition. She first proposes that these others are ‘shocked’ (12) about how ‘sad and desperate’ (17) the condition is. When asked what she means by this phrase, Joanna talks of the ‘horrendous’ (23) nature of the condition and the ‘extent of what you’ve got to go through’ (24-25), appearing to attribute the use of these highly negative descriptive terms to generalized others. This evidence suggests that, whilst Joanna reports not practising selective disclosure in terms of who she tells, she also does not practise partial disclosure in terms of how much she discloses, as her construction of others being shocked by ‘the extent’ (24) of the condition suggests she discloses full details of her symptoms.

Joanna proposes further reason for others being shocked upon learning the full extent of her IBD because she looks ‘so normal on the outside’ (25-26), a phrase again attributed to others. This constructs the condition as non-outwardly apparent, in Joanna’s case. In the constructed-views of these others, then, they emphasise the disparity between her inner and outer bodily appearance, the difference between Joanna being ill on the inside, experiencing ‘horrendous’ symptoms (23), and her apparently ‘normal’ appearance on the outside, which is displayed in the ‘frontstage’ area (Goffman, 1969: 109). They therefore appear to have presuppositions regarding what a chronically-ill person *should* look like, and that signs of chronic illness should in some way be apparent in the individual’s outer-appearance. This is further emphasised through Joanna again drawing on the reported speech of others: ‘yeah but you’re disabled’ (26). This constructs even

further disparity with Joanna's outwardly 'normal' appearance, as the term 'disabled' has strong connotations of physical impairment, which most would expect to be outwardly apparent. This ignorance on the part of these others towards chronic illness and disability can be considered a form of 'enacted stigma' (Scambler and Hopkins, 1986).

Whilst Joanna's use of reported speech constructs her IBD as removed from the normalcy of others who do not have the condition, it also has a rhetorical function in enabling her to construct a positive identity. The fact that she is able to appear normal on the outside, to the point where others are shocked at how normal she looks, means Joanna is able to construct herself very positively as *not allowing* her condition to become outwardly apparent, implicitly constructing this as an achievement on her part. Through reporting others as stating: 'you could be on benefits for life if you wanted to be' (26-27), this emphasises that Joanna is in fact not on benefits, and works fulltime in spite of the fact that her illness is so severe that she is not required to (which she discusses during other parts of the interview). Joanna is therefore able to construct a heroic identity as somebody who struggles against the odds, and is able to appear normal and partake in normal working activities, in spite of the challenges presented by her condition, challenges which, in the reported views of others, do not correspond with models of normalcy. Portraying this identity through 'self-as-other' (Sarangi, 2007) orientation means that Joanna is able to avoid appearing immodest or boastful in constructing these achievements, or in any way self-pitying regarding her plight.

Joanna distances herself from these reported views of others, by contending that she finds it 'weird' (12) when people react to her condition in this way. This could be seen to construct an implicit 'contrast' between these reactions and her own non-fuss, non-self-pitying attitude. This identity is further projected through Joanna reporting a conversation that she had had with a work colleague the previous day: "isn't it really sad you're so young' and it's like 'so young what?' and they're like 'so young to be like this'" (30-32). The initial comment in this exchange, attributed to Joanna's work colleague, has connotations regarding the counter-normativity that many may ascribe to young adults having a chronic condition, and it is this dissonance which appears to lead him/her to project sympathy and pity towards Joanna. This again emphasises Joanna's

‘differentness’ (Goffman, 1963: 14), implicitly representing the condition as removed from the normalcy of non-IBD others. Joanna strongly distances herself from such pitying views, however, by not only arguing that she does not hold such a view herself, but also that when others voice these comments she finds it upsetting: ‘their reactions really get me down ‘cause it’s like (.) don’t talk like that I don’t talk like that (.) (chuckling) you don’t talk like that’ (32-34).

This reported sympathy, whilst perhaps well-intentioned, can also be viewed as a form of ‘enacted stigma’ (Scambler and Hopkins, 1986), which is how Joanna portrays her interpretation of this, with her explicit rejection of these perceptions displaying ‘project stigma’ (Scambler and Paoli, 2008). This again aligns with cultural models of moral-appropriacy, or perhaps more so, avoids moral-*inappropriacy*, as those who attempt to elicit sympathy are commonly looked upon unfavourably.

As similarly observed in relation to T1DM-respondents in 7.3, the accounts of IBD-respondents demonstrate some similarities, but also variation. Extracts 14-17 all display ‘self-as-other’ (Sarangi, 2007) orientation, through which respondents construct the (lack of) normalcy of IBD in relation to others who do not have the condition, and the subsequent implications this has on their self-presentation of illness. Sally (Extract 14) constructs ‘felt stigma’ as outweighing ‘felt deviance’ in most contexts, therefore choosing to disclose only minimal details of her condition, and thus risking ‘enacted deviance’ in relation to unexplained behaviours. Rosie (Extract 15) represents herself as having experienced some degree of ‘enacted stigma’ when disclosing details of symptoms to others; and similarly to Sally, she proposes practising either partial or non-disclosure of her IBD. In relation to friends, however, her partial disclosure is constructed as leading to ‘enacted deviance’, because the imperceptibility of her condition leads friends to perceive her as deviant in her non-participation in certain sociable activities. Lewis (Extract 16) similarly represents himself as having experienced ‘enacted deviance’ as a result of friends’ lack of awareness of his condition; however, this is because his symptoms *were* outwardly apparent, and because he did not disclose his condition, his friends did not realise he was not to blame for his behaviours. Joanna (Extract 17) displays disparity from the other three respondents in that she implies that she *fully*

discloses to everyone the extent of her symptoms and their implications. Whilst she reports that this causes no negative issues with regard to friends, it leads her to experience 'enacted stigma' when people first find out about her IBD.

### 7.5 *Cross-condition comparisons*

Whilst similarities and differences have been observed in relation to both T1DM and IBD vis-à-vis those with the same condition, there are also several similarities and differences *across* the two conditions. As would perhaps be expected, the variation across the two conditions appears to be greater than that constructed amongst those with the same condition.

A cross-condition similarity, which was briefly mentioned at the beginning of this chapter, is that respondents in all the eight extracts orient to others who do *not* have the same condition as them. This may result from the framing of my questions in some cases; however, this also reflects findings observed in other studies looking at young adults' experiences of these two conditions (Dovey-Pearce, Doherty, and May, 2007; Hall, Rubin, Dougall, Hungin and Neely, 2005; Schur, Gamsu and Barley, 1999: see 4.2). It may be the case that respondents do not know of many others, or perhaps even no one at all who has the same condition as them; therefore this reflects the other-orientation that they regularly encounter within their lives. It must be noted, then, that issues of normalcy, stigma, deviance and disclosure may be constructed very differently if respondents were discussing the perceptions and reactions of, and interactions with, others who have the same illness as them.

Respondents with both conditions were shown to commonly construct 'self-as-other' (Sarangi, 2007) orientation, as a way of representing the (lack of) normalcy of their condition relative to others. In the case of T1DM, both Robert (Extract 11) and Mitch (Extract 12) construct T1DM as *not* being highly stigmatized, and thus as occupying a fairly low position on the continuum of discreditability. They do this in differing ways, however. Robert primarily *backgrounds* his illness-identity, minimising his 'differentness' (Goffman, 1963): 'I don't know many people who...are perfectly well'

(Extract 11: 21-22); whereas Mitch *foregrounds* his illness-identity, but minimises the stigma attached to T1DM, and thus ‘normifies’ (Goffman, 1963: 44) the condition. In contrast, Linda (Extract 10) constructs T1DM as being stigmatized in other people’s perceptions, removing her from the normalcy of these others: ‘I know that people think...I’m not like normal’ (Extract 10: 5-6). This demonstrates some of the variation within the corpus of T1DM-respondents; however, Linda is within a minority in constructing others’ perceptions in this way, as most with T1DM do not represent the condition as being considered abnormal in the eyes of others, and afford it quite a low position on the discredibility continuum (see for instance: Steve: Interview 2: 152-196; Shannon: Interview 7: 425-469; Mark: Interview 12: 625-633; Matt: Interview 13: 226-252).

This trend demonstrates some disparity with the findings of Schur, Gamsu and Barley (1999) (see 4.2.1), who claim that young adults with T1DM reported feeling different from others, ‘both in the ontological sense of ‘being’ different, and because of the self-care behaviours and routines they had to engage in’ (Schur et al., 1999: 230). This, Schur et al. propose, led respondents to experience a ‘pervasive fear of stigma’ (1999: 231), thus showing similarity with Linda’s account here. It is difficult to account for this difference in findings between Schur et al. and the present study; however, it could be partially down to the fact that Schur et al. use a slightly younger age-range of 16-22. It may be that those in their mid-late teens and early twenties may be more conscious of any facet of self that may differentiate them from their peers; and the ‘felt stigma’ experienced by those in their late teens could relate to fears of adolescent teasing, something not such a factor in relation to my age-sample, in spite of the four-year overlap between the age-ranges in my and Schur et al.’s respective samples. This explanation would account for Linda, at age 19, constructing ‘felt stigma’. However, with this said, there was no particular trend observed in my corpus regarding those towards the older-end of the age-range constructing lesser degrees of ‘felt stigma’ than those at the younger-end. Additionally, Robert is also 19, but does not represent himself as fearful of being stigmatized in any way. The disparity in findings could in fact be partially due to Schur et al.’s small sample of only 8 respondents, whose experiences may, by chance alone, differ from those of young adults with T1DM more generally.

A cross-condition disparity is apparent, as all four IBD-respondents construct their condition as being somewhat *removed from normalcy*, and as socially unacceptable, due primarily to the taboo nature of the symptoms, thus affording it a relatively high place on the discredibility continuum. This discredibility appears, then, to be based on the *nature* of the condition, as opposed to them having a chronic illness in general. These representations of discredibility reflect those of several other IBD-respondents in the larger data-corpus (see for instance: Lauren: Interview 15: 231-257; Murray: Interview 19: 304-343; Tara: Interview 27: 448-461). In the four extracts, respondents' construction of IBD in this way appears to *mostly* stem not from them actually having experienced stigma as a result of their condition, but from their constructions of how others *may* hypothetically react to their condition. It is thus generally 'felt stigma' being constructed, rather than 'enacted stigma' (Scambler and Hopkins, 1986), the *actual* experience of stigma. Schneider and Conrad (1980) refer to what those with the condition 'think others think of them...and about how these others might react' (1980: 35) as the 'perception of stigma' (1980: 35).

This finding shows similarity with Hall, Rubin, Dougall, Hungin and Neely (2005: see 4.4.2), who noticed respondents with IBD to report fear of 'not being understood, embarrassment and being a burden to others' (2005: 451), but not necessarily having actually experienced such reactions. Similar findings have also been made in relation to HIV (Green, 1995), and epilepsy (Scambler and Hopkins, 1986). Scambler and Hopkins (1986) in fact observe that not only is 'felt stigma' 'rarely triggered by enacted stigma' (1986: 34), but that 'felt stigma' prompts individuals to experience 'far more unhappiness, anxiety and self-doubt than they did, either directly or indirectly, through enacted stigma' (1986: 38). It could be the case that the degree of *social-unacceptability* which unites IBD with conditions such as epilepsy and HIV is not present to the same extent in relation to T1DM, accounting for the lesser presence of 'felt stigma' in Extracts 10-13.

It could therefore be argued that the IBD-respondents in the extracts analysed are basing their 'felt stigma' on pre-held views propagated within society about the *social-unacceptability* of bowel conditions. This argument aligns with that of Sarangi (2008:

158), who proposes that stigma at a societal level, as in the case of HIV/AIDS, can influence the formation of stigma at interpersonal and individual levels. It must be noted, however, that there is evidence of ‘felt stigma’ in relation to Linda’s account, but as already mentioned, this appears to be less common with regard to T1DM-respondents.

In spite of having proposed a greater presence of ‘felt stigma’ than ‘enacted stigma’ in constructions of IBD, Rosie (Extract 15) does report having experienced others reacting squeamishly to her discussion of symptoms; and Joanna (Extract 17) constructs others as displaying ignorance towards her IBD, both constituting ‘enacted stigma’; in Rosie’s construction, however, this ‘enacted stigma’ is not as severe as her construction of ‘felt stigma’ (Extract 15: 54-56). Such examples of ‘enacted stigma’ were not present in the extracts presented here from T1DM-respondents, which may suggest, at least in the representations of the young adults here, that IBD holds more stigma than T1DM, *both* in terms of ‘felt’ *and* ‘enacted’ stigma. With this said, Timothy (Extract 13) implies that the reason for his T1DM not affecting his social relationships is that only his ‘best’ friends are aware of his condition (Extract 13: 6), implying that if he were to disclose to others who he does not know as well there may be potential for him to experience ‘enacted stigma’.

In addition to the social-unacceptability constructed by respondents vis-à-vis IBD, the condition itself may also be less widely known-about. It could be argued that T1DM has greater public currency than IBD; most will likely have at least heard of it even if they do not fully understand its implications; and this greater awareness may also be a reason for lesser ‘felt’ and ‘enacted’ stigma being constructed.<sup>14</sup>

This construction of (lack of) normalcy and (lack of) stigma vis-à-vis their condition appears to influence respondents’ reported disclosure of illness-information to others.

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<sup>14</sup> With this said, some T1DM-respondents do construct enacted stigma in relation to ignorance on the part of others which was *as a result* of them having heard of the condition, but having limited knowledge of it. Examples included others passing judgement when they witnessed respondents eating sugary foods. Stigma in these cases, then, was not directly associated with the condition or its health-effects, but others’ perceptions regarding respondents’ *behaviours* related to the condition (see for example: Melanie: Interview 21: 447-477; Polly: Interview 17: 548-566).



With the exception of Mitch (Extract 12) and Joanna (Extract 17), all respondents report practising *selective* disclosure, in terms of to *whom* they disclose illness-information. In Mitch's case, however, he only orients to *friends*, thus we do not know if he would be as open with those who he does not share a close relationship with. This evidence of selective disclosure demonstrates commonality in the nature of two conditions, in that, due to their *generally* non-outwardly apparent nature, the individual has agency regarding the circumstances under which he or she discloses, representing both conditions as generally 'discreditable' rather than 'discredited' (Goffman, 1963). This is recognised, with varying degrees of explicitness, in all the eight extracts analysed, perhaps being most notable in Joanna's constructions, as she explicitly outlines how others are 'shocked' (Extract 17: 12) by the stark disparity between her outwardly 'normal' appearance and the severity of her condition.

In some cases this selective disclosure is reported as resulting from 'felt stigma', evidencing Goffman's (1963) proposition that 'because of the great rewards in being considered normal, almost all persons who are in a position to pass will do so on some occasion by intent' (1963: 95). In relation to IBD, both Sally (Extract 14) and Rosie (Extract 15) cite these reasons. For Linda, it also appears to be partially a result of 'felt stigma', her fears that others will think that she is 'weird' (Extract 10: 40), that leads her to only disclose in certain circumstances, suggesting that this can influence disclosure in the case of T1DM-respondents also; however, again Linda is an exceptional case in this regard.

In contrast to these constructions, for Robert, selective disclosure is constructed as aligning with his representation of the normalcy of T1DM, as he suggests that because he views T1DM as unremarkable, he therefore sees no reason to disclose: 'not everyone has to know' (Extract 11: 14). It is not, therefore, always the case that *not* being seen as normal is the reason behind an individual's choice to 'pass' (Goffman, 1963), as in fact Robert constructs the motivation behind his non-disclosure as being quite the opposite. Robert does also imply, however, that he at times discloses so that others are aware of his condition, and are thus in a position to recognise the signs of short-term health problems that Robert may experience, such as hypoglycaemia. This presents a cross-condition

disparity, as whilst such ‘safety telling’ (Schur et al., 1999: 232) is commonly reported by T1DM-respondents in the data-corpus, this is not reported by those with IBD.

Another cross-condition disparity apparent in disclosure practices is that whilst, in the extracts analysed, T1DM-respondents generally represent disclosure and non-disclosure as polar opposites, in the case of IBD, respondents report *partial* disclosure at certain times, referring to the *amount* of information shared. In 7.2 above, I proposed that partial disclosure could be considered via extension of Schneider and Conrad’s (1980) ‘closet metaphor’, with individuals not only being in or out of the closet, but remaining partially in, and coming partially out. At this point, however, I feel that a more apt metaphor could be developed to capture both *selective* and *partial* disclosure. We could perhaps talk of disclosure in terms of a *cards player*, a metaphor commonly used in conceptualising concealment or disclosure of information. Whilst this risks diminishing the severity of chronic illness experience by likening it to a game, which is of course not my intention, I feel this metaphor is in many ways well suited. The cards player is able to reveal his or her cards only to certain people, and only at certain points, when he or she feels it is appropriate, and in a similar way those with illness can choose when and to whom they wish to *show their hand*, or whether they wish to conceal their condition, and thus *keep their cards close to their chest*. The cards player can also choose only to reveal some of his/her cards, similar to the chronically-ill person’s choice regarding which details of his or her condition to disclose. In cases where the ill person chooses to fully disclose details of his or her condition, similarly to the cards player, we could talk of him or her *laying all of their cards on the table*. Rosie and Sally both reveal that they disclose some facets of their condition, but not the full extent, therefore *keeping their cards close to their chest*, due primarily to embarrassment about symptoms.

Joanna is in a minority in the data-corpus as a whole with regard to disclosure, as very few others report ‘everyone’ (Extract 17: 3) knowing the full extent of the condition, *laying all of their cards on the table*, as does Joanna. The others oriented to in Joanna’s account are therefore more well-informed than those in the other accounts analysed, which will influence constructed-reactions, explaining why the other respondents do not report the same ‘shocked’ reactions that Joanna does.

In reporting their disclosure practices, some of the respondents in the extracts examined were shown to either 'excuse' or 'justify' (Scott and Lyman, 1968) their selective or partial disclosure, or decisions to 'pass' (Goffman, 1963). This accounting implicitly marks non-disclosure as having the potential to be seen as being morally-*inappropriate*. This could be because individuals who conceal their condition may be deemed as not being true to themselves, or perhaps caring too much what others think of them, behaviours often viewed unfavourably. Excuses and justifications can therefore be seen as attempts to construct a positive identity in spite of these behaviours. A cross-condition disparity is apparent in the extracts examined, with these types of constructions more commonly found in relation to IBD-respondents than those with T1DM, observed at one point or another in the accounts produced by Sally, Rosie and Lewis.

The reason for this cross-condition disparity, again with the notable exception of Linda who *does* account for non-disclosure of T1DM, could be because it is more common for IBD to, at times, become perceptible, in terms of symptoms or associated behaviours becoming outwardly apparent (which I will discuss further below). Straightforward 'passing' is therefore not always an option for IBD-respondents, and 'stigma-management' (Goffman, 1963) is more likely to be employed, which can entail *active* concealment, such as Rosie attributing her symptoms to a 'tummy ache' (Extract 15: 50). Such active concealment could be considered *dishonesty*, and thus especially morally-inappropriate. Circumstances whereby individuals must employ active concealment in order to prevent their illness being known about appear less common in relation to those with T1DM, therefore non-disclosure is not treated as being morally-inappropriate. Robert, for instance, represents disclosure as simply being down to individual choice, and Timothy in fact constructs his concealment of T1DM self-care as being morally-*appropriate*, the reasons for which will also be further discussed below.

Whilst this discussion has so far looked at how respondents construct issues surrounding the 'felt stigma' and 'enacted stigma' attached to their condition, some extracts also address issues of 'deviance' (Scambler, 2004). For instance, some respondents discuss others' perceptions of their *behaviours* related to their condition, behaviours which are *not*

*necessarily* recognised by others as being associated with their condition, and which may therefore be susceptible to negative *moral* judgements of *blame*.

Cross-condition disparities are apparent in relation to constructed-deviance in the extracts analysed. As I proposed above, IBD does not always remain imperceptible, and symptoms ('stigmata', Scambler and Hopkins, 1986: 36) or behaviours associated with symptoms ('stigma cues', Scambler and Hopkins, 1986: 36) *can*, at times, become outwardly apparent, such as when others witness the person with the condition excusing himself or herself frequently to use the toilet. This Kelly (1992a) refers to as the 'inherently unstable nature of the condition' (1992a: 37). As was also shown to be the case in accounts of *self* (Chapter 6), here the *body*, although left implicit, plays an important role in the constructed experiences of IBD-respondents. Sally, Rosie and Lewis are all, to some degree, 'let down' by their bodies through the presence of 'stigma cues' (Sally and Rosie), and 'stigmata' (Lewis), resulting in a conflict between bodily demands and desired self-presentation (Kelly and Field, 1996: 245). In these cases, then, the condition becomes 'discredited', rather than remaining 'discreditable', and the individual must decide how to explain stigmata or stigma cues, or whether to leave them unexplained, which could result in 'enacted deviance' (Scambler, 2004).

There is variation in the ways IBD-respondents in the extracts construct their behaviour in response to this. As mentioned above, Rosie proposes that she would most often conceal her IBD by attributing these symptoms to a less serious, more common illness, thus attempting to 'hide...her condition and seeking to maintain an identity as a well person' (Schur et al., 1999: 231). Whilst through this, she is able to avoid the potential stigma of disclosing she has IBD, by providing an explanation for her behaviour she also avoids potential charges of deviancy. In contrast to this, Sally reports that, in most contexts, she chooses to leave such behaviours unexplained, due to her embarrassment about discussing these symptoms. In Sally's case, then, her 'felt stigma' regarding the discussion of IBD symptoms outweighs her 'felt deviance' with regard to unexplained symptoms.

Whilst Sally does not report having experienced 'enacted deviance' as a result of leaving these behaviours unexplained, Lewis (Extract 16) reports that leaving such behaviours

unexplained has proven problematic, as the lack of awareness on the part of friends about his symptoms led to negative reactions, constituting 'enacted deviance'. Thus, it appears that when the condition becomes discreditable, individuals must weigh up their degree of 'felt stigma' against their 'felt deviance', in deciding how, or whether, to explain outwardly apparent signs of their condition. The 'enacted deviance' Lewis experienced reportedly caused him considerable physical discomfort, and therefore Lewis appears to represent the burden of disclosure as being greater than the burden of suffering the physical consequences of not receiving appropriate accommodation from others.

It appears, however, that as well as risking 'enacted deviance' through choosing not to explain outwardly-apparent symptoms and signs, IBD-respondents can also experience 'enacted deviance' through the *imperceptibility* of symptoms. This is the case with Rosie, who reports that when her symptoms were *not* perceptible, and she did not wish to bring up her IBD to 'justify' (Extract 15: 22) not going out, she experienced negative reactions from friends regarding what they considered to be deviant behaviour, as the restrictions placed upon her by her condition were not evident to them. Here, then, we are talking about a different kind of 'enacted deviance' on the part of Rosie's friends, not reacting to their perceived-deviance regarding behaviours related to stigmata or stigma cues, as was the case in Lewis' account, but deviance in not participating in culturally-expected behaviours (Chatterton, 1999). This demonstrates some similarities with the findings of Hall et al. (2005: see 4.2.2), who found some respondents with IBD to report a lack of understanding on the part of others, because the nature of symptoms at times led others to suggest that the condition was not very serious (2005: 451). In Rosie's case, however, her own behaviour, in her version, contributes to this lack of understanding: 'I haven't really explained it properly' (Extract 15: 11-12). It can therefore be seen that those with IBD can experience 'enacted deviance' both when the condition becomes discredited, but also when it remains discreditable.

Issues of deviancy are not only present in the accounts of those with IBD, however. Timothy (Extract 13) addresses issues of deviancy in relation to carrying out self-care practices, such as injecting insulin, on the 'frontstage' (Goffman, 1969: 109). Timothy suggests that T1DM self-care practices perceptible on the frontstage could be viewed as

deviant both when others are unaware, but also when they *are* aware that this behaviour is associated with T1DM, something which was not observed in the accounts of IBD analysed. Timothy suggests such negative reactions to be on the grounds of the perceived-inappropriateness of these behaviours being publicly displayed: ‘they might think god why’s he doing that (.) in front of us’ (Extract 13: 16-17). The reason for this cross-condition difference is perhaps because, in this case, Timothy *does* have agency regarding whether these practices are carried out in public – and in fact I referred to this earlier as a form of physical disclosure – whereas in the case of IBD, when others *are* aware of the condition, they will know that the individual does not have agency over the public display of symptoms, or associated behaviours, on certain occasions. There is therefore greater potential for moral judgements of *blame* regarding Timothy’s actions, when others are in the know. This is ‘felt’, rather than ‘enacted’, deviance, as Timothy avoids moral judgements through framing the public display of such behaviours as hypothetical, and not something that he actually does.

Schur et al. (1999) also found evidence of young adults with T1DM reportedly excusing themselves in order to inject their insulin in private. They interpret these behaviours differently in relation to their data, however, proposing this to be ‘stigma management’ (Goffman, 1963: 69), with respondents intending to “‘contain” their sense of being different’ (Schur et al., 1999: 230: see 4.2.1). This suggests, then, that some young adults with T1DM *do* experience ‘felt stigma’ in relation to others witnessing self-care practices. However, the reason for this disparity may be that Schur et al. do not distinguish between ‘stigma’ and ‘deviance’, thus they may consider the deviance-management displayed here by Timothy under a more general conceptualisation of stigma-management.

As in the analysis of *self* data (Chapter 6), the respondents were shown to draw upon various rhetorical discourse strategies in the performance of *morality* (Radley and Billig, 1996). One is the use of ‘contrast’ on a few occasions, also conceptualised as ‘self-vs.-other’ (Sarangi, 2007) orientation. Linda, for instance, was able to construct a heroic identity through contrasting the morally-*inappropriate* behaviour of friends, represented

as making a fuss over minor ailments, with her positive behaviour of having 'still got on with everything' (Extract 10: 14), in spite of her T1DM.

Reported speech was also observed, most notably in Joanna's account (Extract 17), as she is able to demonstrate, through a reported exchange with a work colleague, her explicit rejection of others' pitying attitude towards her IBD, displaying 'project stigma' – the conscious rejection of attributions of shame (Scambler and Paoli, 2008). Joanna is therefore able to construct a morally-appropriate identity, as not only does she avoid appearing self-pitying, but she presents herself as a strong-willed person able to reject others' stigmatization: 'I don't talk like that (.) (chuckling) you don't talk like that' (Extract 17: 34).

Respondents' pronominal use, especially in the context of self/other constructions, was found to serve rhetorical functions. In several of the extracts, respondents, at times, switch between the first person singular pronoun 'I' and the second person 'you'. Robert, Sally and Rosie all use the second person 'you' or 'your' on several occasions. For all the three respondents, this appears to be an *ingrouping* device, intended to attribute their perceptions and behaviours to others who also have the condition, suggesting that anyone else in their position would think or do the same. Robert also uses the third person plural 'they' and third person singular, 'the individual': 'it's entitled to the individual whether they want to say (.) look I'm diabetic' (Extract 11: 5-6). This even further constructs his reported-perceptions as not being his alone, implying reference to anybody who has T1DM. This functions to further legitimate Robert's construction of T1DM as normal; whereas in the case of Sally and Rosie, their pronominal use further supports their claims to morality, in legitimating their non-disclosure of illness-information in certain contexts.

This chapter, and that immediately preceding it, have explored the ways in which young adults with T1DM and IBD construct their condition in relation to *self* and *others*, respectively. The next chapter will focus on the third predominant macro-theme: *control*. I will investigate the ways in which respondents construct the control they have over both the condition itself, and their lifestyle in relation to illness.

## 8. Negotiating *Control*: How Young Adults Construct the Control they have over their Condition and Lifestyle

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This chapter will address the third macro-theme identified in the preliminary analysis – *control*. It will address two different, but highly interrelated types of control. Firstly, it concerns control over the condition itself, in terms of respondents’ reported attempts to gain or maintain control over their treatment-regimens, and to prevent the onset of symptoms and health-effects arising from their condition, or at least minimise their incidence and severity. This will be referred to as *condition control*. Secondly, respondents will be shown to address control over their lifestyle, discussing their attempts to manage the intrusiveness of treatment-regimens and disease symptoms upon their lifestyle activities. This will be referred to as *lifestyle control*. In relation to both conditions, T1DM and IBD, the relationship constructed between these two types of control is complex, and at times, gaining greater control in one area can undermine control in terms of the other, often leading to a tension in accounts, a tension which respondents attempt to discursively negotiate.

### 8.1 *Clarification of relevant concepts*

In 4.3, I argued that whilst the terms ‘control’, ‘coping’, and ‘management-strategies’ are commonly used in research exploring experiences of T1DM and IBD, in none of these studies have they been adequately defined, and the use of the three terms is often overlapping and ambiguous. For this reason, I refrained from addressing the possible differences between these terms when coding my data, and for the purposes of *preliminary* analysis I coded all data which could relate to the themes of ‘coping’ or ‘management-strategies’ within the theme of ‘control’, which was therefore treated as



generic. It will be shown, however, that all the three terms are useful in relation to the data, providing that the concepts they are referring to are properly defined. I will therefore attempt, for analytic purposes, to establish a workable distinction between these three terms. Whilst I have already outlined above how I will conceptualise control, the other two concepts are defined as follows.

*Management-strategies* will here refer to the *reported-behaviours* that respondents engage in in order to pursue or negotiate their condition control and lifestyle control; i.e., *what individuals do* in relation to the demands, restrictions and responsibilities surrounding their condition. One example is individuals adapting their lifestyle, making certain concessions in order to account for the demands of their condition. Another is attempting to resist their condition and carry on with their lives in spite of illness. Whereas previous studies have identified typologies of management-strategies (see for example Kelleher, 1988: see 4.3), and have attempted to categorize each individual respondent within these (Kelleher, 1988; Kelly, 1992), here strategies will be considered as being fluid and dynamic, with different strategies apparent at different junctures within an individual's reported illness experience.

The term *Coping*, on the other hand, will be used to refer to the practical and cognitive ways in which respondents deal with, and find ways to handle, the *psychological stress or feelings* which may arise from living with their condition, issues often resulting from a *lack of* condition control or lifestyle control. One way of coping will be shown to be 'downward social comparison' (Gibbons, 1999; Schur, Gamsu and Barley, 1999), defined by Gibbons (1999) as 'comparing oneself, one's status and/or one's situation with that of others...who are in a worse off position' (1999: 1517). This definition of coping shares similarities with that proposed by Bury (1991); however, whilst in Bury's definition 'coping' encompasses purely 'cognitive processes whereby individuals learn to tolerate or *put up* with the effects of illness' (1991: 460), I will demonstrate that coping need not always be cognitive, but can be action-oriented, for instance communicative, one example being sharing troubles and concerns with others such as friends. However, such actions will be distinguished from 'management-strategies', which involve actions in directly managing illness.

These concepts will all be shown to be relevant throughout the course of the analysis at various points; however, data-extracts will not be introduced as exemplifying one of these concepts alone, as extended extracts cannot be neatly categorized in this way.

In Chapter 6, the role of *the body* was found to influence the constructed illness-selfhood relationship, mostly notably in the case of the IBD-respondents, for whom the bodily restrictions commonly resulting from illness led them to represent lesser agency vis-à-vis their constructions of self. The body was also found to be important in accounts of *other-orientation* (Chapter 7), especially when ‘stigma cues’ and ‘stigmata’ (Scambler and Hopkins, 1986: 36) were reported; individuals were ‘let down’ by the bodies, which was shown to undermine their self-presentation to others. In this chapter, the body’s role will also be shown to be salient – both in relation to how the effects of symptoms and treatments on the respondents’ bodies impacts on their condition control and lifestyle control, and in terms of the bodily practices they engage in in their attempts to gain greater control over both condition and lifestyle. Analysis will draw upon Balfe’s (2009) extension of Shilling’s (2003) ‘body projects’ framework, discussed at length in 4.4.1. This is a useful conceptual model, which complements the concepts introduced above. It will be shown that respondents are able to discursively negotiate their different ‘body projects’, affording salience to different bodies at various points; and it is through this negotiation of bodies that they construct their attempts to gain either greater condition control or lifestyle control, or to construct a balance between the two. Balfe’s concept of ‘student body’ will, however, be relabelled as *social body*, because, as will be seen, the desire to engage in sociable activities is not an exclusive concern of university students, but is also reflected in the accounts of young adults who are not current students.

In relation to some of the extracts presented, I will also draw upon Sargeant’s (2006: 82) dual concepts of ‘living *within* and *beyond* the confines of illness’ (see 4.3.2). As previously demonstrated, these concepts are potentially interchangeable and interrelated, and analysis will thus explore how both IBD- and T1DM-respondents discursively negotiate the boundaries between *within* and *beyond* in their reported attempts to negotiate their condition control and lifestyle control.

As I also noted in Chapters 6 and 7, it is important to consider my influence in the introduction of this theme, as in three of the six extracts, I use the term 'control' in my initial question, leading the direction of the discussion towards such issues. However, this theme recurred several times throughout these interviews, often being introduced by respondents themselves at various points. Additionally, only in Extract 3 do I explicitly introduce notions of both lifestyle control *and* condition control together; therefore this is a distinction commonly introduced by respondents themselves. These concepts, it can be argued, principally derive from the data itself.

## 8.2 Representations of T1DM

Extract 18 is taken from an interview with Robert, who we also encountered in Chapter 7 (Extract 11), a 20 year-old university student, who had been diagnosed with T1DM for five years. Robert (R) represents himself as paying significant attention to his 'healthy body', his inner bodily health (Balfe, 2009); however, he suggests that this does not prevent him from also pursuing his 'social body'. He does talk of how ill-health related to his condition has significantly affected his lifestyle, but this is represented as being occasional. He therefore constructs himself as being *generally* able to maintain a degree of both lifestyle control and condition control (see Appendix K; Interview 24: 416-514):

Extract 18:

1. BS: mm (.) I mean would you say you feel generally as if
2. you're in control (.) of (.) the diabetes as a whole or do you
3. think (.) oh it controls (.) what I'm able to do or do you
4. think I'm in quite good control of it? (.)
5. R: um I think at the moment I'm in reasonable control over it
6. (.) uh I don't you know I I you do have your (.) your blips
7. like your hypos and your hypers (.) but that's all part and
8. parcel of having the condition (.) but generally it's it's it's
9. okay (1.0) with regards to the um (.) whether it controls

10. you (.) I from very much in the beginning of (.) you know  
11. being diagnosed it did control me (.) um (.) I was meant to be  
12. going on on a German school trip (.) um with with the  
13. school before I was (.) you know when I was (.) just  
14. newly diagnosed (.) I was so looking forward to it (.) um  
15. (.) and I was advised not to go (.)

.  
. For the next seven lines, Robert discusses his initial concerns that  
. T1DM would have a controlling effect upon his life.

16. R: um (.) it hasn't really stopped me from doing anything (.)  
17. um (1.0) it may (.) it it can control you sometimes and it  
18. can't (.) but generally (.) it doesn't (.)

19. BS: mm (.) mm=

20. R: =um (.) yeah you just (.) yeah 'cause (.)  
21. especially with (.) things like driving (.) if you tell them  
22. that you've had a hypo (.) and you've been admitted to  
23. hospital (.) then that's a year off straightaway (.)

24. BS: mm

25. R: [which happened to me before as well (.)

26. BS: right=

27. R: =I had a hypo when I was (.) qualified in September  
28. and in the June I had a hypo (1.0) um (.) which was when  
29. I was unconscious and I was admitted to hospital (.) and (.)  
30. you know you've got you've got your new car that you're  
31. not able to drive (.) I'd only been driving like nine months  
32. (.) and to have that (.) taken away from you (.) and the  
33. independence that it gave you (.)

34. BS: mm=

35. R: =I I oh it was just (.) it's just the end of it I just you  
36. know (.) there are some times when you just thought like (.)  
37. what's the point?

When asked how he views the level of control that he has over his T1DM (1-4), Robert's response is slightly mitigated: 'I'm in reasonable control over it' (5). He initially orients to his *condition* control: 'I I you do have your...blips like your hypos and your hypes' (6-7). Describing experiences of hypo- and hyper-glycaemia (see Appendix A) as 'blips', frames these as minor health consequences, as opposed to serious threats to Robert's 'healthy body' (Balfe, 2009). This term also implies experiences which are exceptional within Robert's general illness trajectory, and thus do *not* necessarily signal a lack of condition control on his part, further supported by the proposition: 'generally...it's okay' (8-9). Additionally, Robert's use of the second person pronouns 'you' and 'your' (6), having self-repaired the initial use of 'I', constructs him as being part of an 'ingroup' of those with T1DM, allowing Robert to represent these experiences as common to those with T1DM more generally. This, along with the idiom: 'that's all part and parcel of having the condition' (7-8), functions to represent experiences of hypo- and hyper-glycaemia as somewhat inevitable, thus minimising any potential blameworthiness on his part on the grounds that he might not be adhering to his treatment-regimen as ardently as he should. This allows Robert to maintain a positive identity of moral-appropriacy (Radley and Billig, 1996).

Robert also addresses his *lifestyle* control, contending that, in spite of fears when first diagnosed, in general his condition does *not* control his lifestyle (16-18). Despite this proposition, however, Robert produces a short narrative exemplifying a context in which his condition *did* control him, when he was disallowed from driving for a year due to a serious episode of hypoglycaemia, represented as significantly impacting upon his lifestyle (20-37). Here, then, a lack of condition control resulted in Robert's T1DM having a controlling effect upon his lifestyle, demonstrating the interrelated nature of condition control and lifestyle control. However, Robert again moves between the first person pronoun 'I' and second person 'you', staving off potential charges of irresponsibility in relation to this episode, through framing these as experiences similar to those of others.

The negativity of this constructed-experience, and the psychological distress Robert constructs this as having had on him at the time: ‘it was just (.) it’s just the end of it...you just thought like (.) what’s the point?’ (35-37), seems to somewhat contradict his assertion that T1DM ‘hasn’t really stopped me from doing anything’ (16). However, earlier in the interview Robert introduces this particular episode of hypoglycaemia as a one-off, isolated experience, supporting his argument that whilst T1DM *can* intrude upon his lifestyle at times, ‘generally (.) it doesn’t’ (18).

Immediately following this, Robert continues:

Extract 18 (contd):

38. R: um (1.0) but generally it’s it’s it’s okay at the moment  
 39. I think you’ve just got to take it a day at a time as well  
 40. sometimes and just get through it like that as well (.)  
 41. BS: mm mm (.)  
 42. R: it’s not like a (1.0) it’s not like I think about (.) months in  
 43. advance about what you’re gonna do with yourself it’s like  
 44. day to day things (.)  
 45. BS: right right (.)  
 46. R: and little things like going out for meals and (.) perhaps  
 47. going out for like (.) nights out you’ve got to think to  
 48. yourself well (.) where am I going to be? what am I going  
 49. to be doing? what do I have to take with me? (.)  
 50. BS: mm mm (.)  
 51. R: is there like a local chippy down the road? (.) is there like a  
 52. place where I can get stuff?<sup>15</sup> (.)  
 53. BS mm=  
 54. R: =’cause I’ve been in places where like (.) there there

<sup>15</sup> When referring to a ‘chippy’, Robert is talking about whether there is a takeaway such as a chip shop where he can buy food on a night out in order to ensure that his blood-sugar levels do not go below the safe range.

55.            isn't a chippy and you think to yourself well what the hell  
56.            am I gonna do? (.)  
57.    BS:    mm mm (.)  
58.    R:    um (1.0) but I've never had to you know (.) go down that  
59.            road but (.) it it does make you think (.)  
60.    BS:    mm (.)  
61.    R:    of having to think ahead (.)  
62.    BS:    mm=  
63.    R:            =and planning (.) um (.) of what (.) of what could  
64.            happen as opposed to that it will happen is what could  
65.            happen (.)

Robert represents himself as employing methods of *coping* with the psychological effects that can, at times, arise from his condition: 'you've just got to take it a day at a time as well...just get through it like that' (39-40). Again, the second person 'you' implicitly attributes these coping methods not just to Robert, but also to others who have T1DM. Robert here suggests coping through thinking about the challenges presented by his condition on a daily basis, thus not having to face the enormity of considerations surrounding T1DM in relation to a larger time frame, for instance 'months in advance' (42-43).

Whilst framed as a method of coping, this extends to Robert's reported *management-strategies* vis-à-vis his treatment-regimen. Through the construction of a habitual narrative, allowing him to emphasise 'repetition and routinization' (Riessman, 1990: 1197) in his behaviours, Robert talks of considerations he needs to make in relation to 'day to day things' (44) such as going out for meals or on nights out: 'you've got to think to yourself...where am I going to be? what am I going to be doing? what do I have to take with me?' (47-49). Again the transition between 'I' and 'you'/'yourself' frames these as being considerations that would be made by anyone in the same position. Describing such considerations as 'little things' (46) could be seen to mitigate the intrusiveness of the treatment-regimen on Robert's life, supporting his argument that the condition does not place significant restrictions upon him. However, despite this construction, Robert

suggests that in a scenario whereby he does not attend to such considerations, the consequences could be very serious: ‘I’ve been in places where...there isn’t a chippy and you think to yourself well what the hell am I gonna do?’ (54-56). These potential consequences are left implicit here, but we can infer that this relates to the fact that not eating regularly can lead to a lowering of blood-sugar levels, possibly resulting in hypoglycaemia. Robert emphasises the importance of *planning* in order to maintain good condition control, and thus avoid these potential consequences. Through use of a ‘contrast’ structure, he emphasises that such planning is to prevent the *possibility* of experiencing T1DM-health problems, rather than these being a certainty: ‘planning...what could happen as opposed to that it will happen’ (63-64). Robert is therefore able to construct a positive, morally-appropriate identity as being careful and responsible with regard to maintaining his ‘healthy body’, through foregrounding his desire to maintain good condition control in such contexts.

Robert thus represents himself as having a degree of *agency* in maintaining his T1DM-related health. This may contradict his earlier suggestion that hypo- and hyper-glycaemia are inevitable factors in living with T1DM (7-8). However, Robert appears to be suggesting that whilst *in general* he does have agency with regard to his T1DM-health, this condition control is not absolute, thus there are times when he cannot prevent himself from experiencing hypo- or hyper-glycaemia.

Through his emphasis on planning vis-à-vis his treatment-regimen, Robert implies making some adaptations to his lifestyle in order to protect against ill-health, thus attempting to create a balance between lifestyle control and condition control. This corroborates Paterson’s (2001) argument that in order for ‘sickness to be distant, management of the disease must be foremost; that is, the illness requires attention in order not to have to pay attention to it’ (2001: 24). However, Robert does not represent this attention to his treatment-regimen as being particularly restrictive or intrusive towards his lifestyle. There is no suggestion that such considerations hamper his enjoyment of ‘meals...and nights out’ (46-47), therefore implying that as well as attending to his ‘healthy body’, he is still able to pursue his ‘social body’, and thus maintain a degree of lifestyle control.



In Extract 19, Helena, a 20 year-old university student, orients primarily to her *condition* control. In contrast to Robert, she constructs a general *lack* of agency, as she represents herself as having poor condition control, in spite of reportedly attending to her 'healthy body'. Helena had been diagnosed with T1DM at the age of three (see Appendix K; Interview 6: 72-105):

Extract 19:

1. BS: okay (.) um so in terms of this sort of control element do you feel that you're
2. in control of your diabetes or do [H: mm] you feel that it controls your
3. lifestyle [H: yeah] and what you're able to do?=  
4. H: =um (.) probably a bit of both
5. (1.0) um (1.0) I just find with diabetes you know you're told (.) to keep your
6. blood sugar between you know a certain amount (( )) four and seven (.) but
7. sometimes I just think that's absolutely not possible like recently I've been
8. testing my blood (.) regularly (.) and even if I eat you know (.) a healthy (.)
9. meal (.) an hour later my blood will be sort of (.) nine ten eleven twelve (.) and
10. it's just (1.0) diabetes does control me I find rather than (.) I control it and you
11. do get (1.0) you know you might have had (.) a really good day of (.) you
12. know (.) what you're eating and exercise etcetera (.) but you'll still get (.) a
13. high blood sugar level that you just it doesn't make sense and I do find (1.0)
14. it's the diabetes that's (1.0) in control but I do try and (.) make it the other way
15. round (chuckles) (1.0)
16. BS: do you find that quite hard to deal with then when like you've been doing
17. everything right (.) but then suddenly your blood sugars ((are not where they
18. should be?))
19. H: [yeah (.) it re- it does (.) piss me off a lot but um (1.0) at the same time
20. I try not to complain about it because (1.0) like my friend (name omitted) I
21. think what she's been through is (.) much worse<sup>16</sup> (1.0) and (.) you know I still
22. have a normal lifestyle you know I'm still (.) there's there's nothing (.) you

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<sup>16</sup> Helena had earlier talked about a friend who had recently undergone a Colectomy (see Appendix A).

23. know people have much worse things to deal with than diabetes so I try and  
24. (1.0) be realistic about it and (1.0) not let it get to me (1.0) because I know  
25. (1.0) I do look after it I mean since being at university like going out drinking  
26. (1.0) that hasn't helped it probably (.) but (1.0) you know (.) generally I do  
27. look after it so if I do have a (1.0) bad day I try (.) my hardest not to let it get  
28. to me (.) and it's quite nice having a housemate who's dia- who's diabetic too  
29. 'cause we can both sort of (1.0) you know I can talk to her about it and I (.)  
30. my friends like my close friends I do talk to (1.0) you know I do (.) you know  
31. say 'oh my blood's high I'm really (.) pissed off' you know I'll just (.) whatever  
32. I do it doesn't work but (name omitted) always understands 'cause she's  
33. diabetic too and (1.0) whereas my other friends I it's obviously (.) they're  
34. understanding but they can't (.) quite understand it

Initially, I return to a discussion from earlier in the interview, explicitly asking Helena whether she feels that she is in control of her lifestyle vis-à-vis her condition, or vice-versa (1-3). Helena's response, in line 4, implies a two-way control relationship, though her hesitation and the adverb 'probably' (4) suggest some uncertainty, perhaps signalling that the way I have framed this question does not reflect her habitual way of thinking about the condition. Whilst my question addresses 'lifestyle' (3), Helena's response initially orients to her degree of condition control, perhaps suggesting that this is more salient within her own subjective experience. She argues that keeping her blood-sugar levels within the medically-recommended range is 'absolutely not possible' (7). Helena thus represents herself as lacking agency vis-à-vis her condition control, as in spite of her best efforts to follow her treatment-regimen (7-13), she still experiences poor glycaemic control. This leads Helena to propose that 'diabetes does control me I find rather than (.) I control it' (10), to some degree contradicting her earlier assertion that in terms of her control relationship with T1DM there is 'a bit of both' (4). These concerns regarding the lack of control over her 'healthy body' (Balfe, 2009) is a recurring theme throughout Helena's interview.

Helena projects considerable frustration with her lack of condition control: 'it does (.) piss me off a lot' (19). Through contending that she is not simply willing to accept that her

T1DM will control her (14-15), Helena can be seen to construct a morally-appropriate identity as somebody who is concerned about her T1DM-related health, and does not find it acceptable to have poor glycaemic control, actively taking practical steps in an attempt to gain better control. Her chuckle at the end of this statement (15) perhaps signals a degree of 'troubles-resistance' (Jefferson, 1984: 360) in relation to these frustrations, demonstrating that the 'trouble is not getting the better' of her, and that she is 'in good spirits' (1984: 360).

Helena juxtaposes expression of these frustrations, however, with the statement: 'at the same time I try not to complain about it' (19-20). She thus conforms to culturally-accepted models that it is morally-*inappropriate* to complain or make a fuss about one's ailments or hardships. In lines 19-24, she makes a 'downward social comparison' (Gibbons, 1999; Schur, Gamsu and Barley, 1999). Drawing comparison with somebody who has an illness Helena presents as being worse than her own (20-21), as well as those with 'much worse things to deal with' (23) which are not necessarily related to chronic illness, rather than comparison with those who have worse experiences of T1DM, can function to mitigate the severity of T1DM relative to other problems; however, it could also be the case that Helena does not know of anyone who has had worse experiences of T1DM. This comparison is further supported through the proposition: 'I still have a normal lifestyle' (21-22), implying that many illnesses and problems are far more intrusive. Therefore, despite Helena's earlier assertion that her lack of glycaemic control leads her to feel controlled by her condition (13-14), through characterising her lifestyle as 'normal' she suggests that T1DM does not exert any significant control over her *lifestyle*. Helena does not specify here, however, what she considers to constitute a 'normal' lifestyle.

Helena's subsequent statement: 'so I try and...not let it get to me' (23-24) suggests that one function of this downward social comparison is a way of her *coping* with the frustrations and psychological strain of the condition. As Gibbons (1999) puts it, Helena is 'able to discern some clear distinction between the self and worse off target' (1999: 1525), allowing her to 'feel better about [her] own situation' (1999: 1518). In this context, however, this strategy also has a rhetorical function in *displaying to me as the interviewer*

that she is able to deal with her frustrations, thus again aligning with cultural and ideological models of moral-appropriacy, through emphasising that she recognises her good fortune relative to many others.

Another way in which Helena constructs herself as coping with the condition is by sharing her experiences and frustrations with her housemate who also has T1DM (28-29). This implies a therapeutic catharsis in talking about one's frustrations surrounding illness experience (Frank, 1995: see 2.2) – a catharsis which from Helena's perspective is most significant when the other person shares similar concerns, as Helena proposes that non-diabetic friends with whom she shares these frustrations 'can't (.) quite understand it' (34). This kind of orientation to those with the same condition is less common within the data-corpus as a whole than orienting to those without, as was discussed in Chapter 7.

Whilst Extract 19 shows Helena struggling to gain condition control, despite reportedly attending to her 'healthy body', Extract 20 demonstrates Melanie, a 28 year-old university student (who we also encountered in Chapter 6; Extract 2), attempting to gain a greater degree of *lifestyle* control in a particular context, through *ignoring* her treatment-regimen, giving salience to her 'social body' ahead of her 'healthy body'. Melanie (M) had been diagnosed with T1DM for four years (see Appendix K; Interview 21: 207-249):

Extract 20:

1. BS: okay (.) um (.) in terms of your overall control (.) not just you
2. know your glyceimic control but generally the effect that the
3. diabetes has on your life (.) do you feel as if you're in control
4. or do you feel as if it controls (.) certain things that you're
5. able to do? (.)
6. M: um (.) I'd definitely say (.) I'm in control of it rather than
7. it's in control of me (1.0) um (1.0) but then I do think (2.0)
8. mm (2.0) I dunno there are some situations that I don't know
9. (.) really how to handle very well (1.0) and like for example I
10. went skiing a couple of weeks ago (.) and (.) I was (.) with (.)

11. I was spending most of the day with people that I didn't  
12. really know very well (.) and you know when you're up on a  
13. mountain (.) like the last thing I wanted to do was have a  
14. hypo (.) so basically for the whole week I was just running  
15. my blood sugars (.) really quite high (.) and it all basically  
16. just (.) I think I tested my blood sugar about twice (.) the in  
17. the whole week (.) and that's really not like me like over here  
18. I'm quite sort of (.) not obsessive (.) but you know I check  
19. my blood sugars at least sort of four times a day (.)  
20. BS: mm (.)  
21. M: so (.) like that like the whole time I was (.) and 'cause my  
22. blood sugar was higher I was tired the whole time you know  
23. and I was skiing as well so [BS: mm] I was (chuckling)  
24. properly really tired (.)  
25. BS: mm (1.0)  
26. M: so (.) like in that respect like I was just (1.0) those are the sort  
27. of situations where you just think you know it's really  
28. actually it's a real (.) pain in the arse (.)  
29. BS: mm (.)  
30. M: having it (1.0) and (.) I know that in that situation I really  
31. wasn't handling it very well and in that sort of situation I  
32. would say that it was sort of controlling me rather than I was  
33. controlling it (1.0) or I was ignoring it more than anything I  
34. suppose (.) but um but the rest of the time (.) I think  
35. definitely (.) I'm in control of it (1.0) I like to think I am  
36. anyway (.)  
37. M: [(chuckles) (.) don't want to over analyse it (chuckles)  
38. [BS: (chuckles)] (.) but yeah (1.0)  
39. BS: okay=  
40. M: =I think that's the main thing I don't think it stops me  
41. doing anything
- .

. Melanie briefly returns to discussion of her skiing holiday later  
 . in the interview (876-879):

42. M: but um (.) but I wouldn't just do that regularly 'cause I know  
 43. (.) you know what (.) what effect that could have (.) so yeah  
 44. it is a balance (.) like I did that so I could have a good time  
 45. while I was on holiday (.)

When initially asked whether she feels in control of her condition *and* lifestyle (1-5), Melanie responds ardently: 'I'd definitely say (.) I'm in control of it rather than it's in control of me' (6-7). This proposition is mitigated, however: 'but then...there are some situations that I don't know (.) really how to handle very well' (7-9), which Melanie exemplifies through discussion of a skiing holiday during which she kept her blood-sugar levels above the recommended range,<sup>17</sup> due to her concerns about experiencing hypoglycaemia (14-15).

Melanie describes this management-strategy as her 'ignoring' her T1DM (33). She thus represents herself as intentionally allowing her adherence to her T1DM treatment-regimen to slip, and whilst this was in order to prevent short-term health consequences, this management-strategy was ultimately employed so that her lifestyle activities at that time were not affected: 'I did that so I could have a good time while I was on holiday' (44-45). Melanie was thus attempting to gain greater *lifestyle* control, despite the longer-term health risks associated with having high blood-sugar. This management-strategy is similarly observed by Hillege (2005), who found respondents reporting that hypoglycaemia made them feel 'out of control', so they would at times neglect their T1DM self-care as they preferred to deal with hyperglycaemia than hypoglycaemia (2005: 133).<sup>18</sup> She talks of 'the reality of profound hypoglycaemia in the 'now' competing with the reality of T1DM complications 'later'' (2005: 252).

<sup>17</sup> Not regularly monitoring blood-sugar levels or administering enough insulin can lead blood-sugar levels to go above the recommended range.

<sup>18</sup> Though *hypoglycaemia* (low blood-sugar) and *hyperglycaemia* (high blood-sugar) can both result in serious short- and longer-term consequences, in most cases hypoglycaemia is more immediately serious in the short-term, whereas hyperglycaemia is more commonly associated with longer-term health issues, See next page

Whilst intending to gain greater lifestyle control through this strategy, Melanie equates this 'ignoring' of her treatment-regimen with the condition having a controlling effect upon her: 'in that...situation I would say that it was...controlling me rather than I was controlling it' (31-33). The reason given for this is that because she allowed her blood-sugar levels to go high, this resulted in her being very tired, a symptom of *hyperglycaemia* (high blood-sugar), which was compounded by the effort of skiing (21-24). Thus, whilst she was attempting to gain greater lifestyle control through her strategy of 'ignoring' her condition control, this adversely affected her participation in the activity in another way, leading to *less* lifestyle control. This demonstrates the complex nature of the relationship between condition control and lifestyle control in the case of T1DM, as in this context it appears that both good *and* bad condition control had the potential to affect Melanie's lifestyle activities. If, hypothetically, she had attended to her treatment-regimen more carefully, she may have avoided the effects of *hyperglycaemia*, but risked experiencing *hypoglycaemia*, as when partaking in vigorous exercise this is a risk even when the individual is being careful to monitor his or her blood-sugar levels. As it was, ignoring her T1DM did not prevent Melanie from partaking in this activity, but resulted in less enjoyment due to this tiredness, as evidenced in her evaluation of this context: 'those are the sort of situations where you just think...it's a real (.) pain in the arse' (26-28). Viewed through the lens of Sargeant's (2006) dual concepts, Melanie can be perceived as projecting 'living *beyond* the confines of illness', through deciding to partake in her skiing holiday unhindered by her treatment-regimen. However, the tiredness she experienced as a result of this, and subsequent lack of enjoyment of this activity, also signal her living '*within*' its confines (Sargeant, 2006), demonstrating the interrelated nature of these concepts.

Melanie implicitly constructs this 'ignoring' as being somewhat irresponsible and morally-*inappropriate* through producing a 'justification' (Scott and Lyman, 1968), proposing that this is *not typical* of her illness-management: 'that's really not like me over here...I check my blood sugars at least...four times a day' (17-19). Melanie thus

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which explains Melanie's preference for risking experiencing *hyperglycaemia* in order to ensure that she does not experience *hypoglycaemia* (see Appendix A).

frames her ‘ignoring’ as exceptional behaviour only undertaken while she was on holiday, contrasting this with her daily life in which she *does* adhere to medical advice regarding her T1DM-related health. She also ‘excuses’ her exceptional behaviour through emphasising the difficulty in controlling her condition in this context: ‘when you’re up on a mountain (.) like the last thing I wanted to do was have a hypo’ (12-14). Melanie therefore emphasises that ordinarily she does not foreground her ‘social body’ to the detriment of her ‘healthy body’, thus allowing her to perform a positive identity in spite of the potential negativity of her behaviours whilst on holiday.

Melanie’s admission that she ‘wasn’t handling it very well’ (31) suggests that she feels she does have a degree of agency regarding her control, presumably both in terms of her condition and lifestyle, as she *could* have managed her T1DM better within this context. Whilst this implies responsibility on Melanie’s part, indicating a negative identity-performance, there is also the implication that she has learned from this experience, and may therefore manage her T1DM more successfully in the future. This could suggest that control is, in some cases, *incremental*, with experience potentially leading to better condition control and lifestyle control.

In addition to proposing that she *ordinarily* attends to her ‘healthy body’ in order to gain greater condition control, Melanie also emphasises that in everyday life she maintains a significant degree of *lifestyle* control: ‘the rest of the time (.) I think definitely (.) I’m in control of it...that’s the main thing I don’t think it stops me from doing anything’ (34-41). This suggests that, in general, Melanie’s morally-appropriate management-strategy of attending to her ‘healthy body’ does not prevent her from simultaneously pursuing her ‘social body’. Melanie frames the disparity between her everyday illness-management and her management-strategy whilst on holiday, through the linguistic metaphor of a ‘balance’ (44), presumably between giving salience to her ‘healthy body’ in some contexts, and her ‘social body’ in others. This metaphor has a rhetorical function, as through viewing her holiday-behaviour within the context of her T1DM-management as a whole, she is able to mitigate the negativity of this behaviour by suggesting that it is *balanced out* by her usual positive behaviour.



Extracts 18-20 have been shown to display some similarities, but also variation, in representations of control. Whilst Robert constructs himself as generally able to maintain both good condition control and lifestyle control, attending to both his 'social' and 'healthy' bodies, Helena constructs herself as having poor condition control, in spite of her attention to her 'healthy body', thus representing herself as having less *agency* over her condition control. However, her lifestyle control is constructed as largely separate and unaffected by this lack of condition control. Melanie, however, presents a complex tension between lifestyle control and condition control, whereby foregrounding either her 'social body', or her 'healthy body' has the potential to undermine the other, which, in relation to one particular context, in fact resulted in an adverse affect on both condition control *and* lifestyle control. This is represented as an exceptional case, however, and Melanie proposes ordinarily being able to simultaneously maintain both types of control.

### 8.3 *Representations of IBD*

I will now examine extracts from interviews with IBD-respondents. In Extract 21, Frank orients primarily to his *lifestyle* control, representing himself as adopting a positive outlook towards the effect of IBD upon his lifestyle. He constructs his management of the condition in terms of him adapting aspects of his lifestyle to fit around his IBD.

Frank (F) was aged 27, and had been diagnosed with Crohn's disease for two years. At the time of the interview, he was working fulltime as a senior physical activity development officer (see Appendix K; Interview 29: 524-555):

Extract 21:

1. BS: okay so I mean how would you rate it [IBD] sort of the overall effect
2. that it has on your life and your overall identity and stuff like
3. that? I mean would you say now obviously that it's less than it
4. was presumably a year ago or?
5. F: [yeah]=
6. BS: =yeah (.)

7. F: yeah definitely (.) I dunno (.)
8. BS: I mean is it just kind of like a background factor now or?
9. F: [yeah (.)
10. it is (.) um possibly because that's how I look at that's the way
11. I take it and the way I look at it whereas other people may feel
12. that oh (.) being ill is the be all and end all and you've got to
13. take this and you've got to do that and these sort of things
14. which (.) having spoken to some people that's the way they are
15. and because they've been diagnosed they're like 'oh I'm ill and
16. I can't do that and I can't do this' well I'd be the opposite (.) I
17. can do this but (.)
18. BS: right yeah (.) so look at the stuff you can do as opposed to what
19. you can't do
20. F: [yeah (.) and I can do this but I have to bear in mind
21. that (.) if they say 'I can't go to the gym 'cause I'm too ill' I'd
22. say 'well I can go to gym but I can't go everyday' (.) just got to
23. manage it a little bit better or go for a short space of time rather
24. than going (.) for a couple of hours or those sorts of things (.)
25. BS: so it's kind of like making concessions and fitting things
26. around (.) your illness in a way? (.)
27. F: yeah (.)
28. BS: yeah
29. F: [yeah yeah so it does play a part but it's a background part
30. (.) whereas I suppose if you've got children you'd say 'I can do
31. this but (.) I've got to be home to pick up the kids from school'
32. or (.) in that sort of context (.)

When asked whether IBD is now only a 'background factor' (8) in his life compared with its previous role,<sup>19</sup> Frank responds that he does feel that this is the case (9). He supports this proposition through contrasting his perceptions and behaviour with that of others who

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<sup>19</sup> Frank had explained earlier that he experienced a severe flare-up of disease symptoms the year before, whereas at the time of the interview his IBD was in remission.

have illnesses, though he does not specify these others as being others with IBD. Through this 'contrast' structure, in lines 11-17, Frank constructs a positive identity by representing others as viewing their condition as the defining factor in their lives: 'other people may feel that...being ill is the be all and end all' (11-12), whereas he proposes that 'I'd be the opposite' (16). He therefore draws upon culturally-accepted models regarding the moral-*inappropriacy* of making a fuss about one's ailments or hardships, or letting these take over one's life, explicitly placing himself in opposition to this. He can therefore be seen to construct 'self-vs.-other' orientation (Sarangi, 2007), 'othering' these individuals as a way of distancing himself from these morally-inappropriate behaviours. Whilst the modal verb 'may' (11) suggests these others are hypothetical, Frank presents more robust evidence for this contrast, proposing that he has witnessed this type of attitude first hand: 'having spoken to some people that's the way they are' (14).

Frank contends that, because these others view illness as the defining factor in their lives, they focus upon the restrictions their condition imposes upon them, and therefore what they *cannot* do: 'they're like 'oh I'm ill and I can't do that and I can't do this'' (15-16). Through using the reported speech of these others, Frank gives greater legitimacy to his claims (Arribas-Ayllon, Sarangi and Clarke, 2008: 1524), though its framing suggests that this is not directly-reported speech. Frank again contrasts this with his own perspective that he focuses on things that he *can* do (16-17), rather than what his condition prevents him from doing. It appears, then, that the contrast Frank is making with others is not based on the severity of his condition relative to others, or the degree to which IBD impinges upon his lifestyle relative to its effects upon others, but the psychological element of living with the condition, the perception taken towards this impact. Thus, through constructing himself as adopting a positive attitude, Frank portrays himself as *coping* more successfully than others.

This representation of coping is constituted via the practical management-strategies Frank reportedly employs, which he again outlines through contrasting his behaviour with that of others, using the example of going to the gym: 'if they say 'I can't go to the gym 'cause I'm too ill' I'd say 'well I can go to gym but I can't go everyday'' (21-22). Frank suggests here, then, that the lack of coping on the part of these others affects their degree

of lifestyle control, as by allowing themselves to become ‘immersed’ (Charmaz, 1991: 76) in their condition, they are prevented from partaking in certain lifestyle activities. Frank proposes that whilst he accepts the limitations his condition imposes upon him, he still attempts to partake in desired lifestyle activities, and thus pursues his ‘social body’, albeit ‘within the confines of illness’ (Sargeant, 2006: 82). So by talking of going to the gym only on certain days, or for a short duration, Frank constructs his illness-management in terms of him adapting his lifestyle to accommodate for his IBD. In this construction, he is not ignoring his symptoms and carrying on with his life in spite of his IBD; however, at the same time he is not giving in to his symptoms and letting them prevent him from partaking in desired lifestyle activities, but is finding middle ground between the two. Frank therefore constructs himself not only as coping better than others, but also as having a greater degree of lifestyle control, in spite of making some concessions.

Whilst up until line 24, Frank contrasts his behaviour with that of others with illnesses who behave in a morally-inappropriate manner, in lines 30-32, he implicitly constructs *similarity* between himself and hypothetical others, demonstrating ‘self-*and*-other’ (Sarangi, 2007) orientation: ‘I suppose if you’ve got children you’d say ‘I can do this but (.) I’ve got to be home to pick up the kids from school’’. Frank implicitly likens the concessions he makes for IBD to those someone might make in relation to other roles and responsibilities unrelated to chronic illness, such as the restrictions that caring for children might impose on people’s pursuit of their ‘social bodies’. Frank therefore aligns more with others who do not have a chronic condition, than many who do, in terms of how he represents the constraints on his life. Through this placing of chronic illness-management alongside everyday activities such as raising children, Frank implicitly constructs living with chronic illness as a ‘normal’ role (Guggenbühl-Craig, 1980). The construction of IBD as somewhat unexceptional further supports Frank’s positive identity-performance as somebody who does not make a big fuss about illness or let it dictate his life.

In Extract 22, Mary also constructs a positive representation of her lifestyle control, though her reported-management of IBD appears to differ from Frank’s. She constructs

herself not as limiting or making concessions to lifestyle activities, but as actively resisting the impact of her condition by pursuing her 'social body' in spite of her IBD. However, the effects of this management-strategy upon her 'healthy body' are represented as forcing Mary to make *subsequent* concessions to her lifestyle.

Mary (M) was aged 28, and was working fulltime as a pharmaceutical dispenser. She had been diagnosed with Crohn's disease for eleven years. Mary has suffered considerable ill-health as a result of her IBD, having undergone surgery on several occasions, resulting in significant disruption to her life. This extract follows a longer discussion about the role of IBD within Mary's life (see Appendix K; Interview 26: 401-438):

Extract 22:

1. M: it's had a big big influence on my life and it still has an influence
2. on my life (.) but now I feel I've got a handle on it rather than it
3. having a handle on me (.)
4. BS: mm mm
5. M: [so although it's (.) make I'm aware of the choice
6. I'm making because of the Crohn's (.) sometimes I just
7. think (.) sod it I'm (.) uh (.) it's not gonna stop me (.)
8. BS: mm (.)
9. M: and a (.) good example of that (.) it would be something
10. that's happened to me today (.) I applied for a job in
11. London (.) because I (.) I've always lived (.) with my
12. parents or with somebody (.)
13. BS: mm=
14. M: =so there's an element of care (.) but because I've
15. been so well (.) I've kind of (.) got this urge to (.) try
16. living on my own like in a house share but with people
17. you don't know (.)
18. BS: mm (.)
19. M: probably the stuff you've kind of gone through with uni

20. and things (.)
21. BS: mm mm (.)
22. M: not having your parents (.) there to hold your hand [BS:
23. mm] and things (.) um (.) but it's an internal (.) uh (1.0)
24. job that I applied for (.) they haven't given it to me (.) but
25. they've asked me to move to London and be a locum
26. dispenser there (.)
27. BS: mm (.)
28. M: and that's kind of me (.) giving the finger to the Crohn's
29. because a few years back there's no way I could have
30. done it (.) because I'd have been too scared of (.) what if
31. the Crohn's? (.)
32. BS: mm mm
33. M: [and still it is (.) what if the Crohn's? but (.) I'm
34. stronger (.) to deal with that (.)
35. BS: mm mm (.)
36. M: if that makes any sense (.)
37. BS: no no definitely yeah (.) yeah=

.

. For the next 59 lines Mary talks about ways in which she feels  
. IBD has restricted her in the past, concluding (495-501):

38. (.) but (1.0) it won't win...it won't stop me (.)

Mary suggests a degree of continuity in her illness experience, through expressing that IBD has had a 'big big influence' upon her life in the past, and continues to do so (1-2). She asserts, however, that a temporal change has taken place: 'but now I feel I've got a handle on it rather than it having a handle on me' (2-3), implying through this metaphorical expression that she now feels she has a greater degree of control over her IBD, rather than it controlling her. Again this could allude to control being incremental, with experience perhaps leading to better control.

This shift in the control-relationship with her IBD is represented as resulting from a change in Mary's perception, as opposed to a change in disease-severity or level of condition control; evidenced through Mary's reconstruction of habitual thought processes: 'sometimes I just think (.) sod it...it's not gonna stop me' (6-7). Mary is therefore addressing her degree of *lifestyle* control, proposing that, in spite of the ongoing influence of IBD upon her life, she at times adopts the attitude that she will not let it prevent her from living her life as she wishes, thus framing illness as something to be stood up to and tackled, rather than being given in to. Through this, Mary can be seen to construct a positive, morally-appropriate identity, as being strong-willed and prepared to stand up for herself, a consistent theme running throughout her interview.

This present perspective appears to guide Mary's current illness management-strategy, as, in lines 9-26, she talks of how, on the day of the interview she had applied for a job in London, a significant distance from her home, which, if she were to get the job, would involve living away from her parents for the first time. Mary involves me at this point: 'probably the stuff you've kind of gone through with uni' (19). Through speculating that I, as a fellow young adult, may have had such experiences, Mary frames moving away from home as a culturally-expected activity inherent to young adulthood, but one which she has previously been denied by her IBD (11-14). Through these actions, then, she is now attempting to gain greater control over her lifestyle in this respect.

Mary describes these actions metaphorically, as her 'giving the finger to the Crohn's' (28). 'Giving the finger' is accepted within Western culture as a symbol of animosity and disdain, and through ascribing this gesture to her actions she constructs her condition as an oppressive entity acting upon her from outside her selfhood, but one that she is now fighting. In addition to this metaphorical expression, the act itself of applying for a job in London can be viewed as metaphorical, in representing Mary's new-found resistance towards her condition. Both Gwyn (1996) and Radley (1993) talk of how metaphors 'need not be restricted to the medium of language' (Gwyn, 1996: 194), but can be achieved through 'symbolic action' (1996: 194). This metaphor further supports Mary's positive identity-construction of strong-willed determination.

The strategy Mary reportedly adopts could be suitably termed *resisting through fighting back*; rather than resisting through ignoring the effects of her condition upon her, Mary's resistance is framed as a determination to fight against her condition by carrying on with her life in spite of the influence of IBD. Mary is therefore projecting 'living beyond the confines of illness' (Sargeant, 2006: 82). The metaphorical representation of Mary being engaged in a battle with her condition is further extended, in line 38: 'it won't win...it won't stop me'. In relation to this *illness as war* metaphor, which was similarly observed in Chapter 6, Extract 6 (Tara), Gwyn (1996) proposes: 'illness presented itself in the form of an attack and was consequently perceived as something which had to be *fought*' (1996: 186). Mary's constructions share similarities with Gwyn's observations: 'ultimately the goal is not to 'lose' to illness... by not 'lying down to it' (1996: 189). Through representing her IBD in this negative way, Mary can be seen to extend her positive identity-performance through drawing on cultural models of the courageous hero battling in the face of adversity (Gwyn, 1996; 2002; Herzlich, 1973; Radley and Green, 1987: 198-99).

However, there is some evidence that this strategy is not only a result of a change in Mary's perception of her IBD, as she proposes that one of the reasons she has been able to apply for this job is that recently she has 'been so well' (15). This suggests that a change in disease-severity, and thus the impact that her condition has upon her lifestyle, has had some influence on this action.

Despite these statements, Mary further implies that this temporal shift in her illness-management is principally due to her change in perception: 'a few years back there's no way I could have done it (.) because I'd have been too scared of (.) what if the Crohn's?' (29-31). Whilst she states she is still somewhat fearful, she proposes; 'I'm stronger (.) to deal with that' (33-34). Mary again therefore constructs herself as being psychologically more able to deal with the continued influence of these symptoms upon her life, and thus able to gain greater lifestyle control. Though left implicit, such fears can be assumed to be that she would not be able to manage the symptoms of her condition whilst living on her own. This construction can be viewed in relation to Linde's (1993) discussion of 'life stories', and specifically *reflexivity* in the life story, as Mary separates her present



perceptions from that of her former self. Though not necessarily constructing the perceptions of her former self as morally-inappropriate, through this 'contrast' she is able to construct moral-appropriacy with regard to her present self. In Herzlich's (1973) terms, whereas Mary previously viewed her condition as 'destructive', she now constructs her IBD as 'an occupation' (1973: 105), representing herself as engaged in 'an active struggle against her illness', leading her to 'become "stronger"' (Herzlich, 1973: 125); however, Mary does not appear to be 'occupied with getting cured' (1973: 125), which Herzlich proposes is commonly the case with individuals who represent illness as 'an occupation'. We could also talk of Mary having undergone 'transformation' (Paterson, Thorne, Crawford and Tarko, 1999) in the way in which she represents a 're-structuring of self' (1999: 788) in relation to illness, as was discussed vis-à-vis the accounts in Chapter 6.

This construction of a positive, transformational shift in her 'self-concept' (Charmaz, 1983) can be seen as a way of Mary *coping* with her IBD, with this positive coping represented as influencing her in adopting the management-strategy of resistance. Whilst, then, for analytic purposes I have separated the concepts 'control', 'coping' and 'management-strategies', here they can be seen to be highly interrelated.

Following a brief discussion of the ways in which IBD restricted her life before her reported change in perception, Mary continues:

Extract 22 (contd):

39. M: I'm starting to do more and try more and so I feel I'm  
40. getting more of a handle on it (.) and I've realised a lot of  
41. it's mind set (.) as well (1.0) for example with the NACC  
42. (.) um we had a family day that we organise there's four  
43. of us that organise it for the South West (.) four weekends  
44. ago (.) I knew it would exhaust me and I knew Sunday  
45. morning (.) half past seven (.) I would not wanna get out  
46. of bed 'cause I'd be tired and it was my first day off (.)  
47. BS: mm=

- 
48. M: =in six or seven days (1.0) but I (.) dragged myself  
 49. out of bed because I knew I wanted to do it (.)  
 50. BS: mm (.)  
 51. M: and it took me two weeks to recover from this whole day  
 52. of (.) you know (.) physical activity really not (.) major (.)  
 53. BS: mm (.)  
 54. M: um (1.0) so yeah I think (.) for me anyway there's an  
 55. element of the mind set and (.) sheer (.) gutsy  
 56. determination to not let it stop me doing what I want to  
 57. do but I know I'm gonna pay

Mary draws on another example to demonstrate how she is presently attempting to resist the influence of IBD upon her lifestyle, talking of how she helps to run a 'family day' (42) as part of the *NACC* (the National Association for Colitis and Crohn's disease). Again Mary constructs herself as 'living beyond the confines of illness' (Sargeant, 2006), defying the physical limitations imposed upon her through engaging in desired activities in spite of knowing that this would 'exhaust' (44) her. The phrases, 'dragged myself out of bed' (48-49) and 'sheer (.) gutsy determination' (55-56) emphasise the significant effort that Mary represents herself as undertaking in participating in such activities, with the use of the present tense preceding the latter phrase (54-55) suggesting this example represents her *general* resistance. These constructions further contribute to her identity-construction as courageously resisting her oppressive condition, and getting on with her life against the odds.

Mary suggests, however, that adopting this strategy in this context came at some cost to her: 'it took me two weeks to recover from this whole day' (51); 'I know I'm gonna pay' (57) – this latter statement again projecting this particular example to a general prediction regarding her lifestyle activities. This suggests that resisting her condition has, and will continue to have, negative consequences on her health, in causing significant physical strain. In this particular context, then, Mary is giving salience to the pursuit of her 'social body', as a way of gaining greater lifestyle control, but this could be seen as resulting in less condition control, by undermining her 'healthy body'. However, through framing

herself as heroically battling her condition, she is able to avoid the potential negative-identity construction that she is neglecting her 'healthy body' and pushing herself too far physically, and therefore acting irresponsibly. By proposing that it took weeks for her to recover from this activity, Mary may be suggesting that the strategy of resistance is one which she is not able to adopt at all times, as she needs time to recuperate after having resisted her condition. It could therefore be said that 'living beyond the confines of illness' (Sargeant, 2006: 82) in order to gain greater lifestyle control in certain contexts, may have adverse effects on Mary's lifestyle control in other contexts, thus forcing her to live *within* its confines (Sargeant, 2006: 82).

Extract 23 demonstrates the variation present within the data-corpus, as it will be shown that Rosie, a 22 year-old university student (who we encountered in Chapter 7; Extract 15), also proposes a temporal change in her illness-management, but different to that constructed by Mary. Rosie reports that whilst she previously attempted to carry on with lifestyle activities in spite of symptoms, she now chooses to, at times, abstain from certain lifestyle activities.<sup>20</sup> However, through her framing of this management she is still able to represent herself as maintaining a degree of lifestyle control, and is also able to construct a positive identity aligning with models of moral-appropriacy. Rosie (R) had been diagnosed with Ulcerative Colitis (UC) for six months (see Appendix K; Interview 4: 744-796):

Extract 23:

1. BS: so you were obviously saying that you've only had
2. it [IBD] for (.) well you've only had it diagnosed for a short
3. [R: yeah] period of time but would you say (.) the
4. way that you view it and the way that it fits into
5. your life has changed within those within that period
6. at all or? (.)
7. R: yeah (.) yeah it has changed um (.) I'm more (.) um (.) I

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<sup>20</sup> Comparison of Rosie's account here and in Chapter 7 demonstrates consistency across her interview, in terms of her at times abstaining from certain social activities as a result of her condition.

8. think I'm more (.) forgiving of my (.) body (.) you  
9. know if I'm if I'm not feeling well (.) I'll say okay right  
10. (.) I'm having a bad day just take it easy (.) whereas  
11. before I used to just think (.) you know (.) oh this is  
12. what everyone's dealing with get out there and (.) you  
13. know (.) do the same thing as everybody else is doing  
14. 'cause I honestly thought (.) that you know when  
15. people need to go to the loo or something they need to go  
16. right then and I always thought everybody was doing  
17. the same thing (.) um you know everyone was like (.)  
18. right got to go to the loo find the loo (.) um (.) so I and I  
19. thought everyone else was just (.) in the same position  
20. (.) I don't know why I thought that actually especially  
21. when my mum's got it but I (.) I just never thought (.)  
22. that (.) that people had more warning than I did (.) and  
23. so I I kind of (.) I think I pushed myself a bit too much  
24. which was probably (.) um (.) you know (.) brought on  
25. the rest of the symptoms (.) um so now I think if I yeah  
26. I'm a lot more (.) um willing to (.) not (.) to give myself  
27. a break I think um (.) and it's and it's nice to have stuff  
28. diagnosed you know (.) if um I'm sure people say it's a  
29. relief because you think (.) oh god I'm not making  
30. stuff up and I was tired for so long (.) if you ask my  
31. boyfriend he would say that I was always tired (.) and  
32. he got annoyed (.) and I was annoyed because I thought  
33. (.) I'm getting the same amount of sleep as everyone  
34. else more sleep and I'm still knackered the next day (.)  
35. um (.) and I don't understand I don't do you know loads  
36. of exercise I'm not out partying all night I don't drink  
37. heavily why am I so tired? (.) and then to have (.) the  
38. doctor say this is one of your symptoms was kind of  
39. like (.) oh see that's why you know I'm not making it

40. up it's you know um (.) this is why I'm a bit different to  
41. everybody else (.) which was great do you know what I  
42. mean it's not great (.) being tired but it's nice knowing  
43. that you have a reason for it and that you can you know  
44. (.) give yourself a nap in the afternoon if you need one  
45. you know it's okay um (.) and um yeah have an early  
46. night if you need to that kind of thing (.) and my mum's  
47. always said just listen to what your body says if if  
48. you're tired (.) sleep (.) if you're okay if you're having  
49. a good day make the most of it go out and have a good  
50. time (.) but if you're not then just accept it you know  
51. there's nothing you can do about it and (.) you'll just  
52. make yourself worse if you do try and push yourself  
53. which is what I did (.) last year

When asked whether her view of her condition has changed since being diagnosed (1-6), Rosie proposes a temporal shift has taken place: 'I'm (.) more forgiving of my (.) body' (8). Instead of directly addressing her IBD, as referred to in the question through the indexical use of 'it' (4), Rosie refers to her *body*, which appears to be a quite explicit reference to her 'healthy body' (Balfe, 2009), her inner bodily health. This proposition appears to conflate the body with symptoms/illness, although Rosie is perhaps representing IBD as being *part of* her body. Her reference to forgiveness (8) suggests that she does not hold animosity or resentment towards the effects of IBD *as experienced through* her body, a view differing from that which she reportedly held previously.

In line with this forgiveness of her body, Rosie reports a change in her illness-management whereby presently if she feels ill, or is having a 'bad day' (10), she will 'just take it easy' (10) and 'give myself a break' (26-27), suggesting that she is now willing to adopt the 'sick role' (Parsons, 1951), to some extent, when she is not feeling well, and abstain from certain activities, whereas previously she would 'get out there and...do the same thing as everybody else' (12-13). Rosie does not, however, frame this present

strategy as having negative connotations of restriction or lack of lifestyle control on her part, 'take it easy' instead connoting rest and relaxation.

In discussing this temporal change in her orientation to her 'social' and 'healthy' bodies, Rosie addresses issues of normalcy, by making comparisons between herself and others who do not have IBD. She proposes that previously carrying on with lifestyle activities was not an active attempt to resist IBD, but was due to her being unaware that these were disease symptoms, and instead she thought everyone else was experiencing these same bodily functions, such as the need for frequent toilet access (16-18). The exact timeframe Rosie is referring to here is slightly unclear, but it appears that she is referring to her pre-diagnosis stage, however at a point where she had started experiencing disease-symptoms.<sup>21</sup>

Rosie blames her behaviour at this time for the worsening of her condition (23-25), thus implying that carrying on in spite of symptoms to the point where one pushes oneself 'a bit too much' (23) can be detrimental to the condition. Rosie is here giving salience to her 'healthy body', by implying that pursuing the 'social body' to too great an extent can undermine IBD-related health. Rosie thus implicitly constructs herself as having some agency over her condition control, through suggesting that had she not 'pushed' (23) herself in this way, she may not have experienced these symptoms, or at least not to the same degree. Through this temporal contrast, Rosie demonstrates 'reflexivity' (Linde, 1993), constructing a positive, morally-appropriate identity for her present self, as careful and responsible, in contrast to the negative behaviour of her former self. Her former self is not constructed as wholly negative, however, because at the time she was reportedly unaware that she had IBD. Rosie's agency vis-à-vis her condition control is later minimised, however, through a formulation attributed to her mother (who Rosie explained earlier in the interview has lived with IBD for many years): 'there's nothing you can do about it' (51), suggesting she cannot prevent the onset of symptoms, thus her condition control is very limited.

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<sup>21</sup> It appears common in many cases for individuals to experience symptoms for a significant period of time before being diagnosed as having IBD.

Rosie in fact goes on to frame her condition as a 'liberator' (Herzlich, 1973: 114), discussing how being diagnosed has provided her the legitimacy to, at times, give in to her symptoms, and not feel obliged to try and keep up with everyone else when she is not feeling well (43-46). The use of the second person pronouns 'you' (43) and 'yourself' (44) represents Rosie as part of an 'ingroup' of those with IBD, suggesting that others would also perceive such a diagnosis as somewhat liberating. She again separates herself from the normalcy of her peers, but frames this difference positively, describing it as 'great' (41) that she now understands the *reasons* for this difference (39-41). It is important to note the significance of Rosie's fairly recent diagnosis in her framing the condition in this way, as this representation of liberation relates to the 'relief' (29) of diagnosis, when contrasted with the uncertainty of unexplained symptoms before diagnosis. Rosie therefore frames her condition as allowing 'a lessening of the burdens of which weigh upon her...illness appears as rest, the interruption of everyday rhythm and of social obligations' (Herzlich, 1973: 115). However, for Rosie, these burdens are not only physical, but also relate to the negative reactions of herself and others to her unexplained tiredness prior to diagnosis: 'he [Rosie's boyfriend] got annoyed (.) and I was annoyed' (32). Diagnosis therefore allowed this tiredness to be recontextualised within the domain of illness: 'oh see that's why you know I'm not making it up' (39-40), resulting in a lessening of these burdens, as she no longer faces potential charges of moaning, complaining or fabricating, as her tiredness and other symptoms are now legitimated through being attributed to a medical condition.

Rosie again uses the reported speech of her mother: 'my mum's always said just listen to what your body says if...you're tired (.) sleep' (46-48). Drawing upon her mother's reported views, especially given her mother's long-standing IBD-status, further legitimates her decision to at times give in to her symptoms and abstain from some lifestyle activities. Again it is her 'healthy body', not the illness itself, which is explicitly referred to, with the body represented as knowledgeable, something that should be listened to and obeyed (Frank, 1995), furthering her positive identity-performance of someone who is responsible in relation to her health.

By reportedly adopting her mother's advice that 'if you're having a good day...have a good time' (48-50), Rosie implies a balance where she, at times, pursues her 'social body' project, and at others attends more to her 'healthy body'. However, this is dependent upon the severity of her disease symptoms at the time, suggesting she does not have a great deal of control in terms of which body project she affords salience. This description of *good days* and *bad days* can be seen as a way of coping with her 'intrusive illness' (Charmaz, 1991: 42), through allowing Rosie to make more sense of her experiences in relation to her ongoing condition (Charmaz, 1991). As Charmaz (1991: 49) proposes, dividing one's life in this way 'provides one measure of experiencing illness as a part of the taken-for-granted lexicon through which illness becomes understandable and explainable'.

Rosie further discusses the changes in her perception towards, and management of, IBD symptoms, before continuing (Interview 4: 839-858):

Extract 23 (contd):

54. R: I think it's made me think about (.) the bigger picture a bit more  
55. you know like (.) um (.) I don't worry about try not to worry  
56. about the little things too much and I do think whenever (.) I  
57. wallow sometimes everybody does (laughs) (.) I have days  
58. when I think oh this is just (.) you know it's so unfair  
59. (.) I'm you know everyone's out having fun and (.) I'm  
60. in front of the TV with a hot water bottle on my stomach  
61. (.) I'm gonna have to do a suppository before I go to bed  
62. (.) I'm gonna be tired the next day (.) I'm gonna have cramps  
63. and it's just not fair (.) and you think (.) why did it happen to me?  
64. but then you think god (.) stop it you know (.) so many people  
65. have much worse it's just (.) not just with Colitis I mean  
66. obviously some people can't leave the house because it's (.) you  
67. know so bad and (.) like Crohn's disease which is much  
68. worse (.) and um (.) yeah and all the other (.) array of



69.           (.) chronic illnesses diseases and things people can have  
70.           I mean (.) if this is the worst I get then I'm (.) I'm pretty  
71.           lucky I think

In spite of her earlier positive identity-performance, Rosie talks here of experiencing frustrations regarding the control that disease symptoms can have over her lifestyle, as at times her abstinence from social activities is forced upon her (56-63), causing her to live 'within the confines of illness' (Sargeant, 2006: 82). Here then, social activities are not represented as 'burdens' (Herzlich, 1973: 115), as earlier in the extract (41-46), but as 'fun' (59) that Rosie has to miss out on. Through her proposition that everybody 'wallow[s]' (57) like this at times, Rosie avoids a negative identity-construction as somebody who is self-pitying or complains about her hardships.

Rosie constructs herself as *coping* with such frustrations in several ways. She talks of trying not to think about the smaller frustrations in her life, and instead focus on 'the bigger picture' (54). She also uses 'downward social comparison' (Gibbons, 1999), drawing a distinction not only with others who have more severe forms of UC, but other 'much worse' (65) chronic conditions which restrict the individual's lifestyle to a greater degree than her condition: 'some people can't leave the house because it's...so bad' (66-67). Rosie describes herself as 'pretty lucky' (70-71) when compared with these others, thus constructing herself positively as coping well with these frustrations.

Extracts 21-23 have demonstrated some similarities, but also a degree of variation. Frank (Extract 21) represents himself as adapting, and making some concessions to, his lifestyle, in order to balance his 'healthy' and 'social' bodies. Mary represents herself as pursuing her 'social body' in order to gain better lifestyle control, in spite of the detrimental effect upon her 'healthy body'. However, she suggests having to make subsequent concessions to her lifestyle as a result. Rosie constructs herself as attending to her 'healthy body' through abstaining from some social pursuits; however, she frames this as not always demonstrating a lack of lifestyle control. All the three respondents frame their respective management-strategies in different ways, constructing positive identities which align with differing models of moral-appropriacy.

#### 8.4 *Cross-condition comparisons*

Analysis has revealed a complex picture vis-à-vis the constructed relationship between condition control and lifestyle control, and the management-strategies and coping mechanisms respondents reportedly adopt in negotiating this control. Whilst some similar trends are apparent, there is a degree of variation both in the accounts of respondents with the same condition, and to a greater extent, across the two conditions.

In terms of *condition* control, in relation to T1DM, Robert (Extract 18) and Melanie (Extract 20) both implicitly construct themselves as having a degree of *agency*, in terms of being able to adhere to their treatment-regimen in order to minimise the risks to their present and future health. The notion of agency must be problematized, however, as having the ability to take measures to control the condition is represented as not necessarily always equating with having condition control. For instance, Robert implicitly represents experiences of hypoglycaemia as inevitable, and thus unpreventable: ‘that’s all part and parcel of having the condition’ (Extract 18: 7-8), suggesting that despite his agency, his condition control is not absolute. However, through representing such ill-health as exceptional, he is able to represent himself as having *generally* good condition control. It could be argued, then, that Robert implicitly frames ill-health, at least in terms of short-term hypoglycaemia, as attributable both to *endogenous* causes (resultant of actions of the individual), and also to some degree *exogenous* causes (attributed to outside causes) (Gwyn, 1996; Herzlich, 1973: see 3.4). This enables him to simultaneously claim a degree of agency, yet also mitigate responsibility for exceptional ‘blips’ (6) in health. Melanie represents herself as using her agency in a different way, opting *not* to adhere to her treatment-regimen *in one particular context* in order to give salience to her ‘social body’. Agency should therefore not be viewed only in positive terms, but can be used to undermine the ‘healthy body’.

It is too simplistic, however, to talk simply of Melanie undermining her ‘healthy body’ through her behaviours. The complexities in her extract extend beyond Balfe’s (2009) conception of the ‘healthy body’, as Melanie’s account suggests that the ‘healthy body’

can be divided into different facets: the opposing shorter-term health concerns of hypoglycaemia and hyperglycaemia, as well as longer-term health complications which can arise as a result of having high blood-sugar. In the holiday context reported, Melanie is ignoring, and thus undermining, her '*longer-term* healthy body' (letting her blood-sugars run high), so that she can mitigate the risks to her '*short-term* healthy body' in relation to experiencing hypoglycaemia, in order to ultimately allow her to pursue her 'social body' (enjoy her skiing holiday). Melanie's frustration appears to arise from the fact that undermining her 'longer-term healthy body project' in this way, whilst allowing her to guard against the serious short-term health consequences of hypoglycaemia, also undermined her 'short-term healthy body' in other ways, as the consequences of hyperglycaemia, whilst perhaps not being as serious in Melanie's view, resulted in her not fully enjoying the pursuit of her 'social body'.

A complex picture therefore emerges regarding the relationship between condition control and lifestyle control in relation to T1DM, and how one can be given salience over the other through the pursuit of different body projects. In this case, Melanie's attempts to give salience to certain projects in order to gain greater lifestyle control appear not to have been entirely successful, leading her to feel as if her condition has controlled her.

In contrast to Robert and Melanie, Helena (Extract 19) constructs herself as *not* having a great deal of agency over her condition control, as she reports struggling to maintain good glycemic control despite her best efforts to adhere to her treatment-regimen. Although in this extract Helena does not represent her lack of condition control as causing her ill-health, in another part of her interview she talks of having experienced 'kidney problems' (Appendix K; Interview 6: 212-229), suggesting this lack of agency negatively affected her '*short-term* healthy body'. However, Helena appears to be an exception within the data-corpus as a whole, as in general those with T1DM represent themselves as having agency to maintain good condition control through adhering to their treatment-regimen. Reported cases of ill-health are commonly attributed to respondents pursuing their 'social body' in a particular context and temporarily neglecting their self-care, as Melanie reports doing.

Cross-condition differences are apparent regarding respondents' degree of agency over their condition control. Generally in the data-corpus, those with IBD represent themselves as having *less* agency vis-à-vis condition control than is constructed by T1DM-respondents, as reflected in the extracts examined. This is most probably due to the nature of the two conditions, with these findings reflecting current biomedical evidence. Whilst it is known that closely adhering to one's treatment-regimen can significantly decrease the chances of experiencing T1DM-related complications (both in the short- and longer-term), less is medically proven about how individuals can reduce the risks of experiencing IBD-related ill-health, aside from taking medication, which is not effective in all cases (Andrews and Holtmann, 2011; Papadakis and Targan, 1999).

In the extracts analysed, all the three IBD-respondents make no suggestion that they can in any way *prevent* ill-health, or stop themselves experiencing disease flare-ups. Frank (Extract 21) and Mary (Extract 22) both imply a continuous presence of the condition: 'it still has an influence on my life' (Mary: 1-2), and Rosie (Extract 23) explicitly proposes her lack of agency over having a 'bad day' (10) regarding symptoms: 'there's nothing you can do about it' (51).

Whereas I proposed above that a distinction can be made in relation to T1DM, between the 'short-term healthy body' and 'longer-term healthy body', with T1DM-respondents found to attend to both in their accounts, it seems to be the '*short-term* healthy body' which is primarily attended to by IBD-respondents. Though in the data-corpus as a whole there are examples of IBD-respondents expressing concerns about longer-term health issues, such as increased cancer risks linked to IBD (see for example, Appendix K; Murray: Interview 19: 507-510), it appears to be a general trend that those with IBD focus on the effect of the condition on their immediate present, or short-term future health.

Again, however, agency over condition control is not entirely straightforward. Both Rosie and Mary do imply a degree of agency, as Rosie suggests that because she 'pushed [herself]' (23) too far, she increased the severity of symptoms, and Mary talks of it taking weeks for her to recover physically from pursuing her 'social body', suggesting a

worsening of symptoms as a result of this. This implies that, whilst perhaps not being able to prevent the onset of symptoms, both respondents feel that they can avoid behaviours which may *worsen* these symptoms. Again here, then, the concepts of illness as endogenous or exogenous (Gwyn, 1996; Herzlich, 1973) are not entirely clear-cut, as these representations suggest that whilst illness is generally 'exogenous', the individual's actions can, to some degree, facilitate its appearance; thus IBD is also in some ways 'endogenous'. In Mary's case, similar to Melanie vis-à-vis T1DM, this agency in fact allows her to undermine her 'healthy body' to some extent, by participating in lifestyle activities in spite of the consequences to her health: 'I know I'm gonna pay' (Extract 22: 57). This exemplifies the metaphor Gwyn (1996) identifies of 'the candle being burned at both ends', whereby the individual's actions result in 'lessening...resistance to disease' (1996: 177, see 3.4).

It seems, then, that comparison of condition control across the two conditions reveals *different kinds* of agency: with T1DM-respondents actively engaging in behaviours in order to gain condition control, i.e., injecting insulin, monitoring blood-sugar, eating regularly and so on; and those with IBD *avoiding* certain behaviours, i.e., strenuous physical activities. This distinction is not entirely clear-cut, however, as although not given salience in the extracts analysed here, T1DM treatment-regimens also include avoidance of certain behaviours, such as eating too many sugary foods, or excessive alcohol intake; and those with IBD do also engage in proactive behaviours to control their condition, the main one being taking medication.

Because those with T1DM generally represent greater levels of agency over condition control, I would argue that attending to the 'healthy body' is seen as a *moral practice*, which is less so the case in relation to IBD. This finding vis-à-vis T1DM reflects those of previous research literature (Balfe 2007; 2009; Dovey-Pearce, Doherty and May, 2007; Hillege, 2005); however, these studies have not explored how this morality is discursively constructed, as is exemplified especially well here through Melanie accounting for 'ignoring' her treatment-regimen by stressing that this was a temporary strategy employed only in a particular context.

Variation is also present regarding respondents' constructed *lifestyle* control. All the three T1DM-respondents construct themselves as having a fairly high degree of lifestyle control in relation to their condition. Their discussion centres more around practical issues involved in the adherence to their treatment-regimen, as opposed to the effect of present health issues on their lifestyle. Those with IBD, however, because condition control relates primarily to the severity of disease symptoms, orient principally to the effect that *bodily limitations* resulting from these symptoms can have upon their lifestyle (in the case of Mary and Frank, however, details of these symptoms are left implicit as they are outlined during other parts of their interviews). Whilst none of the three IBD-respondents represent themselves as considerably lacking in control over their respective lifestyles in the present, these bodily limitations appear to have the potential to be more intrusive to those with IBD than is the case with T1DM-respondents. This shows consistency with the accounts analysed in Chapters 6 and 7, vis-à-vis *self* and *other-orientation*; the impact of symptoms upon respondents' bodies and subsequently their desired lifestyle activities and self-presentation was found to be a more salient issue for those with IBD than for T1DM-respondents.

There are, however, a few examples in the extracts analysed of T1DM at times controlling respondents' lifestyles. Robert talks of being disallowed from driving for a year as a result of hypoglycaemia; however, this example is used to demonstrate an exception in terms of his lifestyle control in general. Melanie similarly presents an example which she proposes is atypical in relation to her ordinarily good lifestyle control. Additionally, this lack of lifestyle control was because Melanie felt tired and therefore did not fully enjoy her skiing holiday; however, she was *not prevented* from skiing, thus still maintaining some lifestyle control in this context. Although orienting primarily to her condition control, Helena also constructs her T1DM as not significantly controlling her lifestyle, and she frames the two types of control as being somewhat separate.

On this evidence, then, it appears that in relation to T1DM, lack of condition control does *not necessarily* result in poor lifestyle control for people of this age-cohort. This is because, as also proposed in 6.3, whilst young adults with the condition can experience present ill-health related to T1DM, it is often the case that serious health consequences do

not occur until middle-older age. This differs quite markedly from those with IBD, for whom the impact of symptoms on their lifestyle in the *present* is the major issue with which many have to contend, as reflected in the above findings that IBD-respondents' commonly orient to their 'short-term healthy body'. This is demonstrated in the accounts of both Rosie and Mary, who talk of at times being prevented from engaging in desired lifestyle activities as a result of symptoms, though only Rosie explicitly outlines these symptoms here: 'I'm gonna be tired the next day (.) I'm gonna have cramps' (62).

Some similar trends, as well as some variation, can be observed in the strategies reportedly adopted by respondents in managing these lifestyle issues, as well as in the discursive strategies drawn upon in their construction. Frank frames his IBD as not having a significantly detrimental effect upon his lifestyle, and he reportedly adopts the management-strategy of balancing his 'social body' and 'healthy body' projects, by continuing to engage in desired lifestyle activities, but to a lesser extent or frequency than previously, thus still allowing him a degree of lifestyle control: 'I can go to gym but I can't go everyday' (Extract 21: 22). This balance is similar to that constructed by Robert; however, this appears to be differently manifested in relation to T1DM. Whereas Frank implies making *concessions* to his lifestyle, Robert makes no suggestion of having reduced his activities in any way, proposing that he plans his T1DM-regimen to fit around his lifestyle activities: 'having to think ahead...and planning...what could happen' (Extract 18: 61-64).

This 'balancing' of 'healthy bodies' and 'social bodies' has similarities with the findings of Kelleher (1988, see 4.3.1) in relation to respondents with T1DM 'normalising' their condition through 'adapting' their lifestyle to it. However, a key difference between Kelleher's findings and those in relation to Robert and Frank here, is that Kelleher proposes that adapting entails 'giving up some social activities such as eating out or going to places' but that respondents 'accepted them as part of their 'normal' lifestyle' (1988: 147). For Frank and Robert, however, adapting their lifestyle does not entail 'giving up' activities, but fitting such activities around the concerns of their conditions, although in Frank's case certain activities are *reduced*. It must be noted, however, that previously in his interview, Frank talked of how his condition had recently been in

remission, thus his symptoms at this time were not as severe as they had been previously. Frank reports that when experiencing a flare-up of disease symptoms, his lifestyle activities *were* restricted to a much greater extent.

Melanie also represents her illness-management strategy in terms of her constructing a balance, using a linguistic metaphor: 'it is a balance (.) like I did that so I could have a good time while I was on holiday' (Extract 20: 44-45); however, this metaphor was in fact introduced by me earlier in the interview. The balance Melanie constructs is slightly different from that suggested by Frank and Robert, however, as rather than adapting her lifestyle, Melanie suggests a contextual balance, whereby she balances her *overall* lifestyle control and condition control by giving salience to either her 'social body' or her 'healthy body' in different contexts. This kind of contextual balance is also observed by Dovey-Pearce et al. (2007) in looking at the experiences of young adults with T1DM, aged 16-25: 'a balance between engagement in and avoidance of self-care may be required in order to manage the practical but also emotional demands of diabetes' (2007: 85). Dovey-Pearce et al. appear to suggest, then, that avoidance of self-care at certain times can actually be beneficial to individuals within their overall illness experience. However, Melanie emphasises that the majority of the time she *does* attend to her 'healthy body'. Additionally, constructing this kind of balance does not mean that Melanie cannot at other times adapt her behaviours to attend to both her 'healthy' and 'social' bodies simultaneously, as do Robert and Frank.

Mary and Rosie construct IBD as having a greater impact upon their respective lifestyles than does Frank. Mary was shown, however, to construct her illness-management in terms of her now choosing to resist the influence of her IBD, participating in desired lifestyle activities in spite of her condition, and thus 'living beyond' its confines (Sargeant, 2006: 82). This strategy demonstrates similarities with that identified by Hall, Rubin, Dougall, Hungin and Neely (2005) who talk of respondents' 'battle for control' (2005: 448), as well as Kelly (1992), who conceptualised respondents as 'resisting' and 'fighting back' (1992: 43) against their IBD. However, there is some disparity between their respective findings and Mary's account, as both the previous studies suggest that respondents resist their condition only within the limitations their IBD imposes upon



them. Mary, in contrast, constructs herself as defying the limitations of her condition. Defying one's condition in this way is a more common construction amongst those with IBD in the data-corpus than in relation to T1DM, again perhaps because T1DM generally does not exert as great an influence on respondents' lifestyles in the present as is the case vis-à-vis IBD (see for example, Nigel: Interview 10: 141-152; Eve: Interview 23: 574-597; Sally: Interview 28: 785-842).

This is not to say that there is no evidence of respondents with T1DM defying the limitations of their condition, as similarly to Mary, Melanie was shown to represent herself as 'living *beyond* the confines of illness' (Sargeant, 2006: 82). Their respective framing of this illness-management is very different, however. As mentioned above, Melanie describes her behaviour as her 'ignoring' (Extract 20: 33) T1DM. It could be argued that in Mary's case, however, it would not be possible for her to entirely ignore her IBD-symptoms. Additionally, because Mary constructs her IBD metaphorically, as an oppressive enemy with whom she is engaged in a battle, she is able to frame this resistance quite positively, constructing her identity as heroic and determined. Melanie, however, does not represent herself as resisting her condition symptoms, but her treatment-regimen; therefore the 'confines' (Sargeant, 2006: 82) presented by their respective illnesses can be seen to differ. Because Melanie's treatment-regimen is not an enemy, but is in fact adhered to in order to prevent ill-health in both the present and future, this strategy is framed as being morally *inappropriate*, resulting in her excusing and justifying this behaviour. This disparity between Mary's and Melanie's accounts therefore exemplifies the argument made above that there is greater moral obligation on the shoulders of T1DM-respondents due to the greater agency they have over their 'healthy body'.

Battle/war metaphors are employed by a few IBD-respondents in the data-corpus other than Mary (see for instance Murray: Interview 19: 232-233 and 656-660), but by none with T1DM. Even Helena (Extract 19), who displays considerable frustration regarding her T1DM, does not position herself as trying to 'win a battle' against her condition. Again, this could be because her condition is not significantly impeding upon her lifestyle in the present, whereas Mary represents her IBD as having considerably affected her life.

As briefly mentioned in 3.4 in relation to Gwyn's (1996) work, several researchers have discussed the use of war metaphors in quite negative terms, as contributing to the individual's suffering (see, most notably, Sontag, 1979; 1991). In summarizing this view, though not necessarily presenting it as his own, Radley (1993) proposes that 'negative ideas drawn from other areas of life imported into illness experience...create an unnecessary burden for the sick' (1993: 113). Mary's use of metaphor does not connote negativity, however, and in fact can be seen to be very positive, forming a central part of her heroic, morally-appropriate identity-performance. I would therefore argue that war/military metaphors can in fact be used by individuals as a way of *coping* with their condition, allaying some of the negative psychological effects of the condition by allowing individuals to feel that they can positively take control of their lifestyles, even if in reality this agency over lifestyle control may be quite limited. From a performative perspective, then, it could be argued that battle/war metaphors, such as those used by Mary, can function in the way Riessman (1990: 1199) proposes, in 'healing some of the discontinuities and contradictions' between the 'reality' of the restrictions imposed by illness and the self that Mary wishes to project to others. However, it should be noted that here Mary is representing herself as presently 'winning' this battle: 'now I feel I've got a handle on it rather than it having a handle on me' (2-3). For those are not able to overcome the restrictions imposed upon them by illness, war/military metaphors could have a very negative, undermining effect, as Sontag (1979; 1991) suggests.

Whilst Rosie (Extract 23) also represents her IBD as having a significant influence upon her lifestyle, she frames this influence very differently to Mary. As opposed to Mary's construction of IBD as 'an occupation' (Herzlich, 1973) something to be struggled against, Rosie constructs her condition as a 'liberator' (Herzlich, 1973), thus not framing the concessions she makes as repressive, or as demonstrating a lack of control. This is not entirely the case, however, as in the second part of Rosie's extract she represents her condition as somewhat 'destructive' (Herzlich, 1973), forcing her to abstain from desired lifestyle activities. However, when framing her condition in this way, she still does not propose actively resisting her symptoms, as Mary does.

Whereas Mary constructs 'living beyond illness' (Sargeant, 2006: 82) as being positive and heroic, Rosie represents this as quite negative. This is because Rosie focuses on her perception of the negative effects of resistance on the 'healthy body': 'you'll just make yourself worse if you do try and push yourself' (Extract 23: 51-52), whereas Mary foregrounds the desire to pursue her 'social body': 'determination to not let it stop me doing what I want to' (Extract 22: 56). Rosie explicitly reifies her *body* rather than her IBD, implicitly representing her IBD as being *part of* her body. She constructs her body as knowledgeable and to be listened to, as a friend rather than foe. Melanie, however, represents her IBD not as part of her body, but as a separate entity acting upon her from outside, and thus she demonises her condition. Therefore, whilst Mary constructs herself as heroic, Rosie represents herself as careful and responsible. In spite of adopting very different management-strategies, then, both individuals are able to construct positive identities, through aligning with different models of moral-appropriacy. When comparing the two, however, it is important to consider their respective illness experiences as a whole. Rosie's short illness trajectory of six months means she is still experiencing relief at being diagnosed and having legitimacy for her symptoms. Mary, on the other hand, has lived with IBD for over a decade, and her experiences therefore differ vastly from Rosie's. Having experienced considerable ill-health during this period, it is hardly surprising that Mary would demonise her condition in this way, and feel the desire to resist its influence.

I have talked so far about the similarities and differences in respondents' *management-strategies*; however, respondents were shown to draw upon a range of *discursive strategies* in their accounts. I have already discussed the use of metaphor, but also notable is the use of 'contrasts'. These are used in differing ways, serving different rhetorical functions. Rosie (Extract 23) and Mary (Extract 22) both construct contrasts that are temporal in nature, drawing distinction between the perceptions and behaviours of their former and present selves, in order to construct their present selves as moral (Linde, 1993). These contrasts also indicate that control can be *incremental*, suggesting that as those with illness become more experienced in managing their condition, they are able to gain greater control.

Respondents were also shown to construct contrasts between themselves and others. Frank's (Extract 21) use of contrasts demonstrates 'self-vs.-other' (Sarangi, 2007) orientation, enabling him to portray himself as coping better, and adopting a more morally-appropriate management-strategy, than others with illness. This use of 'othering' as a way of performing morality demonstrates similarity with findings in Chapters 6 and 7 in relation to those with both conditions, showing coherence across themes with regard to this strategy.

In the case of Helena (Extract 19) and Rosie (Extract 23), contrasts function as 'downward social comparison' (Gibbons, 1999), drawing on both real and imagined examples, which I proposed is a way of *coping* with the psychological effects of their conditions. 'Downward social comparison' has been similarly observed in several studies into chronic illness experience, including those specifically looking at T1DM and IBD (Hall et al., 2005; Schur, Gamsu and Barley, 1999), and thus appears to be a common method of coping with chronic illness. However, whilst being used in a similar way by the two respondents, a cross-condition disparity here is that Rosie and Helena are drawing upon this strategy in order to cope with different things. Helena's frustrations are in relation to her not being able to maintain condition control; however, this is not adversely affecting her lifestyle in the present. Whilst Rosie is also coping with her lack of condition control, in her case this relates to symptoms preventing her from engaging in desired lifestyle activities.

This chapter has explored how young adults with T1DM and IBD represent their control over both condition and lifestyle. The next chapter will continue to explore this theme, but will focus on one area found to be especially salient in the data-corpus, and in relevant research literature – respondents' discussion of their participation in social drinking practices.

## 9. Social Drinking Practices: Young Adults' Accounts of Alcohol-Consumption and Related Social Activities

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This final analytic chapter also addresses issues related to *Control*; however, here I will explore this theme specifically with regard to respondents' discussion of the effect of illness on their participation in alcohol-consumption practices and related social activities, such as going to nightclubs and bars, to be referred to as *social drinking practices*. The reason for selecting this theme for special focus is that, within the broader macro-theme of *Control*, social drinking practices were found to be an especially salient concern of respondents across the data-corpus, reflecting the cultural association such practices have with young adulthood (Brain, Parker and Carnwath, 2000; Chatterton, 1999; Griffin, Bengy-Howell, Hackley, Mistral and Szmigin, 2009). An adapted version of this chapter has recently been published (Saunders, 2011).

As in the previous chapter, the distinction between respondents' *condition* control and *lifestyle* control will be shown to be present, with a tension often displayed in the desire to simultaneously manage both types of control vis-à-vis social drinking. The extracts in this chapter will principally demonstrate respondents attempting to maintain lifestyle control by reportedly participating in social drinking practices in spite of the additional health risks these behaviours pose to their chronic condition, reflecting the findings of previous research in this area (Balfe, 2007; 2009; Eaton, Williams and Bodansky, 2001; Ravert, 2009).

In the case of T1DM, excessive alcohol-consumption lowers blood-sugar levels, leading to the short-term risk of those with the condition experiencing hypoglycaemia. However, in the longer-term, alcohol-consumption can conversely lead to an *increase* in blood-sugar

levels, possibly as a result of insulin resistance (Ravert, 2009), increasing the risk of longer-term T1DM-related complications (see 1.3). With regard to IBD, individuals can experience an exacerbation of symptoms following excessive alcohol-intake. The association between alcohol and IBD is less clear-cut, however, as highlighted by Hey, Schmedes, Nielsen, Winding, and Grønbæk (2007), who in testing the effect of five different alcoholic drinks on people with Crohn's disease, observed that, although participants reported an increase in abdominal pain, there was no increase in disease activity in terms of inflammation of the gastrointestinal tract.

It will be shown that the respondents commonly provide accounts in the form of 'excuses' and 'justifications' (Scott and Lyman, 1968) for engaging in this potentially 'risky' behaviour, with Scott and Lyman's (1968) framework being especially relevant to this theme, given that the morally-*inappropriate* behaviour at issue here is based not only on 'general beliefs and shared theories about the nature of the world' (Radley and Billig, 1996: 223), but on medical evidence. The cross-condition differences regarding the robustness of this medical evidence will be shown to influence the framing of the respondents' accounts.

Analysis will again draw upon Balfe's (2009) 'body projects' framework, which is particularly pertinent in exploring this theme, as social drinking is also Balfe's primary focus in looking at the experiences of those with T1DM (see 4.4.1). As similarly observed in Chapter 8, it will again be shown that respondents can give salience to either their 'social body' or 'healthy body' projects at different junctures in their accounts, and at different points within reported-time, as a way of attempting to negotiate their condition control and lifestyle control.

Sargeant's (2006: 82) dual concepts of 'living *within* and *beyond* the confines of illness' will also again be drawn upon, and analysis will explore how both respondents with IBD and T1DM discursively negotiate the boundaries between *within* and *beyond* in relation to their reported social drinking behaviour.

### 9.1 Representations of T1DM

The first account to be analysed is taken from an interview with Gail (G), a 20-year old university student, who had been diagnosed with T1DM for fifteen years. Gail's discussion of social drinking practices was not directly prompted by a specific question I had asked, and was instead introduced by her following discussion of her general glycaemic control (see Appendix K; Interview 22: 204-281):

Extract 24:

1. G: with the alcohol thing (.) that's (.) it was (.) a massive
2. issue because (.) obviously like I (.) you don't (.) it is part
3. well (.) part of (.) British life [BS: mm mm] and it's daft (.)
4. but everyone does it (.) and (.)
5. BS: and also that's student life=
6. G: =yeah (chuckling) it's student
7. life (.) but luckily like when I was at the children's
8. hospital (.) they explained like drugs sex and alcohol (.)
9. and um (.) alcohol...and (.) they (.) like my mum's like a big
10. Scottish woman and they (.) they knew us (.) as a family and
11. they know that she's quite a big drinker and so is my dad [BS:
12. (slight chuckle)] (.) so they kind of know that (.) it was gonna
13. be part of my life...so (.) I I do drink

. for the next 54 lines, Gail initially continues talking about the  
. drinking culture in her family, as well as amongst her current  
. friends. She then moves onto discussing her disclosure of  
illness-information, before the talk returns to the theme of  
social drinking.

14. BS: do you think oh I shouldn't drink as much [G: um] as everybody
15. else because of my diabetes or?

- 
16. G: [oh (.) I don't know 'cause  
 17. (.) I'm in two minds like I probably shouldn't drink as  
 18. much as I drink (.) but (.) I think (.) I'm only young once  
 19. and (.) I know I know health implications are massive (.)  
 20. but I don't really think about it enough I (.) personally I  
 21. don't think but (.) you're only young once so you can't  
 22. (.) you've got to live [BS: mm] (.) so (.)

Gail opens her account by describing alcohol as being a 'massive issue' (1-2). In the first half of this extract (1-13), Gail accounts for her behaviour *prior* to revealing her own social drinking practices. Her discussion of 'the alcohol thing' (1) is therefore initially decontextualised, and not until subsequently (13ff) is it made explicit that it is *her* behaviour she is discussing.

Her account initially draws upon cultural presuppositions associating alcohol with 'British life' (3), thus situating social drinking practices as being *normal* behaviour. In doing so, she is making social comparisons with the behaviour of others whom she sees as part of her 'in-group'. She therefore displays 'self-and-other' (Sarangi, 2007) orientation, implying that because everyone else participates in these practices she should do too. She thus places her illness-identity in the background, foregrounding the 'preferred identity' (Riessman, 2002: 13) as a member of British youth culture.

This initial part of Gail's account thus functions as an 'excuse' (Scott and Lyman, 1968), as through citing these cultural influences she removes a degree responsibility from herself for engaging in these practices. This 'excuse' is supported, and legitimated by my contribution, in line 5, in offering a further excuse for Gail's participation in such practices, asserting that social drinking is not only part of British culture, but the sub-culture of university students, of which Gail and I are both members.

Another strategy Gail draws upon in excusing her social drinking behaviour is the inclusion of medical voices. Having discussed, in lines 7-8, the medical care she received at the children's hospital, Gail proposes that the healthcare professionals who treated her



were aware of the drinking habits of her parents: 'they know that she's quite a big drinker and so is my dad...so they kind of know that (.) it was gonna be part of my life' (11-13). Gail suggests here, then, that the relevant healthcare professionals accept that, as a result of her acculturation in these practices, alcohol-consumption will have a role in her future adult life. This may explain how Gail is able to frame this behaviour as being acceptable.

In using such strategies to construct her 'excuse', it is not until line 13 that Gail explicitly states 'so...I do drink'. With this disclosure there are still no details provided as to the frequency or degree of alcohol-consumption; however, the framing of this statement implies that she drinks a significant amount. Whereas up until this point Gail's account is quite implicit in excusing her behaviour, in response to my prompting (14-15), Gail provides an explicit, though still slightly mitigated, acknowledgment that she recognises that this behaviour *is* potentially 'risky' to her T1DM-related health (16-18). This admission has the potential to threaten Gail's intended positive identity-construction. It must be noted, however, that her acknowledgement may be influenced by my question (14-15), which implicitly orients to the potential negative effects of this behaviour in relation to T1DM.

Gail accounts for this admission of potential riskiness, however, through drawing on cultural stereotypes that drinking alcohol is a practice culturally-expected of young people (21-22), thus foregrounding her *age*-identity beyond her illness-identity. Through the statement 'you've got to live' (22), she implies that not drinking would amount to 'not living', by which she appears to mean that she could not enjoy herself and have fun through the pursuit of her 'social body'.

Again, Gail is constructing an 'in-group' alliance, based on presuppositions about normalcy, and what people *like her* normally do. Whilst acknowledging social drinking to be potentially 'wrong, or inappropriate' (Scott and Lyman, 1968: 47), she mitigates her self-responsibility for such actions. Gail is therefore attempting to gain greater *lifestyle* control through her behaviours, and is using her account to discursively negotiate the tension that this creates with regard to the effect this may have on her *condition* control. To describe this through the lens of the 'body projects' (Balfe, 2009) framework, in this

foregrounding of certain ‘preferred identities’ (Riessman, 2002: 13), Gail attempts to ‘excuse’ the detrimental effect that pursuing her ‘social body’ could have in relation to her ‘healthy body’.

Another account which functions predominantly as an ‘excuse’ is from an interview with Polly, aged 19, also a university student (who we encountered in Chapter 6; Extract 3). Polly had been diagnosed with T1DM for eight years. This extract follows a longer discussion about Polly’s social drinking, which I initially prompted. Polly (P) is more explicit from the beginning of her account than Gail regarding her social drinking practices (see Appendix K; Interview 17: 425-454):

Extract 25:

1. P: I don’t (.) not go out and not get pissed (chuckles) (.) I probably
2. shouldn’t but I’m aware that the consequences for me will be
3. more than the consequence for (.) a normal person but I don’t
4. go out (.) loads (.) I only (.) I don’t go out more than (.) well I
5. wouldn’t say never but I rarely go out more than once a week (.)
6. and (.) yeah I do just (.) but sometimes you’ve just got to have fun
7. haven’t you (chuckles)...because (.) I don’t do anything different (.)
8. but it will (.) I’m sure it’ll have a worse effect on me than it’ll have for
9. other (.) young binge drinkers (chuckles) (.) but yeah if I was one of
10. these people that could just go out and not drink then that’s what I would
11. do I mean it would save me a lot of money as well (chuckles) but I do
12. like it so (.) (chuckling) I just go for it (.)

.  
. For the next 5 lines, Polly continues to discuss her desire to partake in  
. social drinking.

13. I’m quite lucky that when I’m wrecked I can still function (laughs)

14. BS: [(laughs) (.)

15. P: like my friends one of my other flatmates (.) like she knows I can look

16. after myself like if they go home late and leave me on my own I'll be  
17. fine you know (.) whereas the girl in the other room is an absolute state  
18. (laughs) and we have to look after her so I'm quite lucky like that no  
19. matter how wrecked I am I won't forget to do my insulin (.) or I might  
20. forget (.) but I'll just do it a bit later

Though Polly's opening statement is perhaps slightly mitigated through double negation (1), the colloquial term 'pissed' connotes heavy alcohol-consumption on her part. Similarly to Gail, she demonstrates explicit recognition of the potential 'riskiness' of this behaviour (2-3 and 8-9). This admission displays a complex identity-construction, as Polly can be seen to *simultaneously* separate herself from, and align with, non-diabetic peers. She uses a 'contrast' structure to draw attention to the more serious effects of alcohol on her vis-à-vis a 'normal person' (3), possibly alluding to those without T1DM, thus foregrounding her illness-identity. She also aligns herself with non-diabetic peers through the inclusive statement 'other (.) young binge drinkers' (9), indicating others similar to her in their social practices. This categorization carries highly negative connotations of drinking to excess, as by highlighting that the negative health consequences of her 'binge drinking' may be even more pronounced than those for her peers, Polly potentially constructs herself as *doubly* irresponsible. Her own recognition of this negative identity-performance is perhaps signalled by her chuckling, in line 9, framing this construction as counter-normative (Coupland, Holmes and Coupland, 1998).

Polly proceeds to account for this admission of potentially *morally-inappropriate* behaviour in several ways. Firstly, in lines 3-5, Polly proposes that she mitigates the potential risks of her social drinking behaviour to her T1DM-related health, through 'bracketing' these risks (Balfe, 2009: 136) by going out and drinking alcohol relatively infrequently. Polly thus demonstrates here that, whilst she actively pursues her 'social body', she is also aware of paying attention to her 'healthy body', through her attempt to minimise the undermining effect of her social drinking behaviour on this body project. It is, however, only implicit that this self-regulation is a conscious decision concerning her T1DM.

Polly continues her account through the use of ‘excuses’, in lines 9-12, suggesting that there is an expectation that she engages in practices that she finds enjoyable, and also that she is not able to socialise without drinking. Although she has quite explicitly acknowledged social drinking to be negative (2-3 and 8-9), she now removes a degree of agency from herself for partaking in these practices, thus attempting to excuse the potential riskiness of her behaviour in relation to her ‘healthy body’, by giving salience to her desire to enjoy herself through the pursuit of her ‘social body’.

Polly’s stance again shifts, however, as she further mitigates the potential undermining effect of her ‘social body’ pursuit on her ‘healthy body’ by stating, in lines 18-20: ‘no matter how wrecked I am I won’t forget to do my insulin (.) or I might forget (.) but I’ll just do it a bit later’. There is the suggestion that not only does Polly ‘bracket’ her participation in these potentially ‘risky’ social drinking practices, but that when she does partake in them, her behaviour does not significantly impair her T1DM self-care practices, as she still remembers, and is physically able to administer her insulin, which is an essential component of her ‘healthy body’ project.

Polly’s ability to ‘still function’ (13) when drunk is emphasised through another ‘contrast’, this time with a ‘specific other’ (Sarangi, forthcoming: 3), a girl in her halls of residence, who is *not* able to function, as she is ‘an absolute state’ (17), and therefore needs to be looked after. Polly, however, is represented very differently: ‘I can look after myself’ (15-16), a view attributed to another flatmate, adding weight to this representation. This demonstrates ‘self-vs.-other’ (Sarangi, 2007) orientation, through which Polly ‘others’ the behaviour of the girl in question, distancing herself from undesirable behaviours. Therefore, in spite of the additional health risks of her drinking, Polly is able to represent herself as in some ways behaving *more responsibly* with regard to drinking than this other girl, who we infer does not have T1DM.

At this juncture, Polly’s account can be seen to combine elements of both ‘excuse’ and ‘justification’, as whilst still not denying the potential riskiness of these social drinking practices, she is playing down this negativity by drawing upon evidence of her own past experiences. It can therefore be seen that, whilst attempting to gain greater *lifestyle*

control, Polly is proposing that this does not prevent her from concurrently maintaining adequate *condition* control. Whilst this appears to be a positive statement of moral responsibility on her part, the use of the term 'wrecked' arguably introduces a conflict, due to its negative connotations of extreme drunkenness. This lexical choice, in addition to the use of the term 'pissed' (1), may reflect Polly's recognition that I am also a young adult, and thus she may feel comfortable using descriptive terms similar to those she would use when talking to friends and peers, as well as aligning with excessive drinking behaviours.

Gail's and Polly's accounts have both been shown to predominantly take the form of 'excuses' for what they represent, with varying degrees of explicitness, as potentially 'risky' social drinking behaviour in relation to their T1DM. Their representations will be shown to demonstrate similarities, but also a degree of variation, with those of IBD-respondents.

## 9.2 Representations of IBD

In looking at extracts from interviews with two IBD-respondents, it can be seen that they too provide accounts for their social drinking behaviour. Extract 26 is taken from an interview with Murray (M), a university student, aged 23, who had been diagnosed with Ulcerative Colitis (UC) for nine years (see Appendix K; Interview 19: 241-267):

Extract 26:

1. BS: I was gonna ask you (.) whether it [IBD] has much impact on
2. leisure activities and going out (.) the sort of social side [M: yeah]
3. (.) you mentioned sport [M: yeah] (.) so do you find it doesn't really
4. have any impact on (.) on that kind of thing? (1.0)
5. M: uh (.) no it's (.) not particularly no sometimes I feel a little (.) twinges and
6. stuff but (.) I just try and blank it out and get on with things (.) sometimes
7. when I'm out (.) maybe the alcohol can affect it quite a (.) quite a bit [BS:
8. mm] (.) and I have to (.) you know (chuckling) nip into the toilet for ten

9. minutes [BS: mm mm] (.) um (.) but that's about the only situation (.) maybe I  
 10. think the the drink may affect it I've asked them at the hospital if it does [BS:  
 11. mm] (.) and they say they just can't put (.) they can't put their finger on it (.)  
 12. the doctor says there's nothing to say that it does necessarily (.)  
 13. BS: mm (.) okay (.) I mean when you said about drinking does it affect the  
 14. amount you drink do you do you drink (.) not as much 'cause you  
 15. think it might affect it? (.) or do you  
 16. M: [no (laughs)  
 17. BS: [(laughs)  
 18. M: (laughing) no (.) but I uh (.)  
 19. no I don't at all it's just (1.0) it's it's usually (1.0) after after a night out (1.0)  
 20. 'cause it's usually (.) quite bad in the mornings [BS: mhm] (1.0) and after (.)  
 21. after a night out obviously (.) you've got a lot of (.) just crap in you haven't  
 22. you (.)  
 23. BS: mm mm (.)  
 24. M: and then it's (.) then it's quite bad you know you're up and down quite a lot to  
 25. be fair (1.0) but no that's (.) that's (.) that's about the only time it does affect  
 26. [BS: mhm] (.) does affect me (.) so I can put up with that (.)

When asked about the impact of his condition upon his social activities (1-4), Murray introduces the topic of social drinking, in lines 6-7, expressing that alcohol-consumption does appear to have a negative effect on his IBD, causing an exacerbation of symptoms which results in him needing to go to the toilet for extended periods during a night out. These negative effects are mitigated, however, through the use of 'maybe' (7 and 9), and the modal verb 'may' (10). The verb phrase, 'nip into the toilet for ten minutes' (8-9), also functions to mitigate the intrusiveness of these symptoms on the social activity, 'nip' connoting a short duration of time. Whilst for most people this term would probably not adequately describe the intrusiveness this would cause during a social night out, this formulation implies that, from Murray's perspective, the effects of alcohol on his IBD do not impede his enjoyment of the social activity. Here Murray 'justifies' his social drinking behaviour, not through addressing the potential undermining effects these practices may have upon his 'healthy body', but based on the fact that the effects of this

social drinking on his 'healthy body' do not hamper his ability to participate in, and enjoy, the social activity, and thus pursue his 'social body'.

Murray also introduces medical evidence to legitimate his behaviour, stating that he has enquired at the hospital about the effects of alcohol on his IBD-related health: 'they say they...can't put their finger on it (.) the doctor said there's nothing to say that it does necessarily' (11-12). Thus in spite of Murray suspecting, and providing tangible evidence that alcohol-consumption has 'quite a bit' (7) of an effect on his IBD, he uses reported speech from relevant medical professionals to suggest that these effects are in fact not medically proven, thus supporting the possibility that his behaviour may in fact *not* be 'risky'. This negates any need for him to address, and account for, the possibility that he may be undermining his 'healthy body' project, and the lack of condition control resulting from these behaviours. Murray's account can thus be seen to function primarily as a 'justification', as whilst he accepts responsibility for engaging in these social drinking practices, through providing this evidence he is mitigating the negativity of these actions in relation to his IBD-related health.

Despite this medical evidence casting uncertainty on the effect of social drinking on Murray's IBD-related health, I pose the question, in lines 13-15, as to whether considerations of his IBD cause Murray to drink less when he is on a night out. Murray provides a bold response of 'no' (16), followed by two further categorical denials (18-19), the explicitness of which again perhaps signals that he does not feel his actions are undermining his 'healthy body'. Again, however, the laughter following this response could signal that, in spite of this medical evidence, he views this behaviour as being counter-normative, or counter to my expectations, which is perhaps influenced by the framing of my question, which alludes to the possibility that these considerations may lead Murray to drink less.

Murray does justify this response, in lines 19-26, again through proposing that his social drinking practices do not hinder the pursuit of his 'social body'. He proposes that the effects of the alcohol are 'usually...after a night out' (19), and although describing these effects as 'quite bad' (24), he states he 'can put up with that' (26). This implies, then, that

if Murray is able to enjoy the night out drinking, and thus pursue his ‘social body’, he is willing to accept the exacerbation of his IBD-symptoms the following day as a trade-off.

The account of another IBD-respondent, Frank (who we encountered in Chapter 8; Extract 21) displays some similarities with Murray’s account, in that it also functions primarily as a ‘justification’. Frank is aged 28, and had been diagnosed with Crohn’s disease for two years. Unlike the other three respondents, at the time he was in fulltime employment. I initially asked Frank about how his IBD affects his social life, and following discussion of his social activities more generally, Frank (F) orients to the theme of social drinking (see Appendix K; Interview 29: 194-215):

Extract 27:

1. F: if you drink any alcohol it sets it off and I’m normally
2. quite bad the next day after drinking even one pint one
3. bottle (.) so (.) even though I do go out on a Saturday night
4. and probably suffer for a couple of days afterwards (.) rather
5. than going out where I might be going out every week or
6. every couple of weeks it is (.) going out on special occasions and
7. doing that which is quite different for me (.) so it’s planning
8. when you’re going to go out and drink and making sure you
9. haven’t really got anything on the next couple of days after it (.)
10. BS: yeah yeah
11. F: [‘cause I know I’m gonna suffer (.)
12. BS: yeah (.) but you’re still happy to drink as long as you know that
13. you’ve (.) just got to put up with it afterwards sort of thing?
14. F: [yeah] (.)
15. BS: rather than cut it out altogether (.)
16. F: yeah (.) I think it’s based on what they said at (hospital name
17. omitted) they said ‘you know that it’s gonna upset you for the next
18. couple of days you haven’t really got anything on and you can live
19. with it (.) go ahead and have it because if it’s a one-off’ (.) they just



20.           said 'well you've got to live at the end of the day' (.)

Frank, like Murray, acknowledges that consuming alcohol does have negative effects on his IBD, exacerbating his symptoms in subsequent days (1-4). Whereas Murray insists that this does not in any way prevent or limit him in partaking in these practices, Frank proposes that he limits the frequency with which he participates in these practices because of these negative effects (4-6). Frank thus demonstrates 'bracketing' (Balfe 2009: 136) his social drinking behaviour in order to mitigate the potential undermining effects this could have on his 'healthy body'. This is further evidenced in lines 7-11, and here Frank suggests that the primary reason for him not partaking in these practices more regularly is the potential impact that exacerbation of his IBD-symptoms could have on his daily activities, as opposed to his longer-term health. He thus implies that in circumstances whereby he has not 'really got anything on' (9) the following few days, participating in such practices is acceptable to him. This can primarily be seen as a 'justification', as Frank's acknowledgement of the negativity of these social drinking practices is only partial, and through highlighting his 'bracketing' of the risks, he is mitigating the negativity of these practices.

Frank legitimates this view towards social drinking through proposing that it is 'based on' (16) the information he has received during medical consultations, which he evidences through introducing direct reported speech from healthcare professionals: 'they said 'you know that it's gonna upset you for the next couple of days you haven't really got anything on and you can live with it (.) go ahead and have it'' (17-19). Whilst healthcare professionals are reported here as acknowledging that social drinking may negatively affect Frank's IBD, only the short-term after-effects are mentioned, with no reference to any general IBD-related health risks. What is more, the phrase 'gonna upset you' (17) connotes minor consequences, as opposed to serious health implications; however, it is noted that the healthcare professionals condone this behaviour only 'if it's a one-off' (19). The use of direct reported speech thus supports Frank's justification that engaging in such practices is not significantly detrimental to his 'healthy body', as long as he does not participate in such behaviours too frequently.

### 9.3 *Cross-condition comparisons*

The accounts presented display the young adults attempting to perform an identity of ‘good’ person with T1DM or IBD, portraying themselves as behaving in a morally-appropriate manner (Radley and Billig, 1996: 221), in spite of their participation in potentially ‘risky’ social drinking practices, thus showing consistency with accounts in relation to the themes explored in Chapters 6-8. This identity-construction is negotiated in differing ways, however, revealing similarities and disparities both in relation to the accounts of those with the same condition, but also, significantly, *across* the two conditions.

In relation to the two T1DM-respondents, both Gail and Polly show clear recognition that social drinking could potentially undermine their ‘healthy body’ (Extract 24: 17-19; Extract 25: 2-3 and 8-9), and thus they predominantly produce ‘excuses’ as a way of accounting for what could be deemed to be morally-*inappropriate* behaviour. Their respective attempts, however, to discursively negotiate the ‘tension’ (Balfe, 2009: 136) rooted in the simultaneous pursuit of ‘competing’ (Balfe, 2009: 136), and potentially contradictory ‘body projects’, lead to differing alignments towards their ‘social’ and ‘healthy’ bodies.

Gail’s account is primarily based around her desire to pursue her ‘social body’, both on the grounds of ‘normalcy’, in that it is culturally-expected, age-appropriate behaviour, and that she finds these activities enjoyable. In prioritising her ‘social body’, then, Gail’s account demonstrates evidence of ‘living beyond the confines of illness’ (Sargeant, 2006: 82), as she strives not to let the risks associated with her condition prevent her from participating in what she views as ‘normal’ behaviour, or to control her lifestyle in this respect. Gail’s account can therefore be seen to demonstrate a degree of resistance to her T1DM treatment-regimen, as she is carrying on with desired lifestyle activities in spite of her condition. She thus foregrounds her attempts to gain *lifestyle* control, in spite of the detrimental effect this could have to her *condition* control.

Whilst Polly can be seen to, at times, draw upon similar excuses to Gail for her behaviour, I would argue that she, to a greater extent than Gail, attempts to construct a *balance* (Balfe, 2009: 136) between her 'social' and 'healthy' body projects, as a way of discursively negotiating the apparent tension between the two. This is achieved through shifting her stance in her account to create an interrelationship between living '*beyond*' and '*within* the confines of illness' (Sargeant, 2006: 82). By reportedly participating in social drinking practices in spite of her condition (1 and 11-12), Polly displays 'living beyond the confines of her illness', thus attending to her desire to pursue her 'social body'; however, by limiting the frequency of her participation in social drinking (4-5), she *simultaneously* displays 'living *within*' its confines, thus also allowing her to demonstrate that she is attending to her 'healthy body'. Polly is suggesting, then, that she adapts her lifestyle somewhat, enabling her to maintain control over her lifestyle, but to still have a degree of condition control.

Equally, Polly was shown to, at times, include elements of 'justification' in her account, thus again demonstrating that Scott and Lyman's (1968) distinction between 'excuses' and 'justifications' is not clear-cut, and these constructions are by no means mutually exclusive, often being interwoven at different junctures within the same account.

This negotiation of body projects differs somewhat in relation to the accounts of the two IBD-respondents, who were shown to primarily construct 'justifications' for their social drinking behaviour. Again differences between the two respondents' constructions of these justifications are apparent, based around their respective orientations to their 'social' and 'healthy' body projects. In relation to Murray's account, rather than focusing on the potential undermining effects that social drinking practices could have on his 'healthy body', he justifies his behaviour on the grounds that his social drinking practices do not hamper the pursuit of his 'social body', thus representing himself as 'living *beyond* the confines of illness' (Sargeant, 2006: 82). Whilst similarly to Gail, Murray is reportedly carrying on with his life in spite of his illness, this management-strategy is not framed as a form of resistance to his condition. Frank pays more attention to justifying his behaviour in relation to his 'healthy body', and through reportedly 'bracketing' (Balfe, 2009: 136)

his social drinking behaviour, he constructs a greater balance between ‘living *within*’ and ‘*beyond* the confines of illness’ (Sargeant, 2006: 82). Demonstrating similarity with his account in Chapter 8 (Extract 21), then, Frank represents himself as adapting his lifestyle through making some concessions, but as still being able to maintain a degree of lifestyle control.

Whilst Frank’s and Murray’s respective accounts differ in the negotiation of their body projects, in the case of both, there is the implicit assumption that if they do not have any activities to engage in during the following few days, then such behaviour, as long as not too frequent, is not causing them any significant harm. An apparent *cross-condition* disparity, therefore, is in the respondents’ respective views regarding the ‘healthy body’, and it is this disparity which appears to influence the construction of their accounts as either predominantly ‘excuses’ or ‘justifications’. Whilst in Chapter 8, I proposed a distinction between the ‘*short-term* healthy body’ and the ‘*longer-term* healthy body’, here the concept of the ‘healthy body’ must be further unpacked, in terms of the severity of impact respondents view their behaviours as having upon their ‘healthy body’. Both Frank and Murray appear to view their ‘healthy body’, in this context, as relating to a short-term exacerbation of IBD-symptoms, which they represent as not significantly affecting their overall IBD health. On the other hand, the accounts of the two T1DM-respondents, Gail and Polly, suggest that they view their ‘healthy body’ in terms of more serious health implications in this context (Extract 24: 19; Extract 25: 8-9), although details of these implications are left implicit in the accounts, assumed to be knowledge that both they and I share.

I would contend that the reason behind these differing conceptions of the ‘healthy body’ in this context stems, at least partially, from biomedical knowledge of the two conditions. The stronger medical evidence regarding the effects of alcohol-consumption on T1DM means it is more difficult for those with T1DM to deny the ‘pejorative quality associated with the act’ (Scott and Lyman, 1968: 47), which leads them to provide ‘excuses’ for engaging in behaviour they *know* to be potentially ‘risky’. Contrastingly, it is the ambiguity surrounding the severity of the health effects of alcohol-consumption on IBD that means those with the condition are able to provide ‘justifications’ which mitigate the

'pejorative quality' (Scott and Lyman, 1968: 47) associated with their social drinking practices, suggesting that they are *not necessarily* acting irresponsibly.

The notion of agency over condition control must again be addressed and problematized. In 8.4, I proposed a cross-condition disparity whereby T1DM-respondents, on the whole, construct greater agency than those with IBD in terms of maintaining control over their condition. I argued that in relation to T1DM this agency largely constitutes proactive practices to minimise the risk of ill-health, whereas with IBD, in cases where agency is constructed this usually involves avoiding certain behaviours. In relation to social drinking, however, for respondents with *both* conditions it is choices regarding the *avoidance* of these behaviours that allows them a degree of agency over their condition control – agency that it has been shown can be used by respondents in differing ways.

Another cross-condition *similarity* that is observed concerns how respondents with both conditions construct the motivation for the pursuit of their 'social body'. Whilst Balfe (2009) discusses this almost exclusively in relation to individuals striving to project an image of *normalcy* to their peers, the extracts analysed here suggest that this is by no means the only motivation. Whilst the performance of normalcy is clearly an issue apparent in these extracts, demonstrated through the respondents' framing of social drinking as being culturally-expected of young adults, a primary motivation appears to be their *own enjoyment* of the activities, and wish not to have their lifestyle controlled by their condition, as displayed most explicitly by Polly: 'but I do like it so...I just go for it' (Extract 25: 11-12). This finding extends those of previous research (Balfe, 2009; Eaton, Williams and Bodansky, 2001), in suggesting that young adults are participating in such activities not only as a way to 'fit in' with peers, but for their own personal enjoyment and gratification.

It should be acknowledged that, in the extracts chosen, the two T1DM-respondents are female, whilst the two IBD-respondents are male. However, this is not considered to be significant in the present analysis, because no particular gender differences were observed across the breadth of the data in relation to this theme, and similar cross-condition disparities were observed regardless of gender, something found to be common across the

themes explored in this thesis (for further examples from the data-corpus of accounts regarding social drinking, see for instance, Steve: Interview 2: 305-355; Rosie: Interview 4: 447-473; Helena: Interview 6: 113-136; Malcolm: Interview 8: 101-105; Mark: Interview 12: 331-360).

Chapters 6-9 have investigated, in considerable detail, discursive representations in relation to the predominant macro-themes identified within the data: *Self*; *Other-orientation*; *Control*; and *Social Drinking Practices*. I will next attempt to draw some conclusions, bringing together findings in relation to these themes as a way of addressing their interrelated nature. I will also consider the contribution these findings can make to the broader fields of chronic illness experience and discourse analysis.

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## 10. Conclusion

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### *10.1 Lifestyle Representations and the Performance of Morality*

This thesis has explored the discursive representations of the lived-experiences of young adults with T1DM and IBD. A range of findings have been presented in relation to the predominant themes identified: *Self*; *Other-orientation*; *Control*; and *Social Drinking Practices*. Several theories and concepts have been subsequently developed, addressing each of the research questions posed (see 1.7). Whilst these predominant themes display similarity with those identified in previous research literature (see Chapter 4), this thesis extends the findings of these studies through micro-examination of the articulation of these themes, including further calibration of the key themes.

Perhaps the main, overarching finding this discursive perspective gives rise to concerns how the conflict commonly constructed between the priorities, desires and demands of young adulthood and the complex considerations regarding multifactorial chronic illness, at times gives rise to tensions in accounts, which must be discursively tackled and negotiated in the interview context. The commonality observed across the data-corpus in the lifestyle priorities and concerns of the respondents (in terms of issues surrounding college/university, employment, sociability and leisure), warrants my argument that young adults as an age-cohort are worthy of study in their own right. Yet, across all themes there was found to be significant *variation* in *how* young adults' experiences, behaviours and perceptions are constructed in relation to these themes, both within and across the two conditions, thus showing that the *construction* of these experiences certainly cannot be treated in homogenous terms.

This finding has significance not only for future discursive research regarding this age-group, but also for contexts of interaction such as the clinical setting. Such variation demonstrates that the approach that may be taken in many medical interactions, of asking the same kinds of questions, framed in the same ways, and subsequently eliciting the same kinds of talk, is not always appropriate to the needs and concerns of young adults with these conditions. These findings therefore support those of research calling for a more individualistic approach to patient care, putting patient concerns at the forefront of enquiry – a notion that has come to be known as *patient-centredness*. This includes those campaigning for a move towards ‘narrative-based medicine’ (Charon, 2006; Elwyn and Gwyn, 1998), an approach which sees patients being given greater interactional space in medical consultations to construct their subjective experiences. It has been argued that such an approach offers ‘a possibility of *understanding* which cannot be arrived at by any other means’ (Greenhalgh and Hurzwitz, 1998: 6). I would contend that the complex nuances, tensions and contradictions observed in the representations in this thesis present a strong case for the relevance of the patient-centred approach to young adults with either of these two conditions.

In spite of this variation in constructed lived-experience, a consistent finding running throughout the data analysis is the constitution of the morally-driven self, which appears to function as a means to ease the tensions present in accounts. Respondents were seen to draw upon a range of discursive strategies in their construction of positive, morally-appropriate identities. This included various metaphorical representations; the use of second person pronouns to create ‘in-group’ alliances; ‘contrasts’, either with the undesirable behaviour of others (Smith, 1978), reflexive contrasts between respondents’ present perceptions and behaviours and that of their former selves (Linde, 1993), and contrasts in terms of different self-other configurations (Sarangi, 2007); as well as reported speech. The construction of narratives and habitual narratives were also shown to often serve the rhetorical function of constructing morality and (lack of) normalcy. Where reported-behaviours conflict with moral-appropriacy, respondents commonly produced ‘excuses’ and ‘justifications’ (Scott and Lyman, 1968) in order to account for this moral-*inappropriacy* and thus maintain a positive identity-performance.



This coherent thread of morality-alignment commonly saw respondents drawing from a small number of ideological and cultural schemas, which reflect 'general beliefs and shared theories about the nature of the world' (Radley and Billig, 1996: 223), through which they were able to construct particular moral figures for themselves. These moral figures often portrayed respondents, in Frank's (1997a) terms, as 'rising to the occasion', and as striving to be 'successfully ill' (1997a: 135). The first is the *heroic* figure battling on with life in spite of the demands and restrictions of illness – a common representation amongst those whose lives have been most affected by illness, and who therefore frame their resistance to illness in very positive terms. This, Gwyn (1996: 259) describes as 'the mythical model of the heroic quest, or struggle'. The second common representation was of a figure who avoids self-pity, not wishing to make a fuss about illness, or for others to make a fuss over him or her, who just gets on with things, often with more grace and calm than those who do not have the same worries to contend with. This figure is also heroic, but is represented as a quiet hero, rather than a battling one. A third moral figure is that of the responsible ill person who takes care of his or her health as best they can, and through consistent efforts, is at times able to represent himself or herself as 'healthy', in spite of being chronically-ill. At points when respondents constructed 'felt stigma' or 'enacted stigma' (Scambler and Hopkins, 1986), another morally-appropriate identity was that of someone who is strong-willed, and able to reject others' negative perceptions, displaying what Scambler and Paoli (2008) term 'project stigma' – the conscious rejection of attributions of shame. Even when reported-behaviours conflict with the contingent demands of the condition, some respondents were able to construct the moral figure who shows recognition and awareness of this moral-inappropriacy. Far from being reckless with regard to condition-related health, this is somebody caught in the difficult position between lifestyle demands and the restrictions imposed by illness, who is therefore to some extent a victim of circumstance. In these cases, as Bury (2001: 275) similarly observes, 'narrative forms suggesting culpability can be combined with those that exonerate the individual from blame, and help to maintain self worth'.

These findings display consistency both with previous sociological studies into experiences of illness (Bury, 2001; Charmaz, 1999; Frank, 1997a; Williams, 1993), and those which have adopted interaction- and language-based approaches in this area

(Cheshire and Ziebland, 2005; Gwyn, 1996; Radley and Billig, 1996; and Riessman, 1990; 2002; 2003: see Chapter 3). However, the findings here go beyond those of previous research, as none of these studies alone have found this extensive range of moral figures being constructed, or have observed these constructions as occurring consistently across such a large sample of respondents. The present findings are therefore strongly situated within the existing field of research.

## ***10.2 Reflections on Methods***

The methodological approach adopted was discussed in considerable detail in Chapter 5; however, there are a few salient points worth reflecting upon. I attempted to represent the data-corpus as a whole through open-coding, using qualitative software, and then calculated the frequency of words coded within each theme across the whole corpus. This gave me confidence that the themes chosen for more detailed analysis were somewhat representative of my data-corpus. Such methods of systematic coding have been commonly adopted in sociological research into illness experience (Hall, Rubin, Dougall, Hungin and Neely, 2005; Hillege, 2005, amongst others), but not in studies using discourse analytic approaches. The present study is therefore unique in combining these systematic, social scientific methods, with fine-grained analysis of discursive representations, with the aim of conducting a comprehensive and robust investigation of this chronic illness context.

As with most qualitative research, there are limitations regarding the generalisability of findings to a wider population. Whilst the 30 interviews carried out may allow for the trends identified to be seen as indicative of the experiences of other young adults with these conditions, this corpus does not allow for findings of statistical significance, especially as no quantification has been attempted. Additionally, the majority of respondents are white, middle-class, and all lived in South Wales and South-West England regions. However, wide-spread generalisability is not a principle aim, and as previously argued (see 5.1), qualitative methods allow for detailed insights in this area that cannot be gained through relying principally on quantitative methods.

My role in the interviewing process is also of significance. As discussed in 5.2.3, I adopted elements of Gwyn's (1996) 'conversational narrative' approach, aiming for interviews to be largely participant-led. I feel that I was largely successful in this goal, creating a relaxed, informal environment, which reduced any potential power-asymmetries, and resulted in significant levels of disclosure. However, whilst in many instances respondents led the direction of interviews, as shown in the extracts analysed, the framing of my questions was at times somewhat leading, perhaps influencing respondents to construct their experiences in a particular way. However, my influence does not in any way diminish the value of the data. I have emphasised throughout that the role of the researcher is inevitable and integral in the research process, and I treat interviews as 'active' pursuits, and meaning as jointly-constructed (Holstein and Gubrium, 1997: 114, see 5.2.3). This is something I explicitly oriented to throughout the analysis. I have also stressed throughout that accounts must be seen as contextually-contingent, and thus talk is always 'situated and accomplished in social interaction' (Riessman, 2002: 27) (see 10.6 for discussion of how findings here could be of practical use in exploring other contexts).

### ***10.3 Addressing the Interrelationship of Predominant Macro-Themes***

One of the key contributions that the present analysis makes to the field of illness experience is in unpacking many of the conceptual categories used in previous research, allowing for sub-categorisation, i.e., the different types of control identified; the distinctions established between control, management-strategies, and coping; the various ways in which respondents orient to different groups of others; and the different types of, and ways of looking at, disclosure of illness-information. In the case of some existing conceptual frameworks, I have attempted to re-frame these as being continual and interrelated, rather than binary, i.e., Goffman's (1963) conception of stigma; Scott and Lyman's (1968) 'excuse/justification' distinction.

Unpacking some of these concepts and exploring their discursive realisation has necessitated separating the predominant macro-themes for analytic purposes, as attempting to deal with all of the macro-themes simultaneously would be simply

unmanageable. However, in 5.3.3, I highlighted the interrelated nature of these themes. The multifactorial considerations of chronic illness means that, in the reality of lived-experience, issues relating to *Self*, *Other-orientation* and *Control* are not only co-occurring, but are potentially mutually-influential. Whilst these themes were kept largely separate, there were times during the analysis that I explicitly drew attention to the co-occurrence of these predominant themes (Chapter 6; 6.2: Extracts 6 and 7; and 6.3; Chapter 8: 8.2: Extract 2).

In order to demonstrate the interrelationship of these themes, I will briefly return to an extract already analysed in which this is particularly apparent. The extract is taken from Chapter 6, from an interview with Steve (6.1; Extract 4, page 137-139; see also Appendix K; Interview 2: 456-491). I will not reproduce the extract here due to reasons of space. Though I am using the example of someone with T1DM, the interrelationship of these macro-themes was also commonly observed in the accounts of IBD-respondents, while acknowledging that significant variation was observed in the construction of this relationship.

It was shown in Chapter 6 how Steve explicitly rejects an illness-identity, *distancing* T1DM from his 'self-concept' (Charmaz, 1983). One way in which Steve attempts to pull this off is through his *orientation to others*, both real and hypothetical. This is displayed firstly through 'self-vs.-other' (Sarangi, 2007) orientation, constructing a 'contrast' between his family 'panicking' (line 10) about his diagnosis and his own calmer response, as well as through placing himself in opposition to others with illness who attempt to elicit either praise or sympathy: 'they'd want everybody to know about it...look how careful I (.) have to be (.) or (.) worse still (.) look how bad I've got it' (28-31). Steve also constructs consistency between his present and pre-illness selves through orienting to generalized hypothetical others, contending that the way he wishes others to 'perceive' (26) him has not changed as a result of him having T1DM. Here then, Steve is using his representation of other-orientation as a resource to construct his illness-selfhood relationship. Representing his perception of T1DM in this way also allows him to align with the morally-appropriate 'quiet hero' model, proposed above, portraying himself as able to simply 'shrug it off get on with it' (11).

Steve's distancing of illness from his selfhood is also constructed through his representation of *control*. Steve implies that he has a strong degree of agency, allowing him to maintain a good degree of condition control and lifestyle control. He relates an incremental change whereby he has developed an awareness of whether his blood-sugar levels are high or low, meaning it is unnecessary for him to test his blood-sugar as regularly as he did previously: 'I know when I'm beginning to go a bit high on blood sugar and I certainly know about it if it's going low' (17-18). This suggests a high degree of condition control, yet simultaneously a high level of lifestyle control, as this implies that his treatment-regimen does not take up a great deal of his time, or impinge upon his lifestyle to any great extent. He also talks of how a change in the type of insulin he uses has led to him having more freedom over food-consumption<sup>22</sup> (18-21), thus again emphasising his lifestyle control. He also constructs his level of control *through* other-orientation, explicitly proposing that others view illness as a 'controlling factor' (28) in their lives, a perception he represents as differing markedly from his own. It is partially through this construction of good condition control, and at the same time constructing his treatment-regimen as not impeding upon his lifestyle control, that Steve is able to narratively minimise the role of T1DM within his life, allowing him to further distance the condition from his conception of self. This construction also demonstrates the interrelationship between self, illness and *the body*, as it is the minimal impact that Steve represents T1DM as having on his 'healthy body' (Balfe, 2009) and also implicitly on his 'social body', that allows him to represent T1DM as occupying only a peripheral role within self: 'it would be a secondary issue' (24); or at one point *no* role in self: 'it's not an identity thing at all' (36).

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<sup>22</sup> Steve explained at an early point in his interview that he has changed his insulin-regimen, from administering large doses of insulin a few times a day, to taking a combination of short- and fast-acting insulin, a regimen called DAFNE (Dose Adjustment for Normal Eating). This means that he estimates the amount of carbohydrate in the food he is eating, and adjusts his insulin dose accordingly, in order to manage his blood-sugar levels. This regimen is intended to give those with T1DM greater freedom in terms of food-consumption, because if they eat foods with high sugar content, they can adjust their insulin dose accordingly in order to regulate their blood-sugar levels.

#### **10.4 Situating Present Findings within the Wider Research Field**

Whilst principally aiming to provide further insight into the constructed-experiences of young adults with T1DM and IBD, as stressed in the introduction to this thesis, these conditions are intended as case-studies, used to explore an interest in young adults' experiences of chronic illness more generally. I therefore wish to broaden the discussion of findings in terms of their applicability to other chronic conditions, and their contribution to wider conceptual issues surrounding the role of *self*, *other-orientation* and *control* in the lived-experience of chronic illness. I draw on the insights of Conrad (1990), who proposes the notion of 'generalisability of *concepts*', by which he means the potential for concepts and findings developed in relation to particular chronic illnesses to be generalised 'to social processes concerning other forms of illness, disability or social life' (1990: 1258-9). Such an approach can contribute towards 'building a deeply penetrating and more analytical understanding of chronic illness' (1990: 1259). This supports the arguments of Kelly (1992a) cited in 1.3, that whilst different chronic conditions give rise to a range of varying experiences, 'in many ways the problems posed by such illnesses share a quality which cuts across particular medical diagnosis and is common to them all' (1992a: 48).

In terms of the constructed illness-selfhood relationship, the finding that respondents with both T1DM and IBD are able to discursively *integrate* or *distance* illness from their 'self-concept' (Charmaz, 1983), to differing degrees, and at different points in their accounts, may be applicable to a range of chronic conditions. This is evidenced through considering the similar findings of Adams, Pill and Jones (1997), who, in investigating the experiences of people with asthma, aged 29-57, divided respondents into 'Accepters' and 'Distancers/Deniers'. Similarly to my concept of *integration*, Adams et al.'s 'accepters' were found to 'fully assimilate the social identity of 'asthmatic' as part of themselves' (1997: 197), whereas 'distancers/deniers' attempted to avoid constructing the condition as a prominent part of selfhood. A key difference between Adams et al.'s model and the trends observed in my data, however, is that Adams et al.'s 'deniers/distancers' reportedly failed to accept that they have asthma, or that it has any impact upon their lives. In my data, it was not the case that respondents who distanced their condition from self went so

far as to reject their diagnosis; they simply afforded the condition a less salient role within their conception of self.

The construction of temporal changes between respondents' selves prior to illness, or at any earlier point in their illness trajectory, and their present selves, was a consistent finding with regard to both conditions in the present study. This evidences what Kelly and Dickinson (1997) term 'self as object', whereby the self is seen as 'something that can be considered and examined in terms of whether and how it has changed' (1997: 268). Several respondents constructed illness as resulting in 'loss of self' (Charmaz, 1983), whilst some constructed what I termed *gaining* positive elements of self, demonstrating 'transformational' experiences (Paterson, Thorne, Crawford and Tarko, 1999: 786). Some respondents, however, constructed *consistency* between pre- and post-illness selves. Temporal shifts in the role of illness within self were not always represented as linear, however. Many with IBD constructed their condition as having a far more prominent role within self in times of disease flare-up than when the condition is in remission, due to the increased influence of the condition upon their lives at these times. This suggests that, in relation to this corpus at least, chronic illness experience does not follow a predictable phased trajectory towards a particular end point as has been suggested by some (Baumgartner, 2007). This supports Paterson's (2001) 'shifting perspectives' model, which proposes that the foregrounding of 'illness or wellness' can vary at different times in an individual's overall illness trajectory. T1DM was represented as having a more consistent level of influence upon respondents' lives, meaning that, although temporal changes were constructed, the role of illness within self was generally represented as being more stable. This suggests that Paterson's model may be more relevant to some chronic conditions than others, perhaps especially those characterised by relapse/remission cycles.

Perhaps the most significant finding in relation to *self* concerns the notion of *agency*. Individuals' integration of their chronic condition within their self-concept can be constructed as being somewhat through *choice*, in terms of their using experiences of the condition in a proactive manner, in order to *improve* their lives in some way. However, in the present corpus, integration is most commonly reactive, resultant of the intrusive

impact of the condition upon individuals' lives; thus they have lesser agency in this regard. IBD was generally represented as being more intrusive upon respondents' lives *in the present* than T1DM, evidenced as due mainly to the bodily limitations which can result from IBD-symptoms. This led to more negative constructions of the illness-selfhood relationship, including the construction of 'loss of self' (Charmaz, 1983), or in some cases what can be considered an 'uneasy truce' (Hillege, 2005: 116) between self and illness.

In relation to both conditions, a distinction was observed between *condition* control and *lifestyle* control. I proposed that attempts to maintain both types of control principally involve issues related to *the body*, which is not only the primary medium through which illness is experienced in terms of the effects of treatments and symptoms, but also it is through practices involving the body that individuals respond to, and manage illness. Both types of control I distinguished from the concept of 'coping', seen as cognitive and communicative methods of managing the *psychological strain* of chronic illness, as opposed to its physical effects.

My findings extended those of Balfe (2009), that young adults with T1DM engage in distinct, but interrelated 'body projects'. Firstly, Balfe's 'student body' was broadened to include young adult sociable activities more generally, being relabelled 'social body'. Close analysis revealed that the motivation behind the pursuit of this project is not only the wish to display a 'normal' identity to others, as Balfe suggests, but reflects young adults' desire for *enjoyment* and personal gratification. Balfe's (2009) conception of the 'healthy body' was also extended to making a distinction between '*short-term*' and '*longer-term*' healthy bodies. Those with T1DM were commonly found to orient to *both* their short-term and longer-term 'healthy body', addressing health concerns which are represented as being several years into the future, in addition to the more immediate risks of experiencing hypoglycaemia. Those with IBD, however, oriented predominantly to their short-term 'healthy body', in terms of the impact of diseases symptoms on their lives in the present, or fears regarding the possibility of disease flare-ups in the short-term future.



In relation to their management of illness, respondents were found to give salience either to their 'social body' or 'healthy body' in different contexts, or to attempt to construct a balance between the two, as a way of negotiating their condition control and lifestyle control. As Balfe observed, these projects are at times conflicting, as, for instance, attending to the 'social body' in certain contexts can undermine the 'healthy body', and vice-versa. I would argue, then, that as well as *the body* being seen as a 'project' (Shilling, 2003; Balfe, 2009), in some ways managing chronic illness itself can also be conceptualised as a project, something to be constantly *worked upon* through the negotiation of the 'healthy body' and the 'social body' in different contexts. As a way of negotiating the tension between these competing body projects, respondents often attempted to construct an interrelationship between living '*within and beyond* the confines of illness' (Sargeant, 2006: 82). My findings suggest, however, that these 'confines' are perhaps more stringent for those with IBD in the present, at least in times of disease flare-up, than for those with T1DM, again evidently due mainly to the restrictions of bodily limitations upon IBD-respondents' lifestyles. For those with T1DM, issues of lifestyle control more regularly surround adherence to treatment-regimens, which are represented as being less intrusive.

These findings vis-à-vis young adults' negotiation of competing 'body projects' resonate strongly with the arguments of Radley (1989), who in discussing what he terms people's 'styles' of adjustment to illness – 'how the dilemmas of illness are addressed or resolved in the way that sick people cope with chronic illness' (1989: 231) – talks of how individuals' social roles and practices must be taken into account. He argues that people do not just experience illness in terms of the limitations it imposes upon them, removing them from society and social life, but that individuals adjust to illness within the 'definite relationships in society' (1989: 250) in which they are located. As Radley artfully proposes: 'Becoming chronically ill does not remove one from society; if anything it amplifies one's position in it, so that what people adjust *with* is as important a matter as what people attempt to adjust *to*' (1989: 243). Considering chronic illness as a *project* shows how young adults manage their condition *within the context* of the desires, constraints and cultural expectations linked to young adult social roles, those relating to employment, college/university, social relationships, and associated activities such as

social drinking. It is *within* their negotiation of these social roles that the young adults construct their ‘social’ and ‘healthy’ bodies, as part of their overall chronic illness project.

Present findings can also make a tentative contribution to the study of (lack of) normalcy and *stigma* vis-à-vis chronic illness. In general, T1DM-respondents more commonly positioned their condition quite low on the *discredibility continuum* (see 7.1), constructing it as ‘normal’. Several with IBD, however, constructed their condition as somewhat stigmatized and removed from the normalcy of others. This was most commonly those who had experienced the most severe condition symptoms, or frequent relapses, and who therefore framed themselves as having been restricted from partaking in what they perceive as ‘normal’ lifestyle activities. Whilst some IBD-respondents constructed ‘enacted stigma’ (Scambler and Hopkins, 1986), others principally portrayed ‘felt stigma’ (Scambler and Hopkins, 1986), the *fear* of experiencing stigma, fear that was less prevalent in the accounts of those with T1DM. I argued, in 7.5, that this disparity marks a variation amongst chronic conditions, which in some ways aligns IBD with conditions such as HIV/AIDS and epilepsy, research on which has made similar findings vis-à-vis ‘felt stigma’ (Green, 2005; Scambler and Hopkins, 1986). It appears on this evidence, then, that it is not necessarily having a chronic condition that results in the construction of ‘felt’ and ‘enacted’ stigma, but that certain conditions bring about greater stigma, at least in the representations of those with illness themselves, due to *perceived social unacceptability* of these illnesses. In the present corpus, this ‘felt stigma’ appears to relate to *the socially unacceptable and taboo nature of bowel functions*, and the embarrassment some young adults construct in relation to this.

Green (2009) recently posed the question as to whether we may soon witness an end to chronic illness-related stigma, problematizing the relevance of stigma in a modern society in which there is ‘an increasing diversification of roles and identities’, which means ‘all of us (or none) are “available” to be stigmatized’ (2009: 112). These findings suggest, however, that in order for this to become a reality in relation to the perceptions of young adults with IBD, the taboo associated with, and the lack of awareness of, bowel conditions needs to be addressed.

A commonality between the two conditions is that both were constructed by respondents as largely imperceptible; thus in Sargeant's (2006) terms, individuals 'inhabit a world that is ostensibly unaffected in the eyes of the healthy majority' (2006: 25). In relation to both conditions, then, individuals face issues over 'information management' (Goffman, 1963), having to make decisions about illness disclosure. In attempting to represent the complexities surrounding reported disclosure behaviour, I extended existing theories, such as Goffman's (1963) 'passing' and Conrad and Schneider's (1980) 'closet metaphor', proposing a metaphor based around the idea of a *cards player*, who is able to choose to whom and in which contexts to show his or her hand, and who can choose to display only some of his or her cards, or to lay all of the cards on the table at once (see 7.5). This metaphor is applicable not only to T1DM and IBD, but any potentially discreditable conditions, in which imperceptibility makes information-management relevant.

Whilst both conditions are largely represented as imperceptible, it was found that there is the potential for illness to, at times, become outwardly apparent in the form of 'stigma cues' (Scambler and Hopkins, 1986: 36), meaning the issue at hand becomes 'impression management' (Goffman, 1963). Whilst at times being relevant to T1DM, such perceptibility was found to be more commonly present in accounts of IBD, again highlighting the general cross-condition disparity that IBD is represented as having more potential to intrude upon individuals' lives *in the present* than is the case vis-à-vis T1DM, which often revolves more around *future* health concerns. In the perceptions of others, however, such stigma cues (in the case of IBD, for instance, rushing to the toilet frequently), are not necessarily associated with chronic illness. Outward-apparentness of illness in these cases could thus be termed *perceptibility without awareness*. These contexts bring about issues of 'deviance' (Scambler, 2004), as it is not *shame* related to the stigma of chronic illness that individuals face, but *blame*. I proposed that, in such scenarios, individuals must weigh up their level of 'felt stigma' regarding people learning about the condition, against the 'felt deviance' (Scambler, 2004) of leaving these stigma cues unexplained, something which resulted in a discursive tension in the accounts of many respondents. Some were found to respond to this through 'stigma-management' (Goffman, 1963: 69) strategies, such as attributing these signs to a less stigmatized illness, in the case of IBD, a tummy bug. These decisions regarding 'felt stigma' vs. 'felt

deviance' are potentially relevant to many other chronic conditions. Epilepsy, for instance, whilst being largely imperceptible, can become apparent if seizures are witnessed by others (Scambler and Hopkins, 1986), and similarly, Multiple Sclerosis (MS) can also remain largely discreditable, but at times become outwardly apparent through various 'aesthetic considerations' (Green, 2009). Whilst this marks commonality between certain illnesses, issues such as the nature of stigma cues, how apparent they become, and how deviant they are perceived to be, will all differ widely across conditions; therefore certain stigma-management strategies may not always be available to all individuals.

### ***10.5 Suggestions for Further Study***

Based on these findings, future research can be proposed in this area. Firstly, conducting a longitudinal study of the experiences of respondents of this age-group could yield interesting insights. The temporal contrasts in self that were commonly constructed, as outlined above, could be more fully explored through tracing a sample of respondents over a lengthier period, or perhaps interviewing these same respondents again at a future point.

Though throughout this thesis I have championed the merits of researching illness experience outside of the clinical setting, it may also be fruitful to explore clinical interactions involving people of this age-cohort with T1DM and IBD. Comparing my findings with the themes arising in interactions with healthcare professionals, and how young adults construct talk relating to these themes, would allow for greater insight regarding how the accounts produced here might differ from those in the medical setting. This could aid potential practical applications of these findings vis-à-vis the healthcare setting (see 10.6, below).

Finally, having argued that some of the theories and concepts developed in this thesis could usefully be applied to the experiences of those with other chronic illnesses, it would be interesting to explore this further through investigating the experiences of young adults with other multifactorial chronic conditions, for instance epilepsy, asthma or arthritis, in

order to form a more comprehensive picture of how young adults construct their lived-experiences of chronic illness.

### **10.6 Practical Application of Findings**

It is my belief that research in the health communication field, as well as aiming to further knowledge within the area of study, should also have some social relevance and practical application beyond the world of academia, a perspective that has been explicitly voiced by many (Candlin and Sarangi, 2004; Carroll, Iedema and Kerridge, 2008; Sarangi and Roberts, 1999, to name just a few).

There are three main avenues I hope to pursue in this regard. Firstly, I feel that it is an ethical duty of the researcher to continue to involve respondents after the data-gathering phase, something especially important in a deeply personal and sensitive area such as illness experience.<sup>23</sup> The data collected should be viewed as *belonging* to the respondents; these accounts are *their* lived-experiences, created in collaboration with me in the interview setting, therefore they should be my initial focus in terms of the use of findings. I therefore intend to produce a shortened, accessible version of my findings, which will be sent to respondents. Deciding exactly how to present these findings, as well as which findings may be most relevant and potentially helpful to respondents, are issues which require further consideration. Whilst they may find it in some way helpful to learn what others have had to say about living with their condition or another chronic illness, my aim is to present findings to the respondents to use as they wish. I do not want this to be framed as advice or guidance about living with their condition, as this is not what the study aims to achieve, nor is it my place to give such advice. I do however hope that, at very least, in receiving these findings, respondents will feel as if their participation has been valued, and will feel positively about having been involved in a research project that has come to completion.

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<sup>23</sup> In Chapter 5 (5.2.2), I described how I kept in touch with my research respondents throughout the study, as well as seeking their input once I had identified the predominant themes for analysis (see 5.3.2).

The second area of practical application that could be explored, although to be approached more tentatively, is possible implications that findings could have for advice given to young adults with T1DM and IBD in the clinical setting. Within the clinical setting there are a range of constraints, including limitations on time, and clinical/biomedical priorities, which mean that individuals are unable to produce the same kind of lengthy responses, or the same level of disclosure as witnessed in my data, a contention supported by research into clinical encounters (Charon, 2006; Elwyn and Gwyn, 1998; Greenhalgh and Hurzwitz, 1998). That young adults are not always afforded the interactional space to fully voice their concerns is also something explicitly commented upon by a few respondents themselves in my data. The accounts produced here could, then, offer a level of insight that healthcare professionals are unable to glean through their own time- and task-constrained interaction with these individuals.

My intention would certainly not be to try and advise healthcare professionals vis-à-vis their guidance towards young adults with these conditions, as again this extends well beyond the scope of my aims. I take heed of Candlin and Sarangi's (2004) sentiments (as similarly expressed in Roberts and Sarangi, 1999):

At most – and it is a considerable ‘most’ – what applied linguists can do...is to attempt joint problematisation and suggest complementary analytical frameworks that, through processes of mediation, may achieve some utility...in the end, it is for the practitioners...to acknowledge and decide what matters and what is applicable. (2004: 4)

With this in mind, it may be possible to present healthcare professionals with data-extracts, along with the themes identified, and some of my analytic interpretations based on these themes. I could then allow the healthcare professionals to interpret how these findings may be of use to them.<sup>24</sup>

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<sup>24</sup> Healthcare professionals would need to be approached regarding this kind of collaboration, although as mentioned in 5.2.2, professionals working in IBD and diabetes clinics who I met with near the beginning of my research indicated a strong interest in gaining access to my findings. Unfortunately there was not time in these meetings to fully explore how findings would be of most use to them.

A third, perhaps longer-term goal, could be to present findings as some form of online resource for young adults with these conditions. Such resources are already in existence; the twin websites [www.healthtalkonline.org](http://www.healthtalkonline.org) and [www.youthhealthtalk.org](http://www.youthhealthtalk.org) (formally combined as [www.dipex.org](http://www.dipex.org)) comprise a large database of personal experiences of illness, as a resource for those with illness and for healthcare professionals. The latter site contains a section focused on young people's experiences of T1DM, but not currently in relation to IBD. Another relevant outlet, explicitly geared towards giving advice to young people with IBD regarding lifestyle-management, is the website [www.ibdandme.nacc.org.uk](http://www.ibdandme.nacc.org.uk), a sub-section within the NACC (the National Association for Colitis and Crohn's Disease). Data could potentially be presented in a format similar to these sites. Whilst [www.healthtalkonline.org](http://www.healthtalkonline.org) presents transcripts and videos of interviews with individuals, as well as facts and figures about particular health conditions, I would hope to present my interpretations and findings alongside data-transcripts, as a resource for helping young adults to live with these conditions.<sup>25</sup>

### *In closing...*

At the beginning of this thesis, I cited the seminal work of Charmaz (1991):

Chronic illness can set people apart from others and take over their lives...however...most people learn to live *with* their illnesses rather than *for* them. (1991: 4)

On the whole, the accounts in this thesis support Charmaz's claims. Whilst it is clear from the representations in the data that illness *can*, at times, play a very significant role in the lives of young adults, in the case of most, illness is constructed as not occupying *the* defining role; and the young adults largely represent themselves as being able to pursue their desired lifestyle activities alongside the demands of their condition. The complex and interrelated nature of the findings presented here supports arguments regarding the importance of investigating the lived-experiences of young adults with T1DM and IBD,

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<sup>25</sup> In line with ethical procedures, it would be necessary for me to again contact my respondents in order to gain their permission for interviews to be used in this context.

and also demonstrates how methods of discourse analysis can illuminate the rhetorical, performative aspects of young adults' accounts, i.e., *how* they construct the significance of illness within their lives.



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## Appendices

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Appendix A:

Glossary of Terminology



## Appendix A: Glossary of Terminology

### Type 1 Diabetes Mellitus (T1DM)

#### **Blood-sugar monitoring (BMs):**

The simple blood test used to check the amount of glucose in the blood. A tiny drop of blood, taken by pricking a finger, is placed on a test strip and inserted in the meter for reading.

#### **DAPHNE (Dose Adjustment for Normal Eating):**

A training programme that provides people with T1DM with the skills necessary to estimate the carbohydrate in each meal and to inject the right dose of insulin. The treatment-regimen combines the use of short- and fast-acting insulin. It is intended to give those with T1DM greater freedom in terms of food-consumption; because if they eat foods with high sugar content, they can adjust their insulin dose accordingly in order to regulate their blood-sugar levels.

#### **Hyperglycaemia:**

Also known as high blood glucose, this condition occurs when the individual's blood glucose level is too high. Weight loss, thirstiness, and frequent urination are typical symptoms.

#### **Hypoglycaemia:**

Also known as low blood sugar, severe hypoglycaemia can cause a variety of symptoms ranging from dizziness to seizures.

#### **Insulin:**

A hormone produced by the pancreas that assists in the use of glucose for energy. People with diabetes who do not produce enough insulin must administer it via injections.

#### **Insulin Pump:**

A device attached to the body which continually infuses insulin into the subcutaneous tissue (the layer of tissue just beneath the skin). Insulin pumps work by delivering a varied dose of fast-acting insulin continually throughout the day and night, at a rate that is pre-set according to the person's needs. It is intended to help improve diabetes control and minimise the frequency of hypos.

### **Islet Cell Transplant:**

A procedure in which an individual's destroyed islet cells are replaced using cells from donor pancreases. The transplanted cells produce insulin, which stabilises the diabetes and reduces the amount of insulin that needs to be administered. In some cases, the transplanted cells may produce enough insulin to allow a person to come off insulin completely. Islet cell transplantation remains an experimental therapy and is not yet sufficiently well advanced to guarantee insulin independence and freedom from diabetes.

### **Ketoacidosis:**

A condition often caused by an infection or other illness like dehydration, or from taking too little insulin. When the body begins to break down muscle and fat for needed energy, ketones are released into the urine and blood, leading to diabetic ketoacidosis.

### **Nephropathy:**

A diabetic kidney disease in which protein is spilled into the urine. It can progress over time and result in significant kidney damage.

### **Neuropathy:**

Diabetes-caused nerve damage, typically in the feet and hands, however major organs can also be affected.

### **Retinopathy:**

The eye disease that occurs in someone with diabetes when the small blood vessels of the retina become swollen and leak liquid into the retina, blurring vision. This can sometimes lead to blindness.

#### Sources of Information

[www.everydayhealth.com/diabetes](http://www.everydayhealth.com/diabetes)

[www.diabetes.org.uk](http://www.diabetes.org.uk)

[www.dafne.com](http://www.dafne.com)

[www.bupa.co.uk/individuals/health-information/.../type-1-diabetes](http://www.bupa.co.uk/individuals/health-information/.../type-1-diabetes)

## Inflammatory Bowel Disease (IBD)

### **Anaemia:**

Reduced numbers of red blood cells and/or haemoglobin. In IBD, this can be due to blood loss and/or poor intake or absorption of vitamins and iron, which can cause tiredness and shortness of breath.

### **Abscess:**

Sore containing pus which generally develops in response to infection and becomes swollen and painful. In the case of people with Crohn's, abscesses may form in the abdominal cavity or in the anal and rectal area.

### **Azathioprine:**

An immunosuppressant medication which functions to decrease the activity of cells in the immune system and reduce inflammation in the bowel, in order to decrease the activity of IBD.

### **Barium Enema:**

An investigative procedure used to look at the inside of the colon. A liquid containing barium is used as an enema to place in the colon, allowing for the outline of the intestines to show up clearly on X-ray pictures.

### **Colectomy:**

Surgical removal of the colon.

### **Colonoscopy:**

An examination of the colon. A thin, flexible telescope called a colonoscope is passed through the anus and into the colon, allowing for the detection of inflamed tissue, ulcers, and abnormal growths.

### **Colostomy:**

A surgical operation in which the cut end of the colon is brought through the abdominal wall to create a spout-like opening called a stoma. Waste is then collected in a bag which is fitted over the opening and attached to the skin.

### **Endoscopy:**

A general term for the examination of the inside of the body using a flexible lighted tube, called an endoscope.

**Flexible Sigmoidoscopy:**

A medical procedure used to see inside the sigmoid colon (last one-third of the colon) and rectum. Similarly to a colonoscopy, it can be used to detect inflamed tissue, abnormal growths, and ulcers in these particular regions.

**Ileostomy:**

A surgical operation in which the cut end of the ileum (the final section of the small intestine), after a colectomy, is brought through the abdominal wall to create a spout-like opening called a stoma. Waste is then collected in a bag which is fitted over this opening and attached to the skin. This differs from when the large intestine or colon is brought to the surface and connected in a similar way, which is a colostomy (see above).

**Infliximab (Remicade):**

A drug used to treat severe IBD. It may be administered when other drugs have not worked or have caused major side effects, and when surgery is not considered the right treatment option. Infliximab targets a protein in the body called TNF-alpha (tumour necrosis factor-alpha), helping to prevent inflammation and relieve symptoms.

**Mesalazine (Asacol; Pentasa):**

An anti-inflammatory drug used to treat Ulcerative Colitis and mild-to-moderate Crohn's disease. It acts locally in the gut, therefore having few systemic side-effects.

**Mercaptopurine:**

Immunosuppressant medication which functions in a similar way to Azathioprine (see above).

**Pouch (ileo-anal):**

An internal pouch or reservoir made from the lower part of the intestine (ileum) which is attached to the anus. This allows the passing of stool through the anus in the usual way.

**Prednisolone:**

A corticosteroid drug used to reduce inflammation in IBD. It can be taken orally in the form of tablets, by injection into a vein, or by an enema or suppository through the rectum.

**Proctitis:**

Inflammation in the rectum or anus.

**Resection:**

The surgical removal of a part of the intestine.

**Stoma:**

A surgically constructed opening of the intestine onto the abdominal wall over which a bag can be fitted and sealed to the skin.

**Strictureplasty:**

A way of treating strictures (a narrowing of a section of the bowel due to bowel-wall thickening or scarring) and blockages in the small intestine, which avoids removing any of the gut.

**Sulfasalazine:**

A drug which combines 5-ASA with sulphapyridine to treat Ulcerative Colitis. Now used less commonly than other medications.

**Suppository:**

A bullet-like capsule of a drug preparation which is inserted into the body through the rectum. This means the drug acts directly on the affected area.

**Total colectomy (proctocolectomy):**

The surgical removal of the colon and the rectum.

Sources of Information

[www.nacc.org.uk](http://www.nacc.org.uk) (the National Association for Colitis and Crohn's Disease)

[www.ibdstandards.org.uk](http://www.ibdstandards.org.uk)

[www.ccfa.org](http://www.ccfa.org) (Crohn's and Colitis Foundation of America)

Appendix B:

Advertisement Poster

# VOLUNTEERS WANTED

To Help with a PhD Study

People with:

**Type 1 Diabetes,  
Ulcerative Colitis,  
Crohn's Disease**

People **aged 18-29**, who have either Type 1 diabetes Ulcerative Colitis, or Crohn's Disease are wanted to help with a PhD study in the Health Communication Research Centre, at Cardiff University. Volunteers will be given the opportunity to talk about their personal experiences of their condition in a **one-off conversation**, in a private, informal setting. This will be arranged at a **time and place convenient to them**.

If you are interested in taking part and would like further information, please contact **Ben Saunders** either by telephone on **\*\*\*\*\***, email at **SaundersBM@Cardiff.ac.uk**, or by post at the following address:

**Health Communication Research Centre  
Centre for Language & Communication  
Cardiff School of English, Communication & Philosophy  
Cardiff University  
Humanities Building  
Colum Drive  
Cardiff CF10 3EU (UK)  
Tel: +44 (0)29 2087 4243**

Appendix C:

Respondent Consent Form



## CONSENT FORM

**Ben Saunders**  
Doctoral Researcher  
Health Communication Research Centre  
Centre for Language & Communication  
School of English, Communication & Philosophy  
Cardiff University  
Humanities Building, Colum Drive  
Cardiff CF10 3EU

**Title of Thesis:**  
**Young Adults' Experiences of Chronic Illness in Relation to Managing Lifestyle Issues (working title)**

I am requesting your consent to participate in a one-on-one conversation about your personal experiences of illness. This will form part of my PhD research being carried out in the Health Communication Research Centre, Cardiff University.

During this conversation I alone will be present, but the conversation will be audio-recorded, and the conversation, or sections of it, will later be transcribed and analysed. The transcribed data will also be presented in my final thesis, and possibly included in future publications and presentations at academic conferences. You will remain anonymous. Your name will be changed and any other details which might enable participant identification will also be changed. Any other persons mentioned by you during the conversation will also be anonymised.

Your participation in this research is voluntary. You may withdraw from the research at any time for any reason. If for any reason you feel upset or uncomfortable during the conversation the recorder will be stopped. Any part of the recording that you do not wish to be used in the research will be discarded.

After completion of the study, a summary of the findings will be sent to you, which will allow you an insight into the experiences of others who have the same condition as you.

Please make sure you have read the information sheet given to you along with this form before giving your consent. If you have any questions or queries, please do not hesitate to contact me either by phone on \*\*\*\*\*, or by email, SaundersBM@cardiff.ac.uk.

If you agree, please sign below:

I hereby give my consent to being recorded, and for the anonymised data to be analysed as part of a PhD research project:

Signature.....

Name.....

Date.....

Appendix D:

Advertisement in Student Newspaper

Letters' page: **Gair Rhydd** (Cardiff University's Independent Student Newspaper)

Printed on: 08.10.07

### **VOLUNTEERS WANTED TO HELP WITH A PhD STUDY**

Hi,

I'm a 1<sup>st</sup> year PhD student in the Health Communication Research Centre, Cardiff University. I'm looking for people **aged 18-29**, who have either **Type 1 diabetes, Ulcerative Colitis, or Crohn's Disease** to help with my study. Volunteers will be given the opportunity to talk about their personal experiences of their condition in a **one-off conversation**, in a private, informal setting. This will be arranged at a **time and place convenient to them**.

If you are interested in taking part and would like further information, please contact **Ben Saunders** either by telephone on \*\*\*\*\*, email at **SaundersBM@Cardiff.ac.uk**, or by post at the following address:

Health Communication Research Centre  
Centre for Language & Communication  
Cardiff School of English, Communication & Philosophy  
Cardiff University  
Humanities Building  
Colum Drive  
Cardiff CF10 3EU (UK)  
Tel: +44 (0)29 2087 4243

Appendix E:

Respondent Information Sheet

## INFORMATION SHEET (S)

**Ben Saunders**

Doctoral Researcher

Health Communication Research Centre

Centre for Language & Communication

School of English, Communication & Philosophy

Cardiff University

Humanities Building

Colum Drive

Cardiff CF10 3EU

**Title of Thesis:**

Young Adults' Experiences of Chronic Illness in Relation to Managing Lifestyle Issues (working title)

Thank you for expressing an interest in helping with this study. Please firstly read this information sheet and then the consent form that I have sent you along with it.

I am a PhD student in the Health Communication Research Centre, Cardiff University. I am carrying out research into young adults' experiences of chronic illness, specifically looking at the lifestyle management issues that result from their illness. I plan to talk to young adults aged 18-29 who have either Type 1 diabetes, Ulcerative Colitis, or Crohn's disease, about their experiences of illness.

If you agree to help with this study, this will only be a one-off conversation, lasting approximately 45 to 60 minutes. It will be informal, and will take place at a time and location convenient to you, between January-July 08. With your permission (see consent form), the conversation will be audio-recorded, and parts of it, suitably anonymised, will later be transcribed and included in my thesis.

Please find attached an additional information sheet, which discusses some of the lifestyle-management issues that can arise from your condition, as well as an extract from an interview with a young adult with the same condition as you, taken from the Crohn's and Colitis Foundation of America website.<sup>26</sup>

Please read the consent form, and if you would like to help with the study please sign it and contact me to make further arrangements. I can be reached by phone on \*\*\*\*\*, by email, SaundersBM@cardiff.ac.uk, or at the address given at the top of this sheet.

Many Thanks,

Ben

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<sup>26</sup> The information sheets sent to those with the respective conditions differed here. For those with T1DM, the source of this extract was [www.dipex.org.uk](http://www.dipex.org.uk) (since renamed [www.healthtalkonline.com](http://www.healthtalkonline.com)).

## Appendix F:

### Additional Information Sheets sent to Respondents

**“Students with IBD: a guide for students going to university or college”**

**“Employment and IBD: a guide for employees”.**

See: [www.nacc.org.uk](http://www.nacc.org.uk).

**“Travelling with Type 1 Diabetes: Things to check before you go”.**

**“Type 1 Diabetes and Alcohol: Hypoglycaemia”.**

See: [www.diabetes.org.uk](http://www.diabetes.org.uk)

## Appendix G:

### Online Interview Extracts sent to Respondents

**Pages 343-345: Interview Extract taken from [www.ccfa.org](http://www.ccfa.org). Sent to IBD-respondents:**

**See: <http://www.ccfa.org/living/patientstories/shiraglogower>**

**Page 346: Interview Extract taken from [www.healthtalkonline.org](http://www.healthtalkonline.org). Sent to T1DM-respondents:**

**See: [http://www.youthhealthtalk.org/Diabetes\\_type\\_1\\_in\\_young\\_people/Topic/1526](http://www.youthhealthtalk.org/Diabetes_type_1_in_young_people/Topic/1526)**

Appendix H:

Interview Questions



## T1DM Interview Questions:

1. What is your age, and how long have you had diabetes?
2. How did you feel emotionally when you were first diagnosed with diabetes?
3. Do you feel as though diabetes plays a big role in your life, and how do you view it as fitting into your overall identity as a person?
4. Do you feel in control of your diabetes, and are you able to fit it around your current lifestyle, or do you feel that it controls what you are able to do?
5. How do you feel it impacts on your leisure activities, for instance social activities or physical sporting activities?
6. Does your condition impact upon social or romantic relationships in any way?
7. Do you find friends and family to be supportive in relation to your condition, and do they help you in any way in managing it?
8. How does diabetes impact on the food you eat? Do you feel restricted in any way in what you can eat, and if so does this bother you?
9. Does your diabetes have any impact on your consumption of alcohol?
10. Does it cause you any issues when travelling abroad, or when away from home?
11. Have you ever had any experience of hypo- or hyper-glycaemia? How do you feel about these experiences, or the possibility of experiencing these in the future?
12. Do the management issues surrounding food and exercise have any impact on your body appearance/body image?
13. How do you feel about injecting insulin on a daily basis?
14. Are you concerned about possible future health complications associated with diabetes, and does this affect your current lifestyle choices?
15. Are many other people aware of your diabetes?
16. Are you happy to disclose your diabetes to others, or would you choose to conceal it in any contexts?
17. If you had to rate on a 1-10 scale how large a role diabetes plays in your life, how would you rate it? – with 10 being a very large role, and 1 being a very minor role.

18. Would you most likely characterise the role of diabetes within your life as an **'interruption'** – (that is a disruption, which perhaps causes some periods of illness, but these are followed by recovery, and the condition only impinges on some areas of your life); an **'intrusion'** – (causes management issues in several areas of life, which demand continued attention, allotted time and forced accommodation); or do you view yourself as being **'immersed'** within your condition – (the requirements of illness come first and define your pursuits, with your condition affecting every aspect of your life)? – or do none of these apply?
19. Do you make much use of information or advice on the internet or elsewhere about dealing with the lifestyle issues brought about by diabetes?
  - a. If no – are you aware of where to access such information?
  - b. If yes – do you feel that this information/advice helps you in any way in managing your condition?
20. If you had a chance to look at the information/advice sheets I sent you prior to the interview, how useful did you find these? Do you feel that the advice given is useful? Does it correlate with your own experiences of managing your condition?
21. Do you have anything else to add or anything you would like to ask?

## IBD Interview Questions:

1. What is your age, and when were you diagnosed with IBD?
2. Are you currently taking any medication for your condition?
3. How did you feel emotionally when you were first diagnosed with IBD?
4. Do you feel as though IBD plays a large role in your life, and how do you view it as fitting into your overall identity as a person?
5. Do you feel in control of your condition, and are you able to fit it around your current lifestyle, or do you feel that it sometimes controls what you are able to do?
6. How do you feel it impacts on your leisure activities, for instance social activities or physical sporting activities?
7. Does your IBD impact upon social or romantic relationships in any way?
8. Do you find friends and family to be supportive in relation to your condition, and do they help you in any way in managing it?
9. How does IBD impact on the food you eat? Do you feel restricted in any way in what you can eat, and if so does this bother you?
10. Does your IBD have any impact on your consumption of alcohol?
11. Does it cause you any issues when travelling abroad, or when away from home?
12. When away from home, do you worry about toilet access, and does this affect your leisure activities in any way?
13. Do you suffer from pain related to your IBD, and does this affect what you are able to do in your daily life?
14. How do you feel about taking tablets daily?
15. Do you suffer from any side-effects of IBD medication? If so, how does this make you feel? Does this affect your lifestyle in any way?
16. Do you feel any uncertainty about the possibility of future disease flare-ups, and when they might occur? Does this affect your short-term or long-term future planning?
17. How do you feel about possible future health issues related to your condition?

18. Are many other people aware of your IBD?
19. Are you happy to disclose your IBD to others, or would you choose to conceal it in any contexts?
20. If you had to rate on a 1-10 scale how large a role IBD plays in your life how would you rate it? – With 10 being a very large role, and 1 being a very minor role.
21. Would you more likely characterise the role that IBD has within your life as an **‘interruption’** – (that is a disruption, which perhaps causes some periods of illness, but these are followed by recovery, and the condition only impinges on some areas of your life); an **‘intrusion’** – (causes management issues in several areas of life, which demand continued attention, allotted time and forced accommodation); or do you view yourself as being **‘immersed’** within your condition – (the requirements of illness come first and define your pursuits, with your condition affecting every aspect of your life)? – or do none of these apply?
22. Do you make much use of information or advice on the internet or elsewhere about dealing with the lifestyle issues brought about IBD?
  - a. If no – are you aware of where to access such information?
  - b. If yes – do you feel that this information/advice helps you in any way in managing your condition?
23. If you had a chance to look at the information/advice sheets I sent to you previously, how useful did you find these? Do you feel that the advice given is useful? Does it correlate with your own experiences of managing your condition?
27. Do you have anything else to add or anything you would like to ask?

## Appendix I:

### Transcription Conventions

## Transcription Conventions

(.) untimed short pause

(2.0) pause timed in seconds

(quietly) informal commentary on style or context of following utterance(s)

? indicates questioning function (not grammatical interrogative)

[ overlapping speech

[ ] entirely overlapped speech

= 'latched' utterances (following each other without perceptible pause)

**underlining** unusually heavy emphasis

< > quiet speech

**CAPS** loud speech

(( )) indecipherable data: best guess

(laughs) non-lexical, phonological features

Adapted from:

O'Connell, D. C. & Kowal, S. (1995). Transcription Systems for Spoken Discourse. In J. Verschuren, J. O. Ostman & J. Blommaert (eds.) *Handbook of Pragmatics*, 646–656. Amsterdam: John Benjamins.

Appendix J:

Macro- and Micro-Themes Identified During Preliminary  
Analysis

## Macro- and Micro-Themes Identified During Preliminary Analysis

Displayed below is the full list of macro- and micro-themes identified within the data-corpus, along with a description of the content of the talk coded within each theme. As explained in Chapter 5 (5.3.1), macro-themes were identified as being larger, conceptually-based themes, into which several smaller, micro-themes can be categorised.

### ***Self*** (macro theme)

Extracts coded within this theme deal with issues regarding how the young adults represent the role of their condition within their lives, and within their 'self-concept' (Charmaz, 1983). Within this macro-theme, several micro-themes were identified: *Changes in self-perception*; *Acceptance*; *Concerns about the future*; *Diagnosis*; *Positive effects*; *Giving back*; and *Confidence*.

#### ***Changes in self-perception:***

This theme includes extracts in which the respondents discuss any temporal changes, both positive and negative, that their condition has brought about in the way they view themselves and their own 'personal-identity' (Cheshire and Ziebland, 2005: 23).

#### ***Acceptance:***

Respondents discuss whether they are generally accepting of their condition, and the role it plays within their lives, or whether they feel that they struggle to accept certain factors surrounding their condition, or certain restrictions it imposes upon them. This theme includes any discussion of the stages that respondents may have gone through in arriving at a greater or lesser degree of acceptance of their condition. It includes not only discussion of acceptance in terms of the effect of the respective conditions on the respondents' lives in the present time, but also acceptance of the permanent, chronic nature of their illness.

#### ***Concerns about the future:***

Respondents discuss their (lack of) fear regarding their future health related to their condition, and the impact that their condition may have upon their lifestyle in the future.

#### ***Diagnosis:***

Respondents discuss the circumstances surrounding their diagnosis, as well as their emotional reaction to their diagnosis, and the reaction of family and friends.



***Positive effects:***

This theme includes extracts in which the respondents discuss any beneficial effects that their condition has had on their lives.

***Giving back:***

This theme relates to *Positive effects*, above, however, extracts coded within this theme are those in which respondents specifically discuss anything they have done to help others with the same condition as them, or others who have another chronic illness, i.e., participating in events, supporting charities, or sharing their experiences with others.

***Confidence:***

This theme includes extracts in which respondents discuss any effects that their condition may have had on their own self-confidence.

***Other-orientation*** (macro-theme)

Extracts coded within this theme are those in which the respondents discuss how they feel others perceive their condition, as well as how others act based on these perceptions. Also coded within this theme are extracts in which the respondents compare themselves to others – both those with the same condition, and others who do not have the same condition. Several micro-themes were identified within this macro-theme: *Self-consciousness/stigma*; *Disclosure*; *Body image*; *Social relationships*; *Family*; *Romantic relationships*; and *Normalcy*.

***Self-consciousness/stigma:***

Includes extracts in which the respondents discuss any feelings of self-consciousness or embarrassment about their condition and its symptoms or side-effects, or any extracts in which they discuss feeling stigmatized by others in some way. This includes stigma associated with them having a chronic condition, or stigma as a result of the specific signs and symptoms associated with their condition.

***Disclosure:***

Includes extracts in which the respondents discuss their disclosure of illness-information, including to whom they choose to disclose, and in which contexts, as well as how much information they choose to give others.

***Body Image:***

Extracts in which the respondents discuss any factors associated with their condition that may affect their own body image, such as the side-effects of medication. The reason for this theme being included within the macro-theme 'Other-orientation', as opposed to being included within 'Self', is that despite the fact that the extracts deal primarily with the respondents' *own* views about their body-image, their concerns centre on how they appear on the outside to others, and how their bodily appearance may affect the perceptions that others form about them.

***Social relationships (friends and peers):***

Respondents discuss the impact of their condition upon their relationships with friends and peers, and whether they feel that friends see them differently, or treat them differently, when compared with others who do not have the condition, or with their pre-illness selves.

***Family:***

Extracts coded within this theme deal with similar issues to those coded under 'social relationships', but this time in relation to the impact that the respondent's condition has upon his/her relationships with family members.

***Romantic relationships:***

Includes any extracts where respondents discuss the (lack of) impact of their condition on their romantic relationships. This includes whether they report that romantic partners are understanding and accepting with regard to their condition, or whether their condition presents any problems or issues regarding such relationships.

***Normalcy:***

Respondents explicitly discuss their experiences in relation to what they represent as being 'normal', often through comparing themselves with others who do not have the same condition. This could be considered to be a macro-theme; however, I decided to include it under the umbrella of 'Other-orientation', as issues surrounding normalcy appear to be most commonly constructed either in making comparisons with others, or when respondents are discussing others' perceptions of them.

### ***Control*** (macro-theme)

Coded within this theme are extracts dealing with issues regarding the respondents' control over their condition, in terms of their control over symptoms and treatments, as well as their control over their lifestyle activities. This includes whether the respondents report that the condition impedes upon or restricts their lifestyle activities, or whether they report being able to participate in desired lifestyle activities in spite of their condition. Several micro-themes were identified in relation to this theme: *Alcohol*; *Food-consumption*; *Social Activities*; *Travelling*; *Exercise*; *Employment/University*; *Disruption*; *Missing out*; and *Isolation*

#### ***Alcohol:***

Respondents discuss how factors associated with their condition may affect their choices regarding alcohol-consumption, or discuss the effect that alcohol-consumption has on their T1DM- or IBD-related health. This includes their physical and emotional responses to such issues.

#### ***Food-consumption:***

Respondents discuss issues surrounding diet and food-consumption that have arisen as a result of their condition. This includes possible restrictions on what they are able to eat, and their emotional reaction to this.

#### ***Social Activities:***

Includes extracts in which the respondents discuss how their condition may impact upon their ability to participate in desired social activities. This theme is closely related to the themes of 'Alcohol' and 'Food-consumption', given the prominence of food and alcohol in many social activities. There is, therefore, at times, considerable overlap regarding these particular themes.

#### ***Travelling:***

Respondents discuss how their condition may affect their ability or willingness to travel away from home, including going on holiday. This includes ways in which the respondents feel that their condition restricts them when travelling, or extra considerations that they must make when away from home.

#### ***Exercise:***

Respondents discuss issues related to their condition surrounding their participation in sporting activities or exercise. This includes any restrictions that the respondents report that their condition places upon them with regard to such activities.

***Employment/University:***

Includes extracts in which respondents discuss how their condition may impact upon them in a work context, for instance, whether their condition affects their ability to carry out work tasks, or affects their university studies. This also includes any problems they have had in obtaining employment as a result of their condition.

***Disruption:***

Respondents discuss any major disruption in their lives caused by their condition, such as bouts of illness, or surgery forcing them to rearrange life plans or to take long periods of leave from work or university. This theme can be seen to relate to several other micro-themes within the macro-theme of 'Control'.

***Missing out:***

Respondents discuss aspects of life-experience that they feel they have missed out on as a result of their condition. For instance, they may have been prevented from moving away from home, or have been restricted in career options as a result of illness. Respondents may feel resentment or frustration at having missed out on these experiences.

***Isolation:***

Respondents discuss any feelings of isolation resulting from their condition. This may be psychological isolation, in terms of feeling that others do not understand what they are going through. Alternatively, this could be isolation in terms of them not being able to go out, or to participate in social activities due to illness, therefore they are physically isolated from others.

***Medication and side-effects:***

Respondents discuss any medication they are presently taking, or have taken previously, to treat their condition, and any side-effects of this medication. This includes the discussion of how they feel about taking medication, and the effects that certain side-effects have on their lifestyle activities.

***Information and Advice:***

Respondents discuss any sources they use to gain information or advice about their condition. This could be medical professionals, the internet, television, or other people with the same condition. This could relate to the biomedical aspects of their condition, i.e., new treatments/procedures, or could be to do with managing the lifestyle issues arising from their condition.

***Medical Care:***

Respondents discuss any interactions with medical professionals, including doctors' appointments and hospital stays/surgical procedures.

***Symptoms/Pain:***

Respondents discuss any symptoms that may arise from their condition, including pain, and how these symptoms impact on the daily lifestyle activities that they engage in.

***Childhood:***

Respondents discuss their experiences of their condition prior to adolescence.

***Adolescence:***

Respondents discuss their experiences of their condition during adolescence.

***Injecting Insulin:***

This theme is specific to T1DM-respondents. Extracts coded under this theme include any discussion of the practical or emotional issues related to the physical act of injecting insulin on a daily basis.

Appendix L:

Table Displaying the Frequency of Words Coded within each Theme throughout the Data-Corpus

## Code Frequency Table

The table below displays, in the left hand column, the codes created in relation to the data (see Appendix J for full description of these codes). The codes identified as relating to macro-themes are labelled as such. These macro-themes are colour-coded along with the micro-themes relating to each. The macro-themes will form the basis for detailed discursive analysis (Chapters 6-9). As explained in Chapter 5 (5.3.1), macro-themes were identified as being larger, conceptually-based themes, into which several smaller, micro-themes can be categorised.

The right hand column displays the frequency of *words* coded within each theme across the entire data-corpus, *not* simply the frequency of code-occurrence.

<b>Themes</b>	<b>Frequency</b> (number of words coded within each theme, throughout entire data-corpus)
<b>SELF</b> (macro-theme)	23, 933
Changes in self-perception	3, 440
Concerns about the future	15, 646
Acceptance	8, 208
Diagnosis	12, 747
Giving back	1, 334
Positive Effects	2, 496
<b>OTHER-ORIENTATION</b> (macro-theme)	22, 138
Self-consciousness/stigma	15, 918
Disclosure	19, 297
Body Image	10, 298
Social Relationships (friends and peers)	9, 617
Romantic Relationships	7, 277
Family	5, 805
Normalcy	6, 309
<b>CONTROL</b> (macro-theme)	40, 706
Alcohol	17, 655
Food-consumption	16, 655
Social Activities	4, 778
Travelling	13, 657
Exercise	8, 450
Employment/University	10, 372
Disruption	7, 058

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Missing out	1,891
Isolation	936
Medication and side-effects	19, 616
Information and advice	25, 886
Medical care	14, 306
Adolescence	1, 457
Childhood	2, 214
Symptoms/pain	27, 501
Injecting insulin (relevant only to T1DM-respondents)	7, 227

From this table it can be seen that, in a few cases, themes which have a high frequency of occurrence have not been identified as being predominant themes, i.e., *Medication and side-effects*, *Information and advice*, *Medical care*, and *Symptoms and Pain*. I will briefly explain the reasons for these omissions.

*Medication and side-effects* and *Symptoms and Pain* were not selected for sole focus because, despite being included as themes in their own right during the coding process, it was in fact found that issues relating to these two themes were usually discussed in relation to other themes, rather than exclusively. For instance, pain was often discussed in terms of how this may affect the respondent's social or work activities, thus it was unnecessary to focus specifically upon these themes. These themes will, however, be shown to be very relevant at various places during the analysis.

The high frequency of the theme *Medical care* was commonly as a result of lengthy narratives being produced about isolated experiences regarding the respondents' admission to hospital, or particular interactions in the clinical setting. This often involved the respondents talking about their initial diagnosis, as opposed to this being a frequently recurring theme within interviews. Discussion of *Information and Advice* often included respondents talking about the information and advice sheets I had sent to them prior to the interviews, as opposed to their *own* use of information and advice about their condition. Therefore, whilst there was often interesting discussion surrounding this theme, the theme did not appear to be salient within the respondents' own subjective experiences of their condition.

Whilst these themes were not found to be salient issues vis-à-vis the respondents' reported-experiences, they could nonetheless form the focus of future research within this area.