

Accounting for ME/Chronic Fatigue Syndrome
and early stroke:

A discourse analysis of identity and coping

Jennifer Marjory Ferguson Guise

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ABSTRACT

The aim of this study was to explore the experiences of people with chronic illness, specifically ME (Myalgic Encephalomyelitis), also known as CFS (Chronic Fatigue Syndrome), and stroke at a young age. It begins with an analysis of the meanings of these conditions. The study then focuses on two key issues highlighted by a review of the literature on chronic illness. These are, the effects it can have on *identity*, and the ways in which sufferers *cope*. Much of the theory suggests some sort of commonality of experience among people with different long-term illnesses. A further aim of this study was, therefore, to examine this assumption.

Current theory largely uses medical, psychiatric or cognitive models to describe the effects of chronic illness. This study adopts a social constructionist perspective, a fundamental tenet of which is that meanings are made in interaction. Thus, chronic illness, identity and coping are not static, measurable phenomena. Rather, they are treated as something that people *do* in talk (Antaki & Widdicombe, 1998). Discourse analysis, with its focus on the rhetorical function of language, provides the means with which to examine this. There is very little published research using this perspective or this methodology to examine either ME/CFS or stroke.

Participants were recruited via self-help groups. 49 people with ME and 10 stroke sufferers were interviewed via email. Four face-to-face focus groups were also held, comprising a further 7 ME sufferers, and 12 people who had had a stroke (with 5 of their carers).

Analysis focused on how sufferers constructed their condition, the effects it had on identity, and the ways in which they coped. Both conditions were constructed as serious, and poorly understood. However, only ME sufferers constructed their illness as specifically *not* psychological or psychiatric. People in both groups oriented to the problematic nature of sufferers' identity that arose from their accountability for becoming ill, and for their inactivity. ME and stroke sufferers oriented to issues of accountability for the ways in which they coped. People with ME emphasised their previously high levels of activity, and their mental health, and thus oriented to specific aspects of their construction of this condition. There was, therefore, some commonality of experience among the two groups, in that their illness was associated with stigma. In addition, constructions of identity and coping drew on particular features of participants' own illness constructions. The study ends with a discussion of practical implications for sufferers, health professionals, carers and researchers.

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DECLARATION

I certify that I am entirely responsible for the work submitted in this thesis, that the original work is my own except as specified in acknowledgements or in footnotes, and that neither the thesis nor the original work contained therein has been submitted for any other degree or professional qualification.

Jennifer M F Guise

*This thesis is dedicated to the memory of my parents,
Betty Ferguson (née Fisher)
and
David Addison Ferguson,
who managed to make anything seem possible*

CONTENTS

Abstract.....	ii
Acknowledgements.....	iv
Declaration.....	v
INTRODUCTION.....	1
OVERVIEW.....	5
CHAPTER 1: LITERATURE REVIEW.....	7
1. Literature review - strategies	8
2:1 Literature review - introduction.	10
2:2 Literature review - chronic illness.....	10
2:2:1 Psychological perspectives on chronic illness.....	11
The cognitive view.....	11
The experiential view.....	16
2:2:2 The biopsychosocial perspective on chronic illness.....	20
2:2:3 Sociological perspectives on chronic illness.....	22
2:3 Literature review - ME.....	26
2:3:1 Definitions of ME.....	26
The CDC definition (1988)	30
The Oxford definition (1991).....	30
The revised CDC definition (1992).....	31
The international definition (1994).....	31
The physical versus psychological debate.....	32
2:3:2 History of ME.....	34
2:3:3 Treatment of ME.....	36
2:4 Literature review - stroke.....	41
2:4:1 Definitions of stroke.....	41
2:4:2 History of stroke.....	46
2:4:3 Treatment of stroke.....	48
3. A social constructionist perspective on chronic illness.....	51
3:1 Definitions of chronic illness-traditional psychological and social constructionist views.....	56
3:2 Chronic illness and identity-traditional psychological and social constructionist views.....	59
3:3 Chronic illness and coping-traditional psychological and social constructionist views.....	65
4. Research questions.....	67
CHAPTER 2: METHODS.....	69
1. Recruitment.....	70
2. Data collection.....	71
2:1 Use of the internet.....	72
3. Schedules of questions.....	77
4. Participants.....	78
5. Analysis.....	78
CHAPTER 3: SUFFERERS' CONSTRUCTIONS OF ME.....	91
1. Constructions of ME as a serious illness.....	93
2. Constructions of ME as an enigmatic illness.....	104

3.	Constructions of ME as 'not psychological'	106
4.	Summary.....	109
5.	Discussion.....	110
CHAPTER 4: SUFFERERS' CONSTRUCTIONS OF STROKE.....		112
1.	Orienting to the question.....	114
2.	Constructions of stroke in terms of loss of ability.....	122
3.	Constructions of stroke as unpredictable.....	127
4.	Summary.....	132
5.	Discussion.....	132
CHAPTER 5: ACCOUNTABILITY AND STROKE.....		134
1.	Accounting for having had a stroke.....	135
1:1	Constructions of the possible causes of stroke.....	136
1:2	Constructions of the causes of stroke in sufferer-carer interactions.....	142
1:3	Internet participants' constructions of the possible causes of stroke.....	150
2.	Accounting for level of disability.....	151
3.	Summary.....	156
4.	Discussion.....	157
CHAPTER 6: ME SUFFERERS' CONSTRUCTIONS OF IDENTITY.....		159
1.	Effects of ME as a change for the worse.....	160
2.	'Positive' and 'negative' categorisations of ME.....	166
3.	Summary.....	171
4.	Discussion.....	172
CHAPTER 7: STROKE SUFFERERS' CONSTRUCTIONS OF IDENTITY....		174
1.	The changed outlook of stroke sufferers.....	175
2.	Identity work.....	177
3.	The stigma of stroke.....	179
4.	The problem of change.....	183
5.	Summary.....	186
6.	Discussion.....	187
CHAPTER 8: SUFFERERS' CONSTRUCTIONS OF RESPONSES TO ME.....		189
1.	Constructions of initial response to ME.....	190
2.	Constructions of resting as an appropriate response to ME.....	195
3.	Constructions of sufferers as active in their attempts to get better.....	202
4.	Constructions of others' responses to ME.....	205
5.	Summary.....	208
6.	Discussion.....	208
CHAPTER 9: SUFFERERS' CONSTRUCTIONS OF RESPONSES TO STROKE.....		210
1.	Constructions of responses to stroke.....	211
2.	Responsibility for recovery.....	218
3.	Internet participants' avoidance of accountability.....	223
4.	Summary.....	224
5.	Discussion.....	224

CHAPTER 10: CONCLUSIONS.....	227
1. Summary of findings.....	228
1:1 Accountability.....	228
1:2 Identity work.....	229
1:3 The interconnectedness of illness construction, identity and coping.....	231
2. Comparison - focus group and internet data.....	232
3. Evaluation of findings.....	236
4. Implications for theory.....	239
4:1 The individual as an independent, cognitive entity.....	239
4:2 Categorisations of mind and body.....	240
5. Implications for practice.....	242
6. Summary.....	245
REFERENCES.....	246
APPENDICES.....	258

INTRODUCTION

The aim of this thesis is to explore the experiences of ME and early stroke from the perspective of the sufferer. In particular, it examines the ways in which sufferers talk or write about ME and stroke, the effects these conditions have on identity, and ways in which people might cope with them. A further issue of interest examined here is the extent to which there is a commonality of experience among people who suffer from different long-term illnesses. Traditional research into chronic illness has largely used medical, psychiatric or cognitive models. This study adopts a social constructionist perspective and uses a discourse analytic methodology.

ME and stroke are examined for two main reasons. The first is that in the chronic illness literature, there is relatively little research into the ways in which sufferers experience these particular conditions. The second reason relates to their similarities and differences. This can be demonstrated by a brief description of the ways in which these conditions have been defined:

ME is the preferred term among UK sufferers for an illness that is characterised particularly by extreme and debilitating fatigue, along with other symptoms, such as sore throat, headaches, muscle pain and problems with concentration. The effects of ME vary in severity from day to day, and between ME sufferers. Prevalence in Britain has been estimated at between 110,000 and 150,000 per annum (Cooper, 1997; Levine, 1997). More women than men have been reported to suffer from ME, although some research suggests that this imbalance may be a reflection of medical

referral patterns rather than actual morbidity levels (Lawrie & Pelosi, 1995). So far, no biological cause has been found, and there is no established medical treatment. There is some debate about the role that psychological or psychiatric factors may play in this condition. This has implications for the extent to which ME is viewed as medically 'legitimate'. The most commonly reported risk factor is the co-existence of either physical or psychological stress (Levine, Wessely, Hotoph & Sharpe, 1999).

Stroke denotes the sudden death of brain tissue caused by disruption to the brain's supply of blood. The initial stage can involve anything from mild confusion to complete loss of consciousness for a number of days. Those who survive stroke - 35-40% die within the first month - may be left with moderate to severe neurological impairments that can affect speech, sight, movement and memory. For many sufferers, stroke results in overwhelming fatigue and/or depression. There is very little in the way of medical treatment for stroke. The emphasis instead is on rehabilitation, with the aim of regaining functional competence by means of repetitive exercise. Prevalence in Britain is around 110,000 sufferers per annum. The rate of recurrence is around 28,000 per annum (Ellis-Hill, Payne, & Ward, 2000). Although it tends to affect older people, 25% of stroke sufferers are under the age of 65 (Pimm, 1997). Brain scans show that in 80% of cases, stroke is caused by the partial or complete blockage of an artery leading into the brain, referred to as 'ischaemic stroke'. The remainder are 'haemorrhagic', caused by a pooling of blood around the brain that causes pressure and subsequent injury. The *causes* of such disruptions to the blood supply are not clearly understood, although a number of risk factors have been identified. Stroke is more likely to happen to people over the age of 65, who smoke, take little exercise, and have raised blood pressure (Pound, Bury, & Ebrahim, 1997).

Stroke and ME have many features in common. Their prevalence in the population is similar. Both are chronic conditions, the causes of which are unclear. The impact on

the sufferer varies from one individual to another. Fatigue and depression are potentially significant factors in each illness. Symptoms and effects are not necessarily visible to the outside observer. There is no medical or surgical treatment, and prognosis is uncertain. The effects can be life-restricting and socially isolating.

ME and stroke also differ in two important respects. The first is that stroke, unlike ME, is potentially life-threatening. It constitutes the third highest cause of death in Britain (Ellis-Hill *et al.*, 2000). The second is that ME's status as a medical illness is less secure than stroke. Whereas the mechanics of stroke can be explained, and verified using scanning techniques, the origins of ME are not clearly understood. This has led some researchers to question the physical basis of ME, and to consider the possible role of psychological factors in this condition.

Thus, ME and stroke can be considered similar in many respects, and at the same time there are significant differences between these two conditions. Much of the research suggests that there is a commonality of experience among people with different chronic complaints. That is, the long-term nature of illness is the important factor, rather than the condition *per se*. One of the objectives of this thesis is to examine such an assumption. ME and stroke are sufficiently similar to explore the possibility of common ground. However, they are sufficiently diverse to explore any particular influence that might arise from the nature of the illness suffered.

Two aspects of sufferers' experience of chronic illness examined here are its impact on identity, and the ways in which people cope. Research suggests that a significant problem for people with ME is that others may not consider the illness to be legitimate (Clarke, 2000; Cohn, 1999; Ware, 1992; Ware, 1999; Ware & Kleinman, 1992). Thus, sufferers may experience a degree of stigma, and a negative influence on identity. For people who have had a stroke, a particular difficulty arises from the fact

that the responsibility for rehabilitation is on the patient rather than the clinician (Kaufman, 1988; Pound *et al.*, 1997). This raises issues of accountability, which again can affect the sufferer's identity.

Coping with chronic illness has been conceptualised differently according to the perspective used. Cognitive psychologists emphasise the processes that take place within the individual, and describe these in terms of 'coping strategies' (Leventhal & Benyamini, 1997; Moos & Schaefer, 1984; Shontz, 1975; Taylor, 1983). Other researchers have suggested that adjustment to chronic illness requires the sufferer to modify his or her biography, or 'life narrative', in order to make sense of what has happened (Bury, 1982; Corbin & Strauss, 1985; Williams, 1984). Dealing with chronic illness is not, however, simply done in isolation within the mind of each individual sufferer. It involves living with the condition over a long period of time, within a social and cultural framework. Therefore, the relationship of the sufferer to other people is crucial in our understanding of the effects of chronic illness on the sufferer (Goffman, 1963; Herzlich, 1973; Herzlich & Pierret, 1987; Radley, 1994). Chronic illness has, broadly, been conceptualised as having a diminishing effect on the sufferer's sense of self, either because of negative social reactions, or an increased dependence on others (Kleinman, 1988; Murphy, 1987; Zola, 1982). An important aspect of this is the individual's relationship with his or her body, which may come to be regarded as an object beyond control .

In this thesis, I explore the ways in which sufferers describe what it is like to live with ME, or with stroke. I work from a social constructionist perspective, using a form of discourse analysis that also draws on techniques of conversation analysis, to explore the ways in which people construct their illness, how it affects their sense of self, and how they adjust to their condition.

OVERVIEW

The study begins with a literature review, in chapter 1. Research into chronic illness is examined from three broad perspectives - psychological, biopsychosocial and sociological. There follows a review of the literature on ME and on stroke in particular. The social constructionist perspective on chronic illness is then discussed. This provides a basis for a subsequent critique of the traditional psychological perspectives on chronic illness with regard to the three key themes - definitions of illness, identity, and coping. The chapter ends with a summary of the particular research questions addressed in this study.

Chapter 2 describes the methods used in this study. This includes information on recruitment of participants, data collection and analysis.

Analysis of data can be found in chapters 3-9. Chapter 3 deals with sufferers' constructions of ME and chapter 4 with sufferers' constructions of stroke. In chapter 5, I discuss issues of accountability that became apparent in focus group sessions in which both stroke sufferers and carers were present. Chapters 6 and 7 discuss, respectively, ME and stroke sufferers' constructions of identity. An analysis of ways in which sufferers construct coping with ME and stroke respectively can be seen in chapters 8 and 9.

Chapter 10 contains a summary of findings. It therefore recapitulates the ways in which sufferers construct ME and stroke, the effects their illness has on identity and

the ways in which they cope. Comparisons are made between data collected in focus groups and via the internet. There follows an evaluation of findings, and a discussion of implications for theory and practice.

CHAPTER 1

LITERATURE REVIEW

This chapter presents the results of a review of literature in three broad areas. First, the research into chronic illness in general is explored. It is here that we find the theoretical and empirical foundations for approaches which suggest some commonality of experience among those who suffer from different chronic conditions. Second, there is a review of literature on ME. This is followed by a review of literature on stroke.

In the review of chronic illness in general, three research perspectives are discussed. First, the psychological literature was explored. Most of the psychological research into chronic illness takes a traditional approach in which the emphasis is on the internal workings of the sufferer's mind. This thesis takes a social constructionist approach, a fundamental assumption of which is that social processes have a crucial role in how we make meanings. There is, however, very little psychological literature on chronic illness, ME or stroke, from this perspective. The biopsychosocial perspective represents an attempt to encompass a broader view of chronic illness, and this is also discussed. Finally, literature from a sociological perspective is explored for its insights into the potentially social aspects of illness. In general, the literature suggests that chronic illness can affect the sufferer's sense of self, and also his or her relationships with other people, in particular with regard to the moral implications of how people 'cope' with long-lasting conditions.

The review then moves on to the specific conditions examined in this study. It quickly became apparent that a key feature of ME is that this is a contested illness. In order to provide some background to the issues at stake, a review was carried out of the ways in which ME has been described and defined in the medical literature. A similar review was carried out for stroke. This was initially done to provide some consistency of approach across the two conditions. However, it was found that the symptoms of stroke are, similarly, a matter of some debate. This literature is important because of the implications for the ways in which ME and stroke are understood by both sufferers and non-sufferers.

Three themes emerge from this literature review as areas of particular interest. The first is that what it means to suffer ME and stroke are contested, specifically in terms of their causes, symptoms and effects on the sufferer. This has implications for the ways in which these conditions might be treated. The second relates to the effects that chronic conditions can have on the sufferer's sense of self. Third, the way in which people cope with illness, and in particular chronic illness, has moral implications for the sufferer that affect his or her relationships with other people. I will conclude this chapter by discussing each of these themes in turn, and will show how they lead to the research questions that form the basis of this thesis.

Before moving on to a more detailed discussion of the results of this literature review, I will outline the particular strategies used in carrying it out:

1. Literature review - strategies

The effects of illness on the body have historically been conceptualised separately from their personal and social consequences, with the result that these have come to form quite distinct areas of study - respectively, medicine, psychology and sociology. My view was that a broad understanding of the problems of chronic illness in general,

and ME and stroke in particular, would best be gained by exploring the literature from all three perspectives. Since my interest is in the psychological aspects of chronic illness, it was with this literature that I started. An initial review suggested that there were two particular areas of concern for sufferers: impact of chronic illness on identity and how it is that people cope.

I then carried out a full literature search using three databases: the Web of Knowledge (formerly known as the 'Web of Science'), BIDS IBSS and PsycINFO, covering the period from 1st January 1995 - 31st March 2004.

I used the terms 'identity' and 'coping', and synonyms, as follows: 'self'; 'cope'; 'coping'; 'adjust*¹'; 'adapt*'; 'change' and 'changing'. These were combined with the following illness category terms: 'chronic and illness'; 'Myalgic Encephalomyelitis'; 'CFS'; 'Chronic Fatigue Syndrome'; 'CVA'; 'Cerebrovascular accident' and 'stroke'.

I gathered a large number of abstracts, and eliminated those that were not relevant to the subject of this thesis. I then analysed the bibliographies in the remaining abstracts in order to get some idea of the papers and books that were most commonly referenced. I used this, and a reading of the abstracts, to identify those books, chapters and papers to be read in full.

The perspective that I take in this thesis is social constructionist, and so I performed a separate search in which I combined the illness categories, as noted above, with the following terms: 'discourse'; 'construct*' and 'narrative'.

¹ Here, the asterisk is used in truncation to denote the stem used in a word search. In this case, for example, the search terms would therefore include 'adjustment', 'adjusting', 'adjusts' and so on.

Some of my data were collected using the internet, and this led me to carry out a further search in which I tried to find out about the issues that might arise as a result of using this method of data gathering. I combined either 'internet' or 'email' with the illness categories, as noted above, and the following terms: 'psychology and research'; 'health and research'. The results of this review are reported in section 2:1 of chapter 2 which is concerned with the methodology of this research.

2:1 Literature review - introduction

Chronic illness is usually defined as illness that lasts 6 months or more. It is important to note that many of the claims in the literature about 'chronic illness' in general stem from work with specific groups of sufferers. There is therefore an underlying assumption that the extended time span of conditions is, of itself, a feature that draws together the experiences of people with a variety of different ailments. The particular illnesses that are most commonly referred to in the literature are Rheumatoid Arthritis (RA), Chronic Obstructive Pulmonary Disease (COPD), Multiple Sclerosis (MS) and coronary heart disease (CHD). In this thesis, I examine two chronic conditions, with a view to exploring the extent to which sufferers' experiences are similar, and areas in which they might differ. These conditions - ME and early stroke - are also less well represented in the literature.

The review will be in three main sections. I will begin by discussing the literature on chronic illness. I will then review the literature on ME, and finally stroke.

2:2 Literature review - chronic illness

The literature on chronic illness is reviewed from three perspectives. This section begins with a discussion of psychological theory and research. It is followed by a brief examination of the biopsychosocial approach to chronic illness. Finally, there is

a review a body of research which adopts a sociological perspective on the study of long-term illness.

2:2:1 Psychological perspectives on chronic illness

In the psychological literature, chronic illness is conceptualised as something that is dealt with by the mind of the individual, even when implications for the sufferers' relationships with others are acknowledged. This section starts with a description of two types of theory which suggest that adjustment happens to a large extent at the *individual* level. First, there are theories that have emerged from the perspective of cognitive psychology, and which provide general hypotheses and models of the ways in which people think about illness. Second, there are theories in psychology and sociology that have developed from a close study of accounts of individual sufferers, in which the aim is to describe the inner experiences of those with chronic conditions. These theories suggest that chronic illness has some impact on the sufferer's sense of self. At the end of this section, there is a brief discussion of an important criticism of these approaches, which is that they take little account of the social context in which a person is ill.

The cognitive view

Cognitive psychologists have proposed models to explain the ways in which people adapt to illness in the long term. From this standpoint, the effects of chronic illness can be examined in terms of individual *cognitions* and *coping mechanisms*. Thus, Lau (1995) asked participants to describe 'illness', and from this he proposed that we have specific 'illness cognitions' with the following characteristics. In a general sense, illness is seen as an absence of good health. According to Lau, we realise that something is wrong first of all when we feel different from the way we normally feel. We recognise specific symptoms, and can often relate these to particular conditions we already know about. We also have some notion of the usual consequences of different

symptoms or conditions, and of their expected duration, or 'time-line'. Following on from this, after a series of interviews with participants, Leventhal, Benyamini and colleagues (1997) concluded that our illness cognitions provide us with cognitive schemas, which enable us to understand the nature of different conditions. These schemas are said to encapsulate information about illness in five categories, and these categories have inspired a great deal of the subsequent research into chronic illness. They relate to the identity of the illness, its causes, consequences, time-line (expected duration), and finally the potential for the illness to be controlled.

Leventhal and Benyamini (1997) proposed a 'self-regulatory model', in which we are said to deal with the onset of ill-health in three distinct phases. In the first - 'interpretation' - our illness cognitions form cognitive schema, which represent the basis of an intellectual understanding of what is happening. These are mediated by our mood or emotional response. In the second phase, we set about *coping*, and broadly speaking, our strategies here have been categorised by cognitive theorists as either 'approach' or 'avoidance'. Another distinction that has been made is between 'emotion-based', 'appraisal-based' and 'problem-based' coping (Moos & Schaefer, 1984). The third phase involves an *appraisal* of our coping methods. We are said to move from one phase to another until we reach some sort of equilibrium.

Shontz (1975) also suggests that coping with illness is a process that can be broken down into specific stages, and that the best outcome of this process is the development of an ability to face up to the *reality* of the illness situation. Taylor (1983), however, has challenged the notion that we cope better with illness if we are able fully to accept the 'new realities' that it might entail. In Taylor's 'theory of cognitive adaptation', we are said to cope best with threatening events - including illness - when we are able to sustain beneficial *illusions* about our new circumstances. Thus, in a difficult situation, we begin by trying to understand what has happened, and its implications, then we

strive to gain some sense of control or 'mastery'. It is this feeling of control that results in the self-enhancement that constitutes healthy adaptation.

Hagger and Orbell (2003) carried out a meta-analysis of 45 studies in which illness cognitions were correlated with coping strategies. They reported that avoidance and emotion-expressive coping correlated with perceptions of a strong illness identity, a chronic time-line and serious consequences. An example of avoidance coping is the tendency to limp or use some kind of support in order to avoid the adverse consequences of walking on, say, a damaged ankle. While this might be a useful strategy at the initial stage of injury, there comes a point at which saving the ankle is done at the expense of worse longer-term consequences, such as muscle wastage or compensatory postural problems. Emotion-expressive coping describes a response that involves the venting of feelings. Hagger & Orbell also report that problem-focused and emotion-expressive coping strategies were correlated with perceived controllability. Similarly, Penley, Tomaka & Wiebe's (2002) meta-analytic review notes the superiority, in terms of health outcomes, of problem-focused coping, when compared with distancing, seeking social support, avoidance and wishful thinking. What is of interest in these studies is not the precise nature of these correlations, it is the fact that different coping strategies have been identified, and that although there is some debate as to the details, certain types of coping are associated with better recovery.

When research into illness is carried out from a cognitive perspective, two fundamental assumptions are made. The first is that we have each developed a set of beliefs surrounding ill-health in general, as well as specific illnesses, and that we somehow refer to this bank of knowledge as and when necessary. The second is that illness constitutes a threat to our usual, that is *consistent*, mode of being. I will critically discuss each in turn.

The assumption that we have illness cognitions, organised as schemas, has led cognitive psychologists to explore the ways in which we, as lay people, come to recognise the medical categories into which our illnesses might fit. Such recognition allows for a subsequent assessment of the likely causes of our illness, its consequences, expected duration and capacity to be controlled. This notion has been challenged by Ogden (2000), who suggests that the cognitive structures reported may be an artefact of the methods used to examine them. Furthermore, in my literature review of ME, I will show that illness categories are not the clear-cut starting point for understanding that is implied in the cognitive perspective. In both the ME and stroke literature, we can see a complex interaction between imputed causes, consequences and illness identity. Furthermore, in these chronic conditions, there is little certainty as to the illness duration or extent to which it can be controlled by the sufferer.

Herzlich (1973) also explored how it is that we come to recognise illness, and argues that becoming *inactive* is a crucial determinant of this state. The physical body and its limitations are central to our understanding of illness. If we become so ill that we are unable to work, or to fulfil social obligations, this will have repercussions that impact on our relations with the outside world. Thus, the capacity to carry out everyday activities takes on a moral aspect. This was also noted by Pollock (1993), who found that health was not always defined by her respondents as the opposite of illness, but rather was seen in terms of enabling the individual to carry out mundane tasks, the inability to do so being a marker of ill-health. As Williams noted in relation to respondents with arthritis, "'sitting' and 'lying down' [to illness] were doing far more than designating physical positions" (Williams, 1993: 104). One of the major difficulties facing people with chronic illness is that their fitness for activity can vary from day to day. This can mean that their condition is not always easily recognised or acknowledged by others.

Some researchers have gone beyond discrete, cognitive schemas to take into account the social and cultural background in which people are ill (Mechanic, 1977; Zborowski, 1952). Radley, for instance, argues that becoming ill is a thoroughly *social* process, rather than being the unproblematic result of bodily changes: "[s]ymptoms do not necessarily precede sickness; instead, *being deemed to be sick* is an important element in appearing symptomatic" (Radley, 1994: 71; emphasis added). This stresses the crucial role that other people have to play in coming to the decision that one is ill. That is, the state of being ill is not simply decided in the head of the individual sufferer but rather has to be acknowledged by others, in particular those in the medical profession. Symptoms can only come into being as such if these are recognised by people other than the sufferer.

The second fundamental assumption of the cognitive perspective is that health is a relatively stable state, and that illness constitutes an interruption which drives us to self-regulate until we reach equilibrium again. Self-regulation is thought to happen within the individual, and its success is judged according to the method used. This carries the implication that some types of coping are better than others, and that failure to cope well can therefore be attributed to the individual. It also ignores the social nature of illness. Radley, for example, makes the crucial point that "good adjustment [...] is actually a quality *granted by others*. [It] does not spring ready-made from the individual sufferer" (Radley, 1994: 158; emphasis added). He proposes a conceptual framework in which identity and social relations *interact* with modes of adjustment, to describe the ways in which people might, at different times, deal with chronic illness. In this model, sufferers may resist their illness, accommodate to it, or find some secondary gains that stem from their condition. Adjustment to chronic illness is seen as an on-going activity that takes place not just in the mind of the sufferer, but in the context of interactions with significant others:

"[t]his calls into question the idea of coping as bringing to bear a specifiable psychological mechanism upon a definite external difficulty. This view assumes that these mechanisms have a stable form, like tools in a toolbox" (Radley, 1994: 150)

Radley suggests that instead of looking at coping mechanisms, we should consider the strategies that people adopt in the face of illness. The focus, then, changes from the tools in the toolbox to the various things that people actually *do* when they have to deal with chronic illness. This approach can be seen in the psychological research discussed in the next section, the focus of which is on individuals' experiences and accounts of how they deal with chronic illness.

The experiential view

Research into people's experience of chronic illness highlights two important features. The first is that people suffering from chronic conditions seem to experience some kind of disruption of the self-concept, and from this comes a need to find an explanation for what has happened to them. This may require the sufferer to modify the story of his or her life in order to make sense of events. The second is that illness draws particular attention to the importance of the body in the individual's sense of purpose or value. I will discuss each of these aspects in turn.

In relation to the first point, several writers have explored the ways in which illness can affect the sufferer's sense of self. Charmaz (1983), for example, developed the idea that chronic illness involves a 'loss of self'. She suggests that the stigma of illness leads to both a reduction in self-esteem and in the opportunity to have positive relationships with others. After an initial crisis period in which sufferers refuse to acknowledge that they have a chronic condition, they can come to terms with their illness, and at that stage a 'reconstituted self' emerges (Charmaz, 1987; Charmaz, 2000). In a personal account of his own illness, Murphy similarly writes about the

effects of its onset in terms of "new and permanently altered feelings of who and what I was" (Murphy, 1987: 5). For him, though, the illness became something separate from the self. He describes initial feelings of incoherence and a need to regain some sense of order.

Research from this perspective has focused on the ways in which people manage these threats to their self-identity. A common strategy is for sufferers to make sense of what has happened to them by incorporating it into their life story. This can be done, for example, by means of 'narrative reconstruction'. In a content analysis of interviews with people who suffered from chronic rheumatoid arthritis, Williams (1984) found that these individuals constructed a new life narrative in order to reaffirm a sense of a self with purpose. He argues that this is necessary because illness threatens the sufferer's self-identity, and some kind of meaningful explanation for it is needed. This was voiced by one of his respondents: "how the *hell* have I come to be like this? Because it isn't me" (Williams, 1984: 175; emphasis in original). When participants were asked "why do you think you got arthritis?", they offered a *reconstructed* biographical narrative that constituted an attempt to make some sense of their experiences. Bury (1982) has described the experience of chronic illness as 'biographical disruption', and notes that feelings of loss of value or of self, and lack of control over the body, can influence not just the way the sufferer considers his or her future life, but also past and present experiences. That is, the sufferer has to make sense of the illness experience in the context of his or her whole life story. The idea of doing 'biographical work' was developed by Corbin & Strauss (1985; 1987), who suggest that there are three specific areas to be addressed. The first is biographical time, which can be thought of as an orientation to the way in which the story unfolds. Second, the sufferer has to reconsider his or her concept of self. Finally, account must be taken of his or her diminished bodily capacities.

Riessman (1990) also studied chronic illness from the individual's point of view. Using the framework of narrative analysis for her study, she found that her respondent, a man with advanced multiple sclerosis, strategically used 'story-telling' to maintain effectively those aspects of his identity that were important to his sense of self. This was done, as she describes it, against the background of a biography hugely disrupted by illness. Similarly, Pollock (1988) found that an important part of sufferers' search for understanding of their illness involved an attempt to find out why he or she in particular had become unwell. From her work with sufferers of multiple sclerosis, she concluded that people who have chronic illness develop a 'working mythology' to explain how their conditions came about.

These findings can be contrasted with claims from the cognitive psychological perspective that sufferers refer to existing cognitive schemas relating to specific conditions in order to understand what their illness is, how it was caused and so on. They suggest that people with chronic conditions give meaning to their experience not by reference to some schematic knowledge but rather by reframing their particular life story so that the onset and progression of illness make some kind of sense.

The sufferer's relationship with his or her body has been referred to in the work of Bury and of Corbin & Strauss. This is the second main focus of experiential research. When we are in good health, we often pay little attention to our bodies. As soon as we feel pain, or other effects of illness, it is as if the body comes into focus. Its importance becomes central, and yet this is a time during which the sufferer is often struggling to understand and come to terms with the physical changes wrought by his or her condition. The body can become less familiar, and harder to control. According to Lupton "illness may then be conceptualised as the body taking over, as an external environment separate to the self" (Lupton, 1994: 20). This idea of the body as quite separate from the mind is possible because of the mind's capacity to

alienate and objectify the body. As Plessner (1970) describes it, the individual *is and has* a body. That is, we are embodied but this does not prevent us from thinking about our bodies as something separate from our selves.

In the same way that cognitive theory can be criticised for its failure to take account of the social and cultural background to, and implications of illness, research into individual experiences often gives the impression that adaptation to chronic conditions takes place solely within the mind of the sufferer. Adjustment to illness is conceptualised in terms of working on the 'self', or on the relationship that the 'self' has to the body. There is, however, a great deal of research that emphasises the importance of social interaction in the experience of chronic illness. In a personal account, Zola (1982) describes how his condition, and the way it affected him, were changed by the social context in which he found himself. When he lived and worked with able-bodied people, he came to ignore aspects of his own disablement, because of a feeling that limitations of the body reflected limitations of the self. Later, when he spent time with similarly disabled people, he questioned the idealised self that he had previously constructed in the framework of a fully-abled majority. Kleinman (1988) has pointed out the extent to which the sick or disabled person is excluded from a 'healthist' society in which our bodies are expected to function and present normally. He suggests that the capability of the body affects the value attached to the psychological self. Thus, when the body fails, in the judgement not just of the ill person but of others, the person feels him- or herself to be a failure.

People who are chronically ill have to make sense of their experience in a social context, in which the meanings given to illness, by the sufferer and by others, are significant (Bury, 1988; Bury, 1991). That is, the sufferer's interpretation of his or her situation is not necessarily shared by others, a situation that Bury describes in the phrase 'meanings at risk'. This puts the person with chronic illness in a potentially

difficult position with regard to others. Williams (1993) suggests that people with chronic conditions constantly have to strive to gain the understanding and positive regard of others with respect to the way they adjust to or deal with their illness. He refers to this as the 'pursuit of virtue'. A similar process was described by Wiener (1975), who found that respondents with rheumatoid arthritis used a variety of methods to deal with the uncertainty of illness. Thus, at times, they strategically passed themselves off as in good health, and at others they acknowledged their incapacity, according to the circumstances. The important point here is that these strategies are performed in a social context and relate to the individual's interactions with other people. In section 2:2:3, I discuss theories and research in the sociological literature that explore more fully the potentially problematic relationship of the chronically ill person with others in society. I will first give a brief account of the biopsychosocial perspective on chronic illness.

2:2:2 The biopsychosocial perspective on chronic illness

A review of the medical literature shows that there have been moves to broaden the scope of enquiry into illness *beyond* individual, biological and physical aspects, to include social factors in the experience of illness. This can be seen as an acknowledgement of the importance of society and culture on the experiences of the individual with a chronic condition. These issues will be discussed below.

From the medical perspective, the body has historically been the primary focus of attention in the study of illness. This is described as the 'biomedical' approach. In acute, epidemic diseases, such as measles and polio, such an approach was valuable in helping to identify the specific organisms that caused illness. However, in the case of chronic illness, there is much less certainty about causes, and illness has to be lived with in the longer term. The medical perspective on illness has, therefore, moved towards a 'biopsychosocial' approach. This concern to take account of more than the

biological and medical aspects of illness can be seen in efforts to refine the definitions of terms relating to chronic conditions. Thus, the World Health Organisation (WHO) has provided suggested classifications aimed at distinguishing between the physical, and measurable, effects of illness, and the ways in which these effects influence the relationship of the sufferer to non-sufferers in society (Wood, 1980). The WHO suggests that the term 'impairment' should be used to refer to any loss or abnormality of bodily structure or function. This, then, denotes the merely physical aspect of illness. Impairment, for example the loss of a leg, might lead to some restriction in a person's ability to perform physical activity in the normal manner. This is referred to by the WHO as 'disability', and therefore describes the functional impact of an injury. When disability results in disadvantageous treatment in society, the result is 'handicap'. This would describe the situation of, for example, a person who is denied access to a building because he or she cannot negotiate entrance steps. According to the WHO definition then, handicap does not reside in the person, but in the ways in which he or she can live in society.

The WHO classification demonstrates a move away from treating the effects of illness as purely within the individual. However, it is not straightforward in its use. To describe someone with chronic illness as impaired, disabled or handicapped can involve a large degree of judgement (Bury, 1997). Impairment is not always visible to the outsider, and the sufferer cannot therefore assume that others will acknowledge this state of affairs. The term 'disability' is meant to signify a bias-free description of the effect of impairment. However, it is defined as the inability to perform actions in the *normal* manner, which inevitably implies some value judgement as to the correct way in which actions should be performed. When it comes to considering handicap, it is important to remember that the same disability is likely to affect different people in different ways. It is, therefore, crucial to take into account the sufferer's own experiences of the limits imposed by his or her condition.

A number of writers have suggested that the descriptive terminology should reflect the differences between the physical and individual, and the social aspects of being unwell. Thus, Kleinman (1988) suggests that the term 'disease', like 'impairment', should be used only to denote the biophysical impact, while 'illness' should be used to refer to the ways in which the individual, in the social setting, deals with his or her condition. Similarly, Radley (1994) suggests that 'sickness' should be used to denote the social implications of illness. Bury (1988; 1991) also distinguishes between two separate meanings of chronic illness. The physical and real effects are described as distinct from the cultural and social significance attached to the particular condition suffered. Thus, it is possible to feel unwell, in a physical sense. However, to be 'ill' or 'sick' depends on legitimisation from others and this will vary between social and cultural contexts.

These attempts to define what is meant by illness all suggest an awareness of the importance of the wider social context. I will now discuss research that takes the wider social context as the starting point for studying chronic illness.

2:2:3 Sociological perspectives on chronic illness

The last section of the literature review on chronic illness describes a body of research, mainly from the sociological perspective, that has explored the ways in which illness affects the sufferer's relationships with others. In particular, it will be seen that coping with illness has moral implications and that these are crucial for the ways in which the person with illness interacts in society.

In his influential book 'The Social System', Parsons (1951) explores the relationship between the sick and society in general. He suggests that those who are unwell adopt the 'sick role', which confers on them both rights and obligations. Such people are not held responsible for their situation, and are excused their normal duties as long as

they want to get better. This should be demonstrated by appropriately seeking, and co-operating with, medical help. In this classic model, the notion of *motivation* - not just to get better, but also *to be ill in the first place* - is crucial. Furthermore, the physician's role involves re-socialising the person who is sick, by enabling him or her to return to normal duties. Although Parsons assumed that the process was beneficial to society as a whole, this model casts clinicians as one of society's mechanisms of control. Other writers have explored this role further. Turner (1992), for example, notes that the rising status of medical science in western cultures has coincided with a decline in the importance of religion in everyday life. He claims that this has led to a situation in which medicine has an increasingly moral function in society. Radley (1994) similarly points out the role of doctors as gatekeepers to social goods. He describes how, with the introduction of laws relating to sickness benefit, doctors began to be responsible for assessing individuals' fitness for employment, and entitlement to payment when unable to work. This research suggests that the medical perspective on illness is one that carries with it a certain amount of status and power.

Parsons's sick role theory has been challenged, and a useful critique can be found in Turner & Samson (1995). One point of particular relevance to this thesis is that we do not *all* act in the way described by Parsons. People in financially privileged social groups have been found to present more often in medical clinics, although they suffer less illness than those in poorer groups (Townsend & Davidson, 1982). This suggests that social, as well as biological, considerations should be taken into account when we are looking at who might adopt the sick role. Furthermore, the status of the sick person in Parsons's framework depends on whether he or she adequately fulfils the requirements of the sick role. A fundamental duty is that the patient should get better, and this means that admittance to the sick role is assumed to be temporary. It cannot, then, easily be applied to people with chronic illness. Rather than speaking in

terms of access to the sick role, their needs would be more in the nature of a renewable season ticket, allowing them to come and go as their condition changes.

Freidson (1970) developed the notion of entitlement to the sick role, by distinguishing between those who might, and those who would never get better. The latter represents those who are chronically ill with no prospect of improvement, and Freidson suggests that these people have an *unconditional* right to adopt the sick role. However, access to the sick role is not automatic for those whose illness is variable and whose condition might potentially improve.

Parsons's work draws attention to the ways in which being unwell can affect the person's relationships in society. Goffman (1963), in his exploration of the stigmatising aspects of illness, proposes that a person's identity can be 'spoiled' by the negative reactions of others. He suggests that such reactions are based on social stereotypes, so that the individual is not seen as an individual, but as a member of the category of people with illness. It is often in the sufferer's interests, therefore, to conceal or play down the impact of his or her condition. The chronically ill take on the difficult social tasks of appearing to 'cope' with their situation, while hiding their discomfort. People who succeed at these skills tend to be admired and treated with compassion. Those whose illness is chronic must perform them repeatedly over time to deserve this treatment (Radley, 1994).

The above research points to the social implications of, and for, chronic illness. These are described by Herzlich & Pierret, who propose that "it is the individual who is sick, but he [*sic*] is sick in the eyes of society, in relation to it and *in keeping with the modalities fixed by it*" (Herzlich & Pierret, 1987: 11; emphasis added). The last point is particularly important, because of the implied effects that social responses can have on the ways in which illness is presented, and even on the nature of illness itself.

I have discussed the ways in which chronic illness is conceptualised from three perspectives - the psychological, the biopsychosocial and the sociological. Two particular psychological approaches - cognitive and experiential - have been used to research chronic conditions, and I have argued that they stress the role of individual, internal factors and have largely neglected the social context in which people make sense of and manage their illness. The biopsychosocial perspective represents an attempt to integrate individual experience within a wider social framework, and the value of such an approach is demonstrated in research undertaken from a sociological perspective. The literature discussed so far assumes that some commonality of experience stems from the extended timespan of different chronic conditions. In order to explore this possibility, it is now necessary to examine the literature on the particular illnesses studied in this thesis - ME and stroke.

The review of chronic illness literature suggests that the social and cultural context is a crucial starting point for an examination of sufferers' experiences. Medical science has been shown to play a particularly important role in legitimising illness, and therefore the reviews of ME and stroke literature will begin with an examination of how these conditions are clinically defined. The aim is not to reify clinical definitions, but rather to present them as part of the wider cultural context in which people with ME and stroke experience their illness. An exploration of the history of these conditions then sets the clinical definitions in a wider historical context. The reviews of ME and stroke literature end with a discussion of the ways in which these conditions are currently treated.

2:3 Literature review- ME

2: 3:1 Definitions of ME

ME is the shortened form of 'Myalgic Encephalomyelitis'. Myalgia denotes muscle pain, and encephalomyelitis signifies an inflammation of the brain and spinal cord. Thus, the term 'ME' is used to convey symptoms that are associated with a particular physical impairment. Several causes have been investigated. For example, studies have been carried out into the possible role of viruses, of the immune system, toxic exposure, and dysfunctions of the hypothalamic pituitary gland (Pizzigallo, Racciatti, & Vecchiet, 1999). Although there is some research to support these hypotheses (Komaroff & Buchwald, 1998), no-one has yet been able to provide reliable, replicable evidence as to what might bring about this condition, and this has led to some debate about whether this illness has physical or psychological origins. The notion that the two can be separated is itself a contentious matter, and one to which I will return later. The most commonly reported risk factor for ME is the co-existence of either physical or psychological stress (Levine *et al.*, 1999).

Stress has been suggested as a possible explanation for many types of chronic illness. Efforts have been made to find cause-effect links between specific external stressors and particular bodily symptoms, although illness may itself be a stressful experience so that the links become hard to distinguish. Furthermore, there is uncertainty as to which particular aspects of life might cause harmful stress. Some researchers claim that specific life events can be given a score for their potential stress-causing capacities (Holmes & Rahe, 1967). This suggests that the capacity for causing stress resides in the event itself and not in the individual's particular response. Other researchers point to the deleterious effects of long-term but more minor niggles (Pearlin, 1989). A problem with these views is that specific 'stressors' appear to act differently depending on the person affected. One implication of the suggestion that stress might cause ME is that the sufferer can then end up being held to account by others for his or

her condition. If it is known how people can reduce the risk of illness - for example, by avoiding stress-inducing situations, or by coping better with them - there may be some implication that those who have succumbed are, to an extent, responsible. There is, for example, a reported association between avoidance coping and the onset of fatigue (Afari *et al.*, 2000).

Naming this condition is problematic. The term 'Myalgic Encephalomyelitis', which is generally preferred by UK sufferers and their support groups (Jason, Eisels, & Taylor, 2001), suggests a specific physical pathway (muscle pain resulting from inflammation in the brain and spinal cord). Since this is, as yet, medically unproven, the term 'ME' has been largely rejected in the biomedical literature in favour of the description 'Chronic Fatigue Syndrome' or CFS (Holmes *et al.*, 1988), which defines the condition purely in terms of its *symptoms*. That the terms 'ME' and 'CFS' have different implications can be seen in another paper published by Jason and colleagues (Jason, Taylor, Plioplys, Stepanek, & Shlaes, 2002). They found that while medical students perceived CFS to be a serious illness, they rated it less so than ME. Since this research explores the ways in which sufferers construct their illness, I will retain the term ME, except where I am explicitly referring to literature in which another term, such as CFS, is used.

One consequence of the failure to identify a physical cause is that it has not been possible to establish agreed, reliable, biological markers for ME. This means that it cannot be diagnosed by orthodox medical tests - for example blood sampling, urine analysis or scans. In the absence of such tests, the *symptoms* of ME have a special significance, because it is solely on the basis of reported symptoms that a diagnosis can be made. There is general agreement that the most important characteristic is fatigue, but not about the definition of this term, in particular the potential links between tiredness and depression. Fatigue is a noted symptom in many psychiatric

disorders, so that when it becomes chronic and incapacitating, medical practitioners are alert to the possibility that the illness is not necessarily physical. While some writers do claim that the tiredness is of peripheral, or neuromuscular origin (and refer to it as 'muscle weakness' rather than fatigue) (Komaroff & Buchwald, 1998), others stress the role of psychopathologies (David, 1991; Sharpe *et al.*, 1991). Wessely, for example, argues that the source of mental fatigue and neuropsychiatric symptoms, such as poor concentration, cannot be neuromuscular, and that "cognitive (conscious thoughts), attributional (beliefs about illness), and behavioural factors play a crucial role in determining outcome and mediating disability" (Wessely, 1996: 213). For example, research suggests that sufferers avoid activity because they believe they are incapable, but that this belief is not borne out by objective measures of effort such as pulse rate and observed symptom severity (Silver *et al.*, 2002). This of course implies that external observers are better judges of the sufferer's fatigue than the individual him- or herself. Some of the research suggests that sufferers' failure fully to understand their capabilities can be explained in terms of their overly high expectations (Metzger & Denney, 2002). Furthermore, this tendency has been linked to an excessively active pre-illness lifestyle thought by some to contribute to the onset of ME (Van Hudenove, Neerinckx, Onghena, Lysens, & Vertommen, 2001).

The standard medical strategy when an illness is *symptom*-based, is to produce a research definition that might ultimately lead to the development of a clinical case definition. Such definitions arise from a consensus formed on the basis of discussions among a number of clinicians who have recognised expertise in the particular illness. The research definition provides a list of necessary and sufficient symptoms that is designed to identify sufferers as a *homogenous group*, and also to distinguish the condition in question from other symptom-based illnesses. Once this is done, the theory is that large-scale, epidemiological studies can then be made of those people whose symptoms match those in the definition. The point of such

studies is to look for patterns in the data from large numbers of sufferers that might enable a case definition to be made, and also shed some light on the possible causes of the illness, and potential treatments. Research and case definitions, then, are the clinical route to ascertaining what constitutes a particular condition, and who is deemed to be a sufferer. In the case of CFS, efforts have been made to produce a research definition to guide an exploration of this illness in order that a case definition might later be made.

The difficulty in coming to a workable, agreed research definition of CFS has centred around the potential contribution to the illness of psychiatric or psychological problems. The history of some of these endeavours is briefly outlined below. The first case definition was produced by the Center for Disease Control and Prevention (referred to as the 'CDC definition') in 1988. The 'Oxford definition' followed in 1991, and then a 'revised CDC definition' was published in 1992. 1994 saw the publication of the 'international definition' of CFS.

It is worth noting at this point that new research definitions do not supersede previous ones, and that any definition can potentially be drawn on for the purposes of studying this illness. Although there are "strong proponents of the ME concept who still swear by the original CDC definition" (Ranjith, 2003: personal communication), it is the Oxford criteria and the 1994 definition that are most frequently used in the UK (Whiting *et al.*, 2001). The 1994 definition was produced by an international team of researchers, and therefore its influence is the most widespread.

An international study suggests that research definitions have not yet succeeded in identifying a homogenous group of sufferers (Wilson *et al.*, 2001). They propose a sub-stratification within the definition, but note that there is no consensus as to the basis upon which this might be achieved.

The CDC definition (1988)

The original consensus research definition for CFS was produced by a team of 16 researchers for the American Center for Disease Control and Prevention (also referred to as CDC) (Holmes *et al.*, 1988). It was produced at a time when clinicians thought that the most likely cause of CFS was some sort of infectious episode, and this can be seen in the proposals that emerged. The main criterion for inclusion as a sufferer is new onset of debilitating fatigue lasting 6 months or more. To be diagnosed with CFS, an individual has to have at least 8 of the 11 noted symptoms, or 6 symptoms and 2 out of 3 physical signs. Physical signs refer to those effects of the illness that can be observed by the clinician, and they must be verified on at least two occasions, at least one month apart. They are low-grade fever, non-exudative pharyngitis (dry, inflamed throat), and palpable axillary lymph nodes (swollen glands). Symptoms include sudden onset, generalised muscle weakness, prolonged post-exertional fatigue, and a list of neuropsychological complaints, among which are forgetfulness, confusion and mild depression. An important aspect of this research definition is that diagnosis of CFS can only be made if the above criteria are met *in the absence of* other clinical conditions - medical *and* psychiatric - that might produce similar symptoms. With this definition, therefore, CFS would *not* be diagnosed as the cause of fatigue in someone who has a diagnosis of any kind of psychiatric complaint, other than mild depressive illness.

The Oxford Definition (1991)

Sharpe (1991) argued that the CDC definition's requirements to exclude all psychiatric conditions, other than mild depression, was both premature and unnecessary, when so little was known about this illness. He headed up a multi-disciplinary group of 26 British researchers comprising not only medical clinicians, but also psychiatrists. This group produced what is referred to as the 'Oxford' (UK) definition of CFS (Sharpe *et al.*, 1991). Among the changes they made was to restrict the psychiatric complaints

that would *exclude* a diagnosis of CFS to a small number of distinct conditions: schizophrenia, manic depressive illness, substance abuse and eating disorder. This meant that patients having *any other* psychiatric symptoms could, using this definition, be included in research into CFS.

The revised CDC definition (1992)

In the following year, two American bodies, the National Institute of Mental Health (NIMH) and the National Institute for Allergy and Infectious Disease (NIAID) held a workshop whose aim was also to review the original, CDC case definition. A series of modifications was proposed (Schluederberg *et al.*, 1992). The authors, two of whom - Komaroff and Straus - were involved in the original definition, suggested that it was not workable in practice, and that only people with psychotic illness should be excluded. Psychotic illness can be described as illness resulting from mental disorders, which interferes grossly with the sufferer's capacity to meet the ordinary demands of life. Thus, their revisions are similar to those suggested in the Oxford definition. Schluederberg and colleagues also recommended that a psychiatric interview be carried out with people at the point of diagnosis, so that any subsequent interaction between psychopathology and CFS could better be assessed.

The international definition (1994)

Katon & Russo (1992) argued that the required number of symptoms and signs needed for diagnosis of CFS in the original, CDC case definition was too high. The CDC definition requires sufferers to have 8 out of 11 symptoms, or 6 symptoms and 2 out of 3 physical signs before being diagnosed with CFS. Katon & Russo note that research has shown a positive, linear relationship between anxiety and number of physical symptoms. Therefore, they argue, to insist on a minimum of 6 symptoms will lead to the over-representation in research of relatively anxious people. This, paradoxically, is contrary to the aims of the original definition, which, with its

emphasis on physical signs and symptoms, seeks to *exclude* people with psychological problems.

In 1994, two years after Katon & Russo's paper, a further revision was proposed by the International Chronic Fatigue Syndrome Study Group (Fukuda *et al.*, 1994). This group comprised, among others, Komaroff and Straus - who were involved in the original CDC definition, and the 1992 revisions - and Sharpe, who was first author of the Oxford definition. The authors note the great difficulty they had in coming to an agreement, and that indeed the revision constitutes a compromise rather than a consensus. The 1994 definition significantly reduces the inclusion criteria to 4 symptoms (out of a possible 8), although tiredness on its own can be diagnosed as 'idiopathic chronic fatigue'. In the original definition, if there are fewer than 8 symptoms, sufferers have to have specific, medically verified, *signs* of illness. Fukuda and colleagues argued that the identification of signs was unreliable because it did not involve objectively measured tests, such as might, for example, be provided by a blood assay. In this revision, then, there is *no* requirement to show physical signs.

We can see then that there has been some difficulty in coming to an agreed research definition for CFS, and that many of the difficulties in coming to a consensus relate to the relative importance of physical symptoms and psychological factors in the diagnosis of this illness. That this is an issue of wider concern is demonstrated below.

The physical versus psychological debate

The controversy over the extent to which ME or CFS can be explained in physical or psychological terms can be demonstrated in official statements about this condition. These reflect an underlying assumption that 'real' illness is physical, and by

implication, not psychological. In 1987, the British government, in conjunction with an ME charity, instituted a Task Force to look into this illness. Its report, published in 1998, acknowledges that the illness is "a condition which some believe does not exist as a true disease" (Campion, 1988: 78). The Royal Colleges also produced a 'Report on Chronic Fatigue Syndrome' in which it is stated that "some doctors still dismiss the patient's symptoms with such phrases as 'pull yourself together'" (Royal College of Physicians, 1996: 15). The editorial reaction in the 'Lancet' to the Royal Colleges' Report - "psychiatry has won the day for now" (Horton, 1996) - reflects the ongoing 'physical versus psychological' debate. In 1998, Sir Kenneth Calman, then Chief Medical Officer for England and Wales, gave assurances in the media that CFS is indeed "a real entity" (Wilson, 1998: 17).

This debate has implications for people who suffer from ME. It has been reported that psychological illness carries with it the stigma that the sufferer might be in some way to blame, whereas physical illness is commonly perceived to be beyond the control of the individual (Kirmayer & Robbins, 1991). Wessely suggests that both physicians and many CFS patients regard psychosocial problems, such as depression, as "imaginary, malingered or non-existent" (Wessely, 1997: 25). An extract from the jacket cover summary of a recent book, entitled 'Theater of disorder: Patients, doctors and the construction of illness' and published by the Oxford University Press, gives some indication of the potential for stigma with this condition :

"In recent years, many Americans have claimed to have multiple personalities or recovered memories, or to have been abused by satanists or extra-terrestrials. At the same time, disorders like chronic fatigue syndrome and 'total allergy syndrome' have been on the increase."
(Wenegrat, 2001: jacket cover)

Research suggests that people who have ME are often stigmatised because their illness is not held by others to be legitimate (Clarke, 2000; Cohn, 1999; Ware, 1992; Ware,

1999; Ware & Kleinman, 1992). People with ME may, therefore, deny any potential association between psychological factors and their experience of illness. Indeed, one piece of research found that ME sufferers are less likely than people with multiple sclerosis to interpret their symptoms in terms of negative emotional states (Dendy, Cooper, & Sharpe, 2001).

It is not only the definition of ME that has been contested. The history of this illness has also been the subject of some debate:

2:3:2 History of ME

Cohn (1999) has argued that there is no single, undisputed history of ME but rather that its possible antecedents have been reported in a *strategic* manner, depending on the perspective of the author. Some, for example, claim links with neurasthenia. This describes a weakness of the nerves and nervous exhaustion, with a presumed neurological basis. Neurasthenia was first described in the late 1860s (Beard, 1869), and it was held to be a physical reaction to the extra demands put on people who were living in a time of unusual technological change. For example, the introduction of such advances as trains and telegrams was thought to have contributed to a general quickening of the pace of life, which caused some people to have a nervous, physical reaction. The analogy used at the time was one of a store of energy resources being depleted by the extra demands of everyday life, and the advised treatment was rest. Some writers have suggested that the construct of 'neurasthenia' was later gradually broken down into various affective, psychiatric disorders (Ware & Kleinman, 1992).

Another illness thought by some to be a forerunner of ME is Da Costa's Syndrome, or 'effort syndrome'. Like neurasthenia, it was thought to be induced by environmental stress, though of a more extreme type. It was first found in soldiers who had fought

in the American Civil War (Wood, 1994). Da Costa's Syndrome has been compared to modern 'burnout' theories (Freudenberger & Richelson, 1980) in which physical exhaustion is thought to result from a sustained period of environmental stress. By the 1940s, Da Costa's syndrome had been dismissed as neurosis (Ware, 1992).

On the one hand, to suggest that neurasthenia, or Da Costa's syndrome, are antecedents of CFS can imply, then, that CFS is of psychological origin. On the other hand, ME sufferers may refer back to the original 'rest cure' for neurasthenia, to the notion of physical exhaustion in Da Costa's Syndrome, and also to the implication of environmental factors in both conditions. Cohn (*ibid*) has noted that people with ME may, in addition, refer to these as historical antecedents in order to avoid the potential accusation that their condition has appeared 'from nowhere', and might merely be a fashionable ailment that is promoted and maintained by media hype. ME was once better known for its nickname 'yuppie flu', a term that suggests a relatively trivial ailment suffered by a young, wealthy and ambitious set identified in Britain in the 1980s.

There is a second strand of antecedents that has been drawn on by writers describing the history of ME. This relates it to a series of geographically discrete, general outbreaks of what were thought at the time to be some sort of infectious disease, possibly related to poliomyelitis. An epidemic of encephalitis (swelling of the brain) was reported in Los Angeles in 1934 (Gilliam, 1938), and there have since been similar outbreaks in other locations. The most widely discussed case was in 1955 at the Royal Free Hospital in London (Crowley, Nelson, & Stovin, 1955; Medical Staff of the Royal Free Hospital, 1955). Cohn (*ibid*) notes that to quote such epidemics as historical antecedents of ME can imply that ME does indeed have a physical basis, and could also be used to lend support to the theory that it might be caused by some disorder of the immune system. However, a controversial re-analysis 15 years after

the Royal Free epidemic suggested that it was no more than mass hysteria (McEvedy & Beard, 1970). This has meant that references to this particular strand of history can also be used to cast doubt on the legitimacy of ME as a physical illness.

We can see, then, that there has been much debate around the diagnosis and definition of CFS. This has implications for the ways in which it is treated.

2:3:3 Treatment of ME

The lack of an obvious physical explanation for ME is reflected in the fact that there is no medical treatment for this condition. Some researchers have, however, argued that whatever might have caused the illness, it might be *perpetuated* by a dysfunctional belief system, and therefore could be treated with cognitive behavioural therapy. Wessely, David, Butler & Chalder (1989) observed that CFS sufferers avoided exercise because they felt it exacerbated their condition, and that they perceived their illness as poorly understood or mysterious. In a trial at the National Hospital, they presented patients with two sets of beliefs about CFS. The first reflected these observations. The second suggested that the enforced rest, possibly resulting from an initial, acute illness, rendered them unfit, so that when they attempted activity they felt a worsening of symptoms. The problem, they suggested, was that sufferers *wrongly* attributed this exacerbation to a relapse of their illness, and this encouraged them to take even more rest. Thus, the tendency to want to rest is presented as the result of unconscious, associative learning, and not related to any physical need. It leads to more fatigue, and possibly depression. The recommended treatment, cognitive behavioural therapy, is described by Sharpe:

"The therapist and patient work together in a collaborative fashion in order to *clarify* the patient's understanding with a *more accurate* appraisal of the

situation. New ways of coping based on this *improved understanding* of the illness are then implemented and evaluated." (Sharpe, 1996: 241; emphasis added)

Italics have been used here to emphasise the assumption in this treatment that the sufferer does not have a clear or correct insight into his or her condition and this can be rectified by means of such therapy.

As well as cognitive behavioural therapy (CBT), Wessely's National Hospital trial included graded exercise, supportive psychotherapy, involvement of the spouse, and drug treatment for depression. Of the 50 severely disabled patients who were offered treatment, 22 experienced a significant improvement, and for 4 of them, there was no change. The one patient who felt worse was reported to have maintained a tendency to attribute symptoms to physical, rather than psychological, factors. A similar argument can be seen in the paper written by Bentall, Powell, Nye & Edwards (2002), who attributed poor outcome in the psychological treatment of CFS to patients' low motivation and compliance. They suggest that this is linked to a resistance to the therapeutic rationale, and to the existence of secondary gains from being ill.

It is notable that 18 patients refused Wessely's treatment, and 5 dropped out. This suggests some level of resistance on the part of ME sufferers to this treatment. The trial has clear limitations. It was relatively small, and did not involve a control group, although high rates of remission had been indicated elsewhere (Straus *et al.*, 1988). Therefore, the improvements found in the study might have happened without the intervention. The outcomes were not independently verified. Indeed, it would be difficult to either prove or counter Wessely's claims that the patient who got worse did so because of his internal attributions. Other writers have shown that to suggest someone is 'in denial' can work to discount that person's rejection of a psychological interpretation of his or her problems (Harper, 1999; Smith, 1978).

Whiting and colleagues (2001) carried out a systematic review of 44 studies evaluating the effectiveness of treatments for CFS. They faced two main problems. First, inclusion criteria varied in the different studies according to the research definition used. Second, the large number of different outcome measures used made it difficult to synthesise results in any meaningful way. They conclude, however, that the treatments which showed most promise were CBT and graded exercise therapy (GET). It is of particular interest that these treatments also had the highest drop-out rates, which suggests a level of resistance on the part of some sufferers.

Ridsdale and colleagues (2001) note that there has been very little research into the ways in which CFS is managed in primary (non-specialist) care. Their study suggests that counselling and CBT were equally effective. Further research found that CBT and GET were both relatively useful in treating CFS, but that graded exercise had much poorer patient attendance (Ridsdale, Darbishire, & Seed, 2004).

Wessely (1977) described further maladaptive cognitive processes thought to be at play in CFS. In their efforts to monitor their symptoms, sufferers may become both hyper-vigilant and overly-sensitised to physical stimuli. He refers to research which suggests that sufferers' fear of illness and uncertainty as to its origins may result in exaggerated beliefs about the negative effects of activity (Surawy, Hackman, Hawton, & Sharpe, 1995; Wessely, Butler, Chalder, & David, 1991). Wessely (1997) also suggests that there is a mutual lack of trust between CFS patients and the medical profession, and that this could be explained by differences in their attributions relating to the illness. He claims that increased media coverage of lay beliefs about CFS has meant that people with this condition have become more entrenched in their views, and

furthermore

"[w]hereas in the past sufferers were open to medical counter suggestion, this is no longer possible - the balance of power between professional and lay models of illness is changing."
(Wessely, 1997: 26)

Thus, he proposes that sufferers' erroneous beliefs about their illness are strongly influenced by external factors, and that the medical account has been undermined by those of the popular culture.

Horton-Salway (2004) has studied ME from a discourse analytic perspective. She examined discussions between a psychiatrist and ME support group members to see how knowledge claims are locally produced. She analyses techniques of fact construction, and concludes that to refer to a claim as medically recognised is rhetorically more powerful than to describe personal experience of this illness.

We might ask how it is that an initial attack of acute illness will lead to maladaptive thought processes in some people and not in others. Some researchers report that the rigidly-held beliefs typically attributed to the person with ME are a defence against low self-esteem and linked to defensive coping (Cresswell & Chalder, 2001). Researchers have noted certain general characteristics of ME sufferers, the most typical being a highly active and demanding lifestyle prior to the onset of illness, underpinned by high personal standards of achievement (Eichner, 1989; Riley, O'Brien, McCluskey, Bell, & Nicholls, 1990; Ware, 1992; Wessely & Powell, 1989). White & Schweitzer (2000), for example, report that people with CFS had lower self-esteem and were more perfectionist than a control group. Ware has also described a pre-morbid tendency among people with ME to give priority to the needs of others above their own, as well as a pattern of stressful life histories.

Horton-Salway (2001a) notes that in the research, patients' assertions have been taken at face value as evidence of their attributions or personality. This has the effect of appropriating sufferers' constructions of the illness in the interests of furthering the analyst's particular theory. Thus, when a person with ME stresses how active he or she normally is, or used to be, this information can be, and has been, used to argue that the condition *results* from over-exertion, stress or a perfectionist personality. Horton-Salway argues instead that the sufferer's emphasis on previously high physical energy may be strategic, that is, inspired by a desire to *counter* implications of malingering, as well as to depict the seriousness of an illness that has brought about such a reduction in health. She quotes from an illness narrative produced by a sufferer (Angela) and her husband (Joe):

Extract 4
 485 Angela: we always used to go
 486 fell-walking [and hik]ing cycling heh heh heh heh
 487 Joe: [cyclists]
 488 MHS: =outdoor people=
 489 Angela: =yeah (.) swimming (.) physical things 'cause I know
 some couples
 490 aren't into that sort of thing (.) they're quite happy to
 stop at home and
 491 sit (.) aren't they?=
 492 MHS: =yes=
 493 Angela: =well we were never like that (.) but we've been forced
 to be like that
 494 in a way (.) to be sedentary instead of active
 (Horton-Salway, 2001b: 255)

Horton-Salway notes that when an illness is of uncertain legitimacy, the sufferer is more likely to be treated as the type of person who is looking for secondary gain. In her analysis of this extract, she notes the use of a 'before and after' story which constructs the pre-illness self as active. She concludes that the account orients to the implicit rhetorical question of what possible motive Angela could have to give up all the things she enjoyed before becoming ill.

Bülow and Hydén (2003) report on a form of intervention in Sweden known as a 'patient school', a concept introduced there in the 1990s. This takes the form of an education programme run in a hospital clinic in which patients attend lectures and group discussions aimed at increasing their understanding of ME. They note that in these different contexts, patients have the opportunity to view their illness using different frameworks. They can see it from the outside, as a social object and also against the wider perspective of 'sickness'. In addition, by sharing their experiences with others they are able to gain a greater insight into the 'inside' perspective. Bülow and Hydén suggest that it is particularly important for sufferers to consider their illness from viewpoints other than their own when that illness is contested. They also propose that in the process of exposure to and discussion of a variety of views, sufferers can learn the 'discursive management' of their illness, that is, they become more flexible in the ways in which they can talk about and respond to different interpretations of ME.

The review of the ME literature has drawn out features specific to this condition, relating to three particular areas - its medical definitions, the different possible historical antecedents, and treatments offered to sufferers. A similar review of the stroke literature was carried out in order to have some understanding of the culturally available clinical and historical contexts in which this condition might be understood.

2:4 Literature review - stroke

2:4:1 Definitions of stroke

The initial stage of stroke can involve anything from mild confusion to complete loss of consciousness for a number of days. After this, the sufferer may be left with neurological impairments. These have been found to vary according to the size and site of the brain that is damaged. In particular, specific impairments have been related

to the *side* of the brain that is affected (Pimm, 1997). For example, paralysis, or muscle weakness, on one side of the body (hemiparesis) and loss of sight in one side of the visual field (hemianopsia) result from damage to the *opposite* hemisphere of the brain. Some difficulties are specific to the side of the brain that is injured. For example, research suggests that problems in producing, remembering or understanding language (aphasia or dysphasia), unco-ordinated or jerky muscle movements (apraxia), and slow or cautious behaviour, result from damage to the *left* hemisphere. If it is the *right* side of the brain that is affected, symptoms might include spatial and perceptual deficits, memory loss in performance, quick, impulsive behaviour, difficulties in emotional expression, and a denial of impairment (anosagnosia). The effect of muscle weakness on *either* side of the mouth can produce slurred speech (dysarthria).

The size and site of brain damage does not, however, fully explain the impairments that are found in people with stroke. In a systematic review, Bhogal, Teasell, Foley & Speechley (2004) found inconsistencies between studies that attempted to link the area of lesion with the onset of post-stroke depression. Results differed, for example, when outpatients were compared to inpatients, and between measurements taken at the acute and the chronic stage. In addition, there is some doubt about the extent to which linguistic impairment can be associated with specific internal injury. Traditionally, these have been linked to left hemisphere damage. Such deficits are measured by asking patients, usually in the clinical setting, to relate the story depicted in a series of cartoons. This provides a rating based on linguistic *content* in a descriptive task. Manzo, Blonder & Burns (1995), however, studied linguistic difficulties by interviewing stroke sufferers in their own homes, rather than in the clinical setting, and in dialogue with their partners. Here, the focus was on *interaction* rather than the content of what was said. Using the techniques of conversation analysis, they showed that stroke sufferers had little agency in the telling of their stories. Their

'dysfluency' was not related to the side of the brain that was damaged, but instead was a function of their disempowered status in such interactions. For example, they report instances in which the spouse would re-issue questions to the patient, or answer the patient's questions. The following is among the examples quoted. W is used to represent the spouse, and for ease of reading the spouse's talk is in italics:

Excerpt 6

- 14 I: And then what happened? Did you fall down?
15 H: I fell down
16 W: uh huh
17: I: And that was the first stroke?
18 W: *That's the first stroke that he had*
19 I: And how long ago was that?
20: W: *Aw (.) that was May the fifth*
(Manzo, Blonder & Burns, 1995: 317)

Manzo and colleagues note that what follows the interaction in excerpt 6 is a remarkable pattern of dominance by the spouse, even though the patient, H, had suffered a right-hemisphere stroke which did not affect his production of language.

A particularly interesting symptom of stroke is anosognosia, a term used to describe the sufferer's denial of damage that has resulted from his or her stroke. The origins of this phenomenon have been the subject of some debate, and have variously been described as a cognitive, multi-modal sensory perceptual deficit, a form of psychoanalytic denial, and a coping mechanism designed to protect the sufferer's self-image (Pimm, 1997). Bendz (2000) suggests that self-image might be threatened by the stigma that is often attached to a lack of bodily control. She found that the participants in her study were not inclined to reveal the impairments brought about by stroke. It has been suggested that sufferers' tendency to underestimate cognitive impairment renders them less able to adapt to their stroke (Gauggel, Pelaska, & Bode, 2000).

Research suggests that there are two important issues for people who have had a stroke. The first is that people whose lives are disrupted by stroke face uncertainty about the future. Second, they may experience an objectification of the body, so that the self feels as if it is separate. The body may be viewed as something out of the control of the mind. These issues will be discussed in turn.

The research suggests that people who suffer stroke experience a disruption in their lives that brings about uncertainty as to the future. This is discussed by Ellis-Hill and her colleagues who report that: "[a]ll of the respondents described their lives as having undergone a change that could be likened to entering a new foreign world" (Ellis-Hill *et al.*, 2000: 727). This effect was also found in a study in which 100 people were interviewed up to one year post-stroke (Becker, 1993). Glass and Maddox (1992) also describe the post-stroke experience as a psychosocial transition in which the effect of sudden change is to cast doubt on the sufferer's previous assumptions about the world and how he or she is to live in it. Similarly, Bendz (2000) reports that for her participants, stroke brought with it feelings of uncertainty as to the future.

The other fundamental effect of stroke discussed in the literature relates to the relationship between the sufferer and his or her body. In her study of post-acute survivors, Bendz found that the main impact of stroke related to the person's relationship with dysfunctioning parts of his or her body. These were referred to as if they were separate objects, "not included in their personality" (Bendz, 2000: 716).

She suggests that

"[s]uch an objectification allows them to retain their identity better from the time before the stroke. They can imagine themselves as the persons they used to be, and the ones they want to be, with the exception of some dysfunctioning part"
(Bendz, 2000: 716)

This suggests that the sufferer's relationship with his or her body has a direct effect on that person's identity. Keppel & Crowe (2000) similarly reported an association between a negative body image and low self-esteem in people who have suffered a stroke.

This theme was further explored by Ellis-Hill and colleagues (2000), who interviewed 8 stroke sufferers and their spouses, using a life narrative approach. They suggest that people who have had a stroke experience a 'self-body split'. Normally, they argue, the body and self are felt to be inseparable, the self being created by the body's relationship to the outside world (Leder, 1990; Merleau-Ponty, 1963). They refer to Gadow's (1982) proposal that it is the unity of the self and body that makes us able to distinguish ourselves from others. When the body can no longer be made to act by the will, it separates from the self and takes on the nature of an object. Ellis-Hill and colleagues found that the self-body split was experienced for some time. As they describe it,

"[a]fter they had returned home, the participants in our study gradually built up a working relationship with their bodies but even by one year this relationship could break down at times. Maintaining the status quo required constant effort and concentration. One year after the stroke the task of restoring the self-body split was still continuing for most respondents in the face of the emotional, social and physical consequences of a changed body"
(Ellis-Hill *et al.*, 2000: 731-732)

The notion of control over the body has also been explored from a cognitive psychological perspective, using self-regulatory models. Partridge and Johnston (1989) found that beliefs about perceived control over their physical incapacities predicted recovery in stroke patients, and later research found the same relationship, independent of the effects of coping, exercise and mood (Johnston, Morrison, Macwalter, & Partridge, 1999). Thus feelings of being in control over the body have been associated with improved recovery.

These findings resonate somewhat with research already reported in my review of chronic illness from the experiential psychological perspective, discussed in the latter part of section 2:2:1. This research suggests that from the sufferer's point of view, there are two important issues. These are, first, that people in this situation seem to experience some kind of disruption of the self-concept which results in a need for some reassessment of their life story. This includes a consideration of the past, the present and the future, and how they can be reformulated to make some sort of meaningful narrative. Second, researchers describe the importance of the body in the individual's sense of purpose or value. A review of the literature suggests that stroke sufferers experience this condition as a biographical disruption, and that a lack of control over the body can have a negative impact on identity. There appear, then, to be commonalities between the experience of stroke sufferers and people with other chronic conditions.

This review mirrors the review of ME literature, and therefore goes on to explore the history of stroke.

2:4:2 History of stroke

In their paper on the history of stroke, Pound and colleagues (1997) argue that the condition has been conceptualised very differently over the years. The fact that the medical profession is relatively powerless to help, leaving the responsibility for recovery with the sufferer, is reflected in the fact that the lay term 'stroke' has largely supplanted the clinical description 'CVA' (Cerebro-Vascular Accident). This will be discussed more fully below.

The first recorded use of 'stroke' in English literature (in 1599) referred to it as "the stroke of God's hande." Subsequent references to "the stroke of justice" and "a

dreadful visitation" are used by Pound and colleagues to illustrate their argument that stroke was seen, for centuries, as a punishment for such things as indulgence, excess and extremes of passion (especially joy). From the time of Hippocrates, however, until the first half of the 20th century, the *clinical* description of an illness in which the sufferer fell to the ground, losing the powers of motion and speech, was 'apoplexy'. By the end of the 18th century, the classification of diseases on the basis of bodily signs (which could now be seen *post mortem*) rather than reported symptoms, was beginning to take place. Gradually, the theory of arterial wall degeneration led to the use of the term 'cerebrovascular accident' (CVA).

From the 1950s, medical and surgical treatments were explored, but with very limited success. In a review of past volumes of a medical teaching textbook, Pound and colleagues found that in relation to stroke, 'physiotherapy' was first mentioned in 1952, 'rehabilitation' in 1956 and 'occupational therapy' in 1964. Thus, they chart the development of a team approach to stroke in which the sufferer plays an active role in recovery. It is from this period onwards that the use of 'stroke' became widely adopted in the medical literature, although 'CVA' is still used by some practitioners, and especially in the acute phase, during which the sufferer is often highly dependent on hospital care.

The adoption of different terms for stroke seems, then, to reflect the extent to which clinical medicine is able to treat this condition. To revert back to the lay term might suggest that this is limited. Salmon & Hall (2003) argue that when the sufferers of illness are held to be agents in their recovery, this allows clinicians to withdraw from responsibility from problematic areas. This influences the ways in which stroke is treated.

2:4:3 Treatment of stroke

There is little in the way of medical, or surgical treatment for stroke. Any physical recovery that does take place is said to be 'spontaneous' - meaning that it is not the result of medical intervention - and is hard to predict. Recovery is thought to happen mostly during the first 4-10 weeks after the stroke (Ebrahim, 1990; Mayo *et al.*, 2004), and to tail off within six months (Nilsson, Jansson, & Norberg, 1997). The condition of stroke survivors will improve spontaneously when damage is of a temporary nature - for example if it is caused by pressure on the brain that subsequently is relieved. Where brain tissue has died, the effects are thought to be permanent.

The focus of medical care for stroke sufferers is on 'rehabilitation'. Recent research suggests, however, that rehabilitative activities are clinically supported only in the short term, and that stroke sufferers are subsequently given very little follow-up (Langhammer & Stanghelle, 2003). This means that much of the responsibility for getting better rests with the stroke sufferer. In such circumstances, interpretations of illness can take on a moral dimension (Benner, Janson-Bjerklie, Ferketich, & Becker, 1994; Halligan & Cockburn, 1993). That is, the sufferer can be held liable for the onset or the progress of his or her condition. A number of risk factors for stroke, which relate to sufferers' pre-morbid lifestyle, have been identified. It is more likely to happen to people over the age of 65, who smoke, take little exercise, and have raised blood pressure (Pound *et al.*, 1997). Using this information, GPs can calculate a person's 'risk score' for stroke (Coppola, Whincup, Papacosta, Walker, & Ebrahim, 1995). People who have 'mini-strokes' (or TIAs, that is, Transient Ischaemic Attacks), where recovery is complete and takes place within 24 hours, are more likely to have a subsequent stroke (Sacco, 2004). This means that he or she might not just be held liable for the stroke, but might also be seen as responsible for preventing further episodes. Some researchers (Nogueira-Antunano,

Nogueira-Bonanata & Pla-Gaspari, 2003) have even suggested that people who suffer stroke are likely to have a 'Type A' personality - first identified by Rosenman and Friedman (1974) as characterised by free-floating hostility, excessive competitiveness and time urgency .

Research into the ways in which people cope with stroke suggests that some strategies are unhelpful. However, the findings are contradictory. While one study reports the negative effects of problem-focused coping (Kremer & Quednau, 2002b), another suggests that avoidant coping is associated with the onset of depression in stroke sufferers (Finset & Andersson, 2000).

The aim of rehabilitation is to enable the patient to relearn the practical skills that are necessary to prevent physical degeneration - such as that caused by restricted movement - and to regain functional competence. This approach has been criticised because it can fail to take into account the psychological and emotional effects of stroke (White & Johnstone, 2000). Furthermore, the emphasis on *function* may not reflect the interests and experiences of the sufferer (Kirkevold, 2002). Pound, Gompertz & Ebrahim (1998), for example, suggest that the importance of function may have been exaggerated because the research perspective that predominates in the stroke literature is quantitative, and therefore lays particular emphasis on measurable indicators of physical abilities. They quote two qualitative, American studies that show a greater complexity of sufferers' experiences. Kaufman & Becker (1986), for example, found that as well as losing functional independence, stroke sufferers missed their former ease of movement, energy and sense of wholeness. They noted that medical practitioners' preoccupation with the observation and measurement of rehabilitative tasks was shared by sufferers only in the first few months post-stroke. Thereafter, stroke sufferers co-operated, but were not 'engaged', their main interest having moved to *recovery*, "a non-specific, diffuse goal which implies notions of

normality, continuity and identity" (Kaufman & Becker, 1986: 83). Kaufman (1988) reports a discrepancy between sufferer's experiences and their apparent functional recovery:

"When patients are asked, "do you feel you have recovered from the stroke?" or "do you feel your life is back to normal?" the answer is invariably "no." Even patients without a visible disability give this answer, for they believe that they are physically, emotionally, or cognitively different from their former selves, in spite of "perfect" performance in therapy. This may be surprising to practitioners who see that visible rehabilitation goals are being met" (Kaufman, 1988: 86)

Similarly, in her PhD thesis, Ellis-Hill (1998) found that two years after their stroke, participants saw themselves as less active, satisfied, independent or interested than they had been pre-stroke. These perceptions did not appear to be related to the severity of the physical impairment. Thus, the observable level of physical impairment is not a reliable indicator of the stroke sufferer's experience of illness.

The relative lack of qualitative research on stroke sufferers' experiences cannot be put down to communication difficulties. Only between 10% and 16% of people who survive a stroke suffer dysphasia, and in its more moderate form, this may manifest itself only as mild naming problems (Ebrahim, 1990).

This review of the stroke literature suggests that sufferers experience a sense of biographical disruption, and that problems of bodily function can have an impact on the sense of self. From a historical perspective, research suggests that there has been a withdrawal of clinical involvement, so that sufferers bear much of the responsibility for their recovery and treatment. The help that is offered is not always targeted at the priorities of those who have had a stroke.

This literature review has focused on three important themes in the study of chronic illness in general. These are, the ways in which illness is conceptualised, the effects it can have on the sufferer's identity, and the ways in which people can cope with it in the social context. It then moved on to a review of definitions, history and treatment of ME and stroke in particular. Much of the research takes a traditional view on chronic illness. This will now be contrasted with the potential offered by the social constructionist perspective which is adopted in this thesis.

3. A social constructionist perspective on chronic illness

Social constructionism has its roots in a number of different disciplines, including philosophy, sociology and linguistics. A variety of interpretations and theories has therefore developed that could be described using this umbrella term. We can, however, trace the fundamental assumptions that distinguish what Gergen describes as a 'social constructionist orientation' (1985:266) from a traditional, psychological approach. This will illustrate the theoretical basis for the research reported in this thesis. It will also serve to highlight the particular benefits of examining the experience of chronic illness from a social constructionist perspective.

Gergen (*ibid*) argues that there are four basic tenets of social constructionist enquiry. The first is that it takes a critical stance towards conventional knowledge. That is, it challenges the view that what we know about people, or objects in the world, is based on the objective observation and then description of some pre-existing characteristics. The second assumption is linked to the first. One of the reasons that we should be critical of the notion of an objective reality is that our knowledge is highly dependent on social context, history and culture. Thus, conceptualisations of psychological processes differ across time and from one culture to another. The third tenet of social constructionist enquiry is that a form of understanding will appear consistent, and

therefore reliable, to the extent that these characteristics are sustained by social communicative processes, such as negotiation and rhetoric. This means that our knowledge of the world originates in, and is sustained by, social practices. Fourth, "[d]escriptions and explanations of the world themselves constitute forms of social action" (*ibid*: 268). So, for example, to construct illness as either psychological or physical has different implications for the way that sufferers might be treated.

Gergen relates the social constructionist orientation to two key standpoints that have held sway at different times in the history of philosophy and epistemology - empiricism and rationalism. Empiricists propose that things, events, people and so on have an objective reality which imposes itself on us, so that what we know about the world is an accurate reflection of how it is. Rationalists hold that knowledge depends on processes inherent in the individual rather than the essential properties of things and people in the world. Gergen argues that traditional perspectives in psychology are fundamentally rooted in empiricism. Behaviourism, for example, assumes we are shaped, or conditioned, by a process of adaptation to the realities of our external environment. A turn to cognitivism from around the mid-1960s reflects a change in emphasis. From this perspective, the individual's thought processes are said to influence his or her action in the world. For example, an inherent tendency to categorise is thought to influence not only the way we see others, but the way we view ourselves (Turner, 1982). The roots of cognitive psychology could, then, be described as rationalist. However, it is based on empiricist assumptions, inasmuch as it claims objective knowledge of the ways in which we think about the world - for instance, in terms of schemata, and with reference to particular models of information perception and retrieval. The anti-essentialist and anti-realist underpinnings of social constructionism are inconsistent with empirical traditions in psychology. If meanings are socially constructed, it follows that knowledge will be historically and culturally specific. We would therefore expect meanings to change over time and across

different contexts, and this means that there is no such thing as an objective, essential reality that is not potentially open to challenge. Furthermore, "all psychological theorising and the full range of concepts that form the grounds for research become problematic as potential reflectors of an internal reality" (Gergen, 1985: 271).

What we have come to think of as 'facts' do not reflect an objective reality, but instead are the result of a continuing process of negotiation (Berger & Luckmann, 1966).

Thus, definitions of illness, of identity and of coping are the product of social practices in which language plays a central role. The focus of interest is not exclusively on the content of discourse, but on the possible *functions* of what is said. Shotter (1981) describes a process of 'joint action' in which meanings are constantly being negotiated in interaction. There is little value in interrogating a person about his or her intentions or attributions, because joint action takes place not within individuals, but between them. The site of enquiry therefore moves from the individual to the ongoing interaction that takes place between people, because "we constitute ourselves and our worlds in our conversational activity" (Shotter, 1993: preface). Billig (1987) has suggested that a great deal of interaction is argumentative. That is, there is an underlying rhetoric defending the position of the speaker, who is not describing something 'out there', but constructing and defending his or her version of it. It is of particular interest, then, to explore the nature of those rhetorical devices that are deployed in social construction.

There is a long history of psychological research into the importance of language in the ways that we experience our world. The Sapir-Whorf hypothesis (Sapir, 1947) proposed that the nature of thought is determined by the language that is available to the thinker. That is, we can only think in terms of the concepts that are offered by the particular language(s) we speak. This was an underlying assumption of Saussurian linguistics, known as 'structuralism' (Saussure, 1974). Saussure distinguished

between the 'signifier' for an object or concept, that is, the noun used to refer to it, and the 'signified' (that to which the signifier refers). The key point that Saussure made is that the relationship between signifier and signified is arbitrary. That is, signifiers will vary according to the language spoken. There will be concepts that exist linguistically in one language but not in another, and this discrepancy is due to cultural differences. Saussure held that the sign is allocated once and for all to that which it signifies, and it is this consistency that enables people speaking the same language to communicate effectively.

Post-structuralists start from a Saussurian standpoint - the arbitrariness of the sign - but reject the notion that meaning is fixed. Indeed, they stress the extent to which we constantly *negotiate* meaning in everyday life. Language is not, then, merely used for the exchange of ideas. If it were, the important thing would be to establish the conditions under which the truth of utterances could be ascertained. Austin, a philosopher, questioned this notion, claiming in his 'speech act theory' that language can be seen as performative, and that "all utterances both state things and do things" (Austin, 1962: 243). Potter (1996b) notes the limitations that arise from Austin's use of hypothetical examples, in particular that they ignore the interactive context in which meanings are constructed. An utterance may both state and do things, but what it states and does will be different each time that particular utterance is made. Speech act theory did, however, draw attention to some of the action implications of talk. It suggested that if we study what is being done with language, we might understand more about social practices. For example, Austin (1961) suggested that an analysis of excuses would tell us about the kind of conduct that needs justification, and the kind of conduct that is acceptable. Following this, we might study the ways in which people speak about their illness experience to discover how illness is constituted.

The social constructionist perspective that I adopt in this thesis is also rooted in the ethnomethodological work carried out by Garfinkel in the 1960s and 1970s (Garfinkel, 1967; Garfinkel & Sacks, 1970). He demonstrated the value of studying the ways in which people act in their everyday lives. By focusing on these interactions, we can get some idea of how people understand their world to work. For example, in his famous breaching experiments, he showed that there are complex webs of social rules to which we generally adhere in our everyday actions. These rules become clearly apparent when they are broken. This approach was developed by Sacks (1979), who found that it is in everyday talk that people make sense of their worlds, and that there are expected patterns in speech, just as there are in everyday actions. Close attention to such patterns, and to their disruption, shows how it is that meanings are constructed in language. From this point of view, chronic illness, identity and coping are not treated as static, measurable phenomena but instead are treated as things that we *do* in talk (Antaki & Widdicombe, 1998a). There is no 'real' version of events that can be taken for granted. Instead, what we know about the world is accomplished in discourse that is both occasioned and variable. That is, each time people construct things or events, they do this within, and in response to, the local interactional context. We would therefore expect a level of inconsistency in constructions, as speakers orient to differing discursive demands.

Research into the experience of chronic illness, and its possible effects on the self and ways in which sufferers cope would benefit from a detailed study of the various ways in which these concepts are constructed in discourse. This can be demonstrated by a recapitulation of each of the three research themes:

3:1 Definitions of chronic illness - traditional psychological and social constructionist views

Researchers working from the cognitive perspective suggest that we have an internal set of schemas about the nature of different types of illness. We refer to this when deciding whether or not we are unwell, what might be wrong, what might have caused the illness, how it might affect us, and how long it might last. We then adopt particular coping strategies, and these have been associated in the research with different qualities of outcome. However, the research suggests that people suffering from chronic illness do not demonstrate such categorisation in the ways they talk about illness. For example, when Williams (1984) asked participants about what might have caused their illness, they did not talk in terms of medical aetiology, but instead gave a narrative account that made sense of the illness as part of their life stories. The biopsychosocial approach suggests that there are subtle differences between physical impairment and socially acknowledged illness, a distinction that is shown to be crucial from the sociological perspective.

In the particular case of ME, we have seen evidence to suggest that the definition of this illness is contested. Sufferers prefer to use a term that denotes an illness with a distinct physical pathway. The term used by health care professionals - CFS - avoids such an inference. However, clinical research definitions of the illness described by this term have changed over time and remain in a state of flux. This casts some doubt on the usefulness of the concept of illness schemas and suggests, rather, that illness definitions are ongoingly negotiated. The importance of social context is also apparent in the definition of ME. Uncertainty surrounding its origins can put sufferers in a problematic situation with regard to others. There is some debate about the extent to which ME is 'psychological' and not a physical illness, and research suggests that the former is often considered less 'legitimate' than the latter. If, for example, it is caused

by stress, and this is something that could have been avoided, then the sufferer may be held to blame for his or her condition.

In the particular case of stroke, the literature similarly suggests that definitions do not take the form of schemas that can be referred to for an understanding of this conditions. For example, research suggests that the link between type and site of lesion is complex, and that knowledge of the physical injury is not, therefore, sufficient to predict symptoms. This condition has been re-conceptualised over the years and it has been proposed that the clinical adoption of the lay term 'stroke' reflects some level of transfer of responsibility for this condition from the healthcare professional to the sufferer. This can have implications for the sufferer's relationships with other people.

Thus, for both stroke and ME sufferers, there is uncertainty as to the duration of their condition, and indeed the extent to which it might either improve or deteriorate.

Controllability is not a concept that stands on its own, but one that is reflected in the sufferer's relationship to his or her body, which in turn can influence the construction of the self.

From a realist perspective, that is, one that allows for the establishment of an objective truth about the nature of phenomena, illness is definable in terms of its causes and effects. From a social constructionist perspective, the meaning of illness is locally worked up, defended and contested. Thus, a fundamental assumption is that meanings will change over different contexts and different times. In her PhD thesis, Horton-Salway (1998) explores the struggle for authorship of ME in the discourse of medical scientists, general practitioners and sufferers. She shows how diagnostic labels and explanations for illness are both constituted and deployed in participants' talk. In our current western culture, the clinical account of illness is privileged.

Parsons (1951) noted the part that the medical establishment plays in enabling sufferers to access the sick role. This theme has been developed to show how the clinical account can be used to confer or deny access to social goods, such as welfare benefits (Radley, 1994; Taylor, 1992). Freidson (1970) argues that, when it comes to deciding what constitutes a specific illness, the voices of doctors and medical researchers are usually given more warrant than those of lay people. This, however, was not always the case. Jewson (1976) argues that the individual's involvement in diagnosis was greatly reduced with the introduction of tools such as the stethoscope, which were thought to provide doctors with more objective and reliable indicators of the symptoms of illness. Whereas symptoms, as perceived by the patient, were once vital to diagnosis, there has developed an intervening stage involving the interpretation of *signs* of illness, which can be verified by medical tests.

Over time, patients have become, literally as well as metaphorically, further removed from the diagnostic process, a large part of which these days may take place in the hospital laboratory or clinic. Armstrong (1983) points out that for most illness, the patient's participation in diagnosis is no longer required. Signs, being independently verifiable, are seen to provide more reliable evidence than reported symptoms, and to this extent they are the 'gold standard'. Following from that, those illnesses that can be diagnosed by medical tests appear to have a higher 'objective' status than those that can only be ascertained on the basis of reported symptoms. The most recent international clinical case definition of Chronic Fatigue Syndrome (Fukuda *et al.*, 1994) has excluded signs altogether in the diagnosis of this condition. This means that the status of CFS as a legitimate illness is uncertain. Indeed, definitions of this illness are contested and challenged not just among the medical profession, but by sufferers. Similarly, different versions of the history of this condition are provided depending on the preferred definition. Thus, those who judge ME to be a viral disease refer back to previous outbreaks of illness in which clusters of sufferers were

identified. Those who reject any viral aetiology can draw on historical descriptions of various types of nervous disease with similar symptoms to ME. We can see, then, that definitions of ME are contested, and have changed over time.

Even for stroke, a condition whose signs can be verified by medical tests, there is some disagreement as to the extent to which impairment can be linked to the site or size of lesion to the brain. Certain symptoms, such as anosagnosia (denial of impairment) are poorly understood, and some of the speech difficulties of stroke sufferers may not be due to internal damage, but rather to sufferers' disempowerment in interactions with others (Manzo, Blonder & Burns, 1995). Although there are cognitive tests that can be used to assess some of the impairment caused by stroke, the literature suggests that sufferers' concerns about the impact of their illness goes beyond the type of functions that can be measured in this way. Qualitative studies into their experience of illness show a far more complex picture of what it is like to have had a stroke. It is, therefore, crucial to pay close attention to sufferers' accounts of their experience of this condition.

The social constructionist perspective offers a unique insight into the nature of ME and stroke because it starts from the assumption that there is not one, 'real' version of events and instead places the focus on the ways in which meanings are made and how it is that we might understand the processes at work. Similarly, it provides a useful perspective on the ways in which illness might impact on the sufferer's identity.

3:2 Chronic illness and identity - traditional psychological and social constructionist views

Psychological research into sufferers' experience of chronic illness points to two ways in which it can affect the sense of self. First, it is described in terms of an interruption

to the individual's life story. The effects on identity are conceptualised by Corbin & Strauss (1985) in terms of 'biographical work', and by Williams (1984) in terms of 'narrative reconstruction'. Riessman (1990) describes the strategic use of 'story-telling' to maintain a sense of self. Second, its effects on the body can influence the individual's sense of purpose or value. That the effect of illness on the individual is more than simply corporeal is acknowledged in the biopsychosocial approach. The sociological perspective on chronic illness has drawn attention to its potential for stigmatising individuals, and to the moral implications of being sick.

There is little in the ME literature that relates directly to its effects on identity. However, some research suggests that a propensity for developing this condition, or for perpetuating it, can be related to the personality type of the sufferer (Cresswell & Chalder, 2001; Eichner, 1989; Riley, O'Brien, McCluskey, Bell, & Nicholls, 1990; Ware, 1992; Wessely & Powell, 1989). Thus, it is reported by some that characteristics of low self-esteem combined with perfectionism are associated with this illness (White & Schweitzer, 2000). Furthermore, this condition often follows an overly active, stressful pattern of living (Van Hudenhove, Neerinckx, Onghena, Lysens & Vertommen, 2001). Although there has been some criticism of researchers' tendency to assume a simple, causal connection between these factors, the implications for ME sufferers are serious. The review of ME literature, then, supports sociological research which points to the stigma and moral implications associated with chronic illness.

A review of the stroke literature suggests that there are feelings of 'disruption' of the self. Furthermore, the body can become objectified, or seen as something quite separate from the self, and a lack of control over the body can affect the stroke sufferer's self-esteem. This is similar to findings from the psychological perspective on chronic illness which suggest that biographical disruption, and lowered self-esteem

relating to impaired bodily function are key issues for sufferers. The identification of risk factors for this condition can mean that sufferers are potentially accountable for its onset. Furthermore, some researchers have suggested an association between personality type and the propensity to suffer stroke. Thus, we can see that stroke also has moral implications for the sufferer's identity.

From a traditional perspective, research into the association between personality and illness assumes that personality is something fairly stable, residing in the individual, that can be quantified and measured. Further, such measurements can be used to compare different individuals. Social constructionists avoid the term 'personality' because of its traditional, empiricist connotations, and instead refer to the self. There are three ways in which social constructionists have theorised about and studied the self. First, an analysis of grammar and linguistic practices has shed some light on the ways in which the self can be expressed (Harré, 1985). Another strand of research has focused on the ways in which particular discourses about the self help to maintain the power structures that exist in society (Parker, 1989). Others have concentrated on the performative functions of certain constructions of the self, that is, those things that can be discursively accomplished by describing the self in particular ways (Gergen, 1989). This third perspective provides a particularly useful approach to the ways in which chronic illness affects the self. Social constructionists have argued that we become who we are through interactive social processes. Potter & Wetherell argue for the importance of interaction in constructing the self:

"any sociopsychological image of the self, in fact the very possibility of a self-concept, is inextricably dependent on the linguistic practices used in everyday life to make sense of our own and others' actions"
(Potter & Wetherell, 1987: 95)

I have noted above that constructions of the self can be seen as performative. They are therefore likely to change according to what it is that the speaker is trying to

accomplish at any given time. In effect, according to Goffman (1959), the self is 'distributed' across different situational contexts. This notion is not intuitive. We do not necessarily feel that we are constantly, if subtly, changing the way we construct ourselves. Some theorists have suggested that to display consistency in our constructions of the self can itself serve a function. Goffman (*ibid*) suggests that the 'distributed self' must present some level of consistency to the outside world at least, in order to be understood.

Giddens takes the view that "we can learn a good deal about day-to-day situations in routine settings from analysing circumstances in which those settings are radically disturbed" (Giddens, 1979: 123). Bury (1982) argues that chronic illness represents one such set of circumstances. It constitutes a pressing threat to the individual's identity, which might otherwise be taken for granted in the daily routine of life. Much of the research on individuals' experience of chronic illness suggests that it brings about a disruption to the self-concept that demands some kind of recasting of the sufferer's life story. People who suffer from chronic illness often face an uncertain future. Physical incapacity can make it very difficult to assert certain aspects of their identity. They also have to deal with changing social relationships. They do not do this in isolation, but in interaction with other people. Gergen describes the value of discursive abilities in maintaining a sense of identity:

"self-knowledge is not, as is commonly assumed, the product of in-depth probing of the inner recesses of the psyche. It is not the result of acute sensitivity to the nuances of emotion, motivation, intention and the like. Rather, it is a mastery of discourse - a 'knowing how' rather than a 'knowing that'
(Gergen, 1989: 75)

Thus, the social constructionist perspective draws our attention to the ongoing negotiation of identity in a context in which the meanings of illness are also locally contested. In his MSc dissertation, Bland (1995) reports that participants' accounts of

ME were designed to emphasise the severity of symptoms and thus to counter possible ascriptions of deviant identity. Similarly, Horton-Salway (2001a; 2001b) shows how her participants worked up illness attributions and identity formulations in the context of countering potential accusations of malingering or psychological vulnerability. Tucker's (2004) analysis of the accounts of four ME sufferers concludes that narrative themes were employed to construct this illness as physical and that this oriented to the possible negative identity implications of having a psychological disorder. The relationship of the body to the mind is therefore an issue of some importance.

Turner (1992) has pointed out that the dualistic view of mind and body that has dominated research since the time of Descartes has resulted in a situation in which the body has, until recently, been studied in the natural sciences, while the mind has been the province of the humanities. Disease has traditionally been seen as something quite separate from the individual's self. From a social constructionist perspective, however, medicine, disease and the process of illness are all phenomena whose meaning is ongoingly defined in social interaction. Thus, when people who have had a stroke talk about the objectification of the body (Bendz, 2000; Ellis-Hill et al., 2000), this can be examined in terms of the function such a discourse might have, for example, on the sufferer's sense of self.

Foucault (1976) argued that the body is a socially constructed phenomenon, and that the 'medical gaze' has had a profound influence on the ways in which the body has been understood and experienced in western society. Others have proposed that social and environmental factors can only mould what is a (pre-existing) biological structure. Thus, Frank (1991) takes a social constructionist approach to the body and illness, while at the same time acknowledging the body's physicality. He presents the body as

"a recursive process of inscription and projection. Social and cultural processes inscribe the body with meanings, and the body, *which is always more than these meanings*, projects its realities onto social spaces." (Frank, 1991: 209; emphasis added)

Inscription and projection, according to Frank, come about in the course of narratives. He proposes, then, that while the self can to some extent create, or construct, the body, the body can *also* create the self, although the latter process is not well understood.

Shilling (1993) also argues that the individual is able to take part in the construction of his or her body, and that the body as project can be seen in our capacity to alter our physical selves, for example through fitness regimes or cosmetic surgery. Indeed, an ability to change our bodies is seen as a means by which we can exert some control in a changing and uncertain world. Shilling's argument suggests an intellectual self that influences the physical self. As a corollary to this, we might expect that unintentional changes in the body, such as those wrought by illness, may have some effect on the experience of the self.

The importance of the body to our sense of identity has also been noted by Harré (1983). On a practical level, the body identifies us to others. A philosophical exploration of how it is that we know a particular individual is the *same* person when a period of time has elapsed, points to the importance of physical, bodily appearance. Burkitt (1999) similarly argues that identity *depends* on a bodily presence that is capable of interacting with others as a distinct and separate physical entity. From this perspective, physical changes that affect the ways in which we can relate to others would also have an impact on the sense of self. Goffman's (1963) work also suggests that the management of the body plays a key role in social relationships and in the maintenance of identity. This activity is done in the context of social and

cultural influences, and these also provide the background for an understanding of the ways in which people cope with illness.

3:3 Chronic illness and coping - traditional psychological and social constructionist views

From the cognitive psychological perspective, coping with illness has been conceptualised in terms of internal mechanisms, so that inability to cope is the individual's problem. However, the suggestion that some coping strategies are better than others leaves the sufferer accountable to others for any failure adequately to manage his or her condition. Bury (1988; 1991) shows that the meanings given to illness by others are crucial, and Williams (1993) describes as the 'pursuit of virtue' the ways in which people who are chronically ill have to attend to their moral standing in the eyes of those around them. This is not something that is done once-and-for-all, but rather is a skill that has to be constantly worked at in interaction. The biopsychosocial approach to chronic illness acknowledges the fact that people are ill in a social context, and this is the main focus of enquiry in the sociological research.

The current clinical treatment for ME is based on the view that this condition is at the least exacerbated by maladaptive belief systems. These beliefs relate in particular to the seriousness of the illness, the ways in which it affects the sufferer, and the ways in which he or she should manage this condition. There is, therefore, a tension between what is considered to be the 'real' cause of illness, and how it should be treated, and the erroneous beliefs of sufferers. Thus, we can see that the negotiation of illness definitions is inextricably linked with the ways in which sufferers cope. This suggests that the notion of coping mechanisms operating on the basis of internal schemas is of limited value in understanding the ways in which people deal with ME. Furthermore, the suggested association between personality factors and illness attributions leaves the

sufferer potentially accountable for the way in which he or she copes with ME, and this draws attention to the social context in which people manage this condition.

For people who have had a stroke, the fact that there is very little in the way of medical or surgical treatment means that their role in recovery is crucial. This leaves the stroke sufferer responsible to some extent for his or her 'rehabilitation'. Thus the moral implications highlighted in the sociological literature on chronic illness are apparent.

Social constructionism takes as its starting point the importance of interactions in the ways in which we constitute and experience our world. Research has shown that people's talk about health and illness is characterised by ambiguities (Rogers, 1991). For example, people who are ill conceal their condition at some times but not others (Herzlich & Pierret, 1987; Wiener, 1975). From the cognitive, or medical perspective, these findings represent an anomaly. Such apparent contradictions in behaviour can, however, be accommodated if we consider the social constructionist emphasis on the function of language. Each time we speak, it is in response to the local context, and our talk is designed to orient to that context. People with chronic illness might, at times, construct their condition as serious. This is particularly likely to happen when the condition in question is one that is treated with some cynicism, as is the case with ME. However, at other times, the sufferer may be working to maintain his or her status in society as a fully-abled person, and might then strategically downplay the effects of the illness. Pollock (1993) found that people who are ill can, at times, feel morally obliged to make light of their condition, when asked to talk about it, in apparent denial of their observable physical limitations.

We have seen, then, that the social constructionist approach to illness, identity and coping offers the conceptual framework for a fruitful examination of the experiences

of people with ME and stroke. It suggests different types of questions from those that have been raised in traditional illness research.

4. Research questions

Traditional psychological perspectives might ask what ME is, or what stroke is, because of their underlying assumption that such things can be objectively defined. The 'gold standard' for such objective definition would be the clinical account, since this is rooted in empirical, scientific methodology. Sufferers' views have been conceptualised in terms of schemata, a hierarchical set of beliefs about their illness, relating to its identity, causes, consequences, time-line and potential to be controlled. The accuracy of such beliefs can be assessed by comparison with the medical definition. Experiential psychologists are concerned with the ways in which individuals weave the occurrence of illness into their life story in order to make sense of it. Although they do not assume the existence of concepts such as illness schemata, and they take social context into account, they nevertheless suggest that autobiographical work takes place within the individual.

Social constructionist perspectives are anti-essentialist and anti-realist, in the sense that they refute the existence of one, single, accurate definition of illness. Instead, the meaning of illness is produced in social interaction and it will vary according to historical time and context. Language is key in this process, and its action orientation is particularly significant. The objectivity of medical definitions of illness is not taken for granted; both clinical and lay accounts are seen as occasioned in talk or text, and they can be examined for the functions they might serve. In this thesis, then, sufferers' views of their illness are considered in their own right, and not with a view to judging sets of beliefs for their accuracy. Further, they are considered as social practices and not a reflection of inner states.

Social constructionists are similarly critical of the notion that the essence of individuals can be described in terms of personality types or characteristics. Instead, they view the self as an ongoing discursive production. They differ from experiential researchers in the extent to which they stress the social nature of this process. What becomes important, then, is not the sort of person who becomes ill, or the effects that illness has on a pre-existing set of attributes, but rather the ways in which identity is managed *in interaction* by people suffering from chronic conditions.

Finally, the traditional psychological approach to dealing with illness is to attempt to categorise sufferers in terms of their coping styles or behaviour. Again, this suggests that we can form an objective opinion on the nature of coping mechanisms, and that it is possible to attribute these unproblematically to people suffering from chronic illness. Experiential psychologists have drawn attention to the social context in which coping with illness takes place, and the particular relevance this has for people with chronic conditions. The perspective adopted in this thesis allows an exploration of *how* it is that individuals socially construct the ways in which they manage their illness.

The questions I address in this research are therefore:

- (i) How are ME and stroke constructed by sufferers?
- (ii) How do ME and stroke sufferers construct the impact their illness has on their identity?
- (iii) How do ME and stroke sufferers construct the ways in which they cope with their condition?

Chapter 2 provides a description of the particular methods used to explore these questions.

CHAPTER 2

METHODS

The rationale for this research was to analyse the discourses of people suffering from ME and people who had had a stroke. This influenced the ways in which participants were recruited and questions posed. I have already noted that illness definitions are contested, and that this is particularly apparent in the case of ME. Clinical and lay constructions of this illness can be quite different. It is, therefore, possible that there are people who consider themselves to be sufferers of this condition who are not recognised as such by the medical profession. Thus, recruitment via GP surgeries or clinics was not appropriate, and instead approaches were made to sufferers' support groups. For reasons of consistency, the same methods were used to recruit stroke sufferers. Stroke at a young age is defined by the support groups concerned as occurring at or before the age of 55.

There can be practical problems in arranging face-to-face meetings with people who suffer chronic illness. They may, for example, have problems of mobility, or difficulties in producing speech. Therefore, while focus groups were arranged where possible, it was considered a useful strategy to contact people via the internet. This has the added advantage of allowing access to a greater number of potential participants.

The specific details of recruitment are noted below, along with information on how data were collected, the questions that were used, and the numbers of participants. The chapter ends with a description of the analytic process.

1: Recruitment

I used two methods of recruiting participants in this research. To begin with, I looked for support groups for people with ME and those who had suffered stroke at a young age, where members met on a fairly regular basis. This information was found at the city's main public library notice board.

I then looked for web-based support groups for these conditions. The ME group ran a chatline which anyone could join. Correspondence on this chatline was available for everyone to read and respond to, but was not real-time. That is, members received every piece of communication in the form of emails, at around 60-70 messages per day. Personal communication was possible by emailing members 'off-line' on a one-to-one basis. The web-based support group for people who had suffered stroke at a young age worked in a different way. Anyone wishing to communicate did so by posting a message on to the board, to which access was public. In order to see the board, it was necessary to log on to the web site. Responses were linked to the original message, so that 'strings' of discussion could be seen under particular headings. This meant that the discussions were far less free-ranging than on the ME chatline. Furthermore, perhaps because responses did not automatically arrive by email, communication was infrequent, and a message could remain without response for months at a time. I did not, therefore, use this message board to post my questions but instead used it to make initial contact with stroke sufferers.

2. Data collection

All respondents were given assurances of confidentiality and contact details in case they wished to withdraw at a later stage (none did). All personal and place names were changed. Where hospitals were named, this was replaced by a numerical code (from 1-3).

I began by organising focus groups with those people I could meet face-to-face. I telephoned the support group organisers with a view to arranging these sessions. The organiser of the ME self-help group suggested that I conduct the focus group outwith their regular meeting times, and that communication with their members should be via the organising committee. I therefore wrote to the organisers with copies of an introductory letter for distribution, asking group members to come to a research focus group at my house (it was felt that access to the university would be too difficult). I later contacted the organiser for a different group outside the city, and through her I arranged a further two focus groups to take place at the hospital where they met; unfortunately, no-one actually turned up for the second of these. Consent was implied by attendance.

There are regular rehabilitation sessions run by the self-help group for people who have had a stroke at a young age. I contacted the area organiser, and was able to run a focus group following on from one such session at the hospital. Some months later, I conducted a second focus group with a different group of stroke sufferers at the same hospital. Some of the stroke sufferers came to this rehabilitation group with a carer, and these people also joined the focus group discussion. Again, consent to participate was implied by attendance.

With each focus group, I introduced myself and explained to the people attending that I was keen to hear them discuss the questions I asked among themselves, with minimal input from me. This was because my aim was to focus on and give voice to participants' concerns. I had asked permission to take an audio-tape of the sessions, and was able to use individual microphones for most people, with a large desktop microphone in addition to improve the quality of the recording.

I then contacted the web-based support groups. I posted a message on the ME chatline, introducing myself and asking if people would be prepared to answer some research questions - preferably as part of the chatline, but otherwise on a one-to-one basis (that is, via personal email address). Then, over the next several months, I posted my questions one by one on the chatline, each time re-iterating that this was being done in the interests of academic research. I waited until any discussion which had arisen had died down before introducing the next question. I acknowledged all correspondence, and copied all of the discussions to file. At the same time, I sent questions individually to the people who preferred their answers to be private. I posted a similar introductory message on to the stroke website, again noting that the purpose of collecting this information was academic research. Because of the way that this support group was run, and the lack of activity on its message board, the only practical way to get through my questions was to send them individually to people who had responded personally to my original message.

2:1 Use of the internet

I carried out a review of the literature relating to the use of the internet for conducting research. This was focused on four particular areas. The first related to methodological skills involved in reaching particular groups, real-time interacting and appropriate ways of recording data. The second related to the potential ethical problems associated with 'lurking' on real-time chatrooms. This describes a situation

in which a person can log on and observe other people's conversations without them being aware of his or her presence. Since all of my communications were direct, such ethical issues did not arise. There is also a body of literature concerned with the reliability of data gathered, for example, by means of online questionnaires. The issue here is whether people are telling the truth, or whether they are who they claim to be. My focus, however, was to analyse accounts provided by people who constructed themselves as sufferers of either ME or stroke. The underlying assumption, then, was that the reality of such claims is of less interest than the ways in which they are constructed as real. The fourth category of literature explored the potential influence of computer technologies on communication, and I will discuss some key issues relevant to this thesis below.

Computer-mediated communication - commonly referred to by its acronym, CMC - covers a wide range of interactive possibilities. They can be categorised as either synchronous - as in the case of 'real-time' chat rooms - or asynchronous. The latter would include communication via email or notice boards. The internet data collected for this study would be considered asynchronous. Another way of categorising such interactions relates to the (online) co-presence of other people. Since all emails sent via the ME email support group were distributed to every member, there was a potential audience for such communications. One-to-one emails can presumably be considered to be private correspondence.

Lamerichs & Molder (2003) trace the history of CMC research and note that the original focus was on the ways in which interaction was affected by the lack of visual cues available. This was influenced by earlier work into communications technologies. For example, Short, Williams and Christie (1976) compared face-to-face with telephone interactions and concluded that the latter was an impoverished form of communication. Rutter's (1984) 'cuelessness model' suggested that some

media offer fewer cues than others. To the extent that cues are not available, it was argued, interaction loses its personal nature and becomes task-oriented. Furthermore, normative social influences are diminished, and the behaviour of interactants is therefore prone to becoming extreme and uninhibited.

Later research questioned the notion that such interaction effects were an inevitable consequence of using CMC. Spears & Lea (1992), for example, suggest that social cues were not dependent on physical presence alone. Furthermore, they argue that visual isolation and anonymity can, under certain circumstances, increase feelings of group coherence and therefore adherence to group norms. That is, there are fewer indications of difference between people, and so more chance that others might be perceived as similar to us. Similarly, Bowker & Tuffin (2004) suggest that the online environment may facilitate a greater level of social interaction, that the lack of social cues may lessen the opportunities for negative evaluation by others. Although these claims represent a challenge to earlier assumptions regarding the use of CMC, the focus remains on the ways in which such technological advances impact on users.

Another area in which CMC is thought to have an effect on users is in its potential for the dissemination of knowledge. Some writers are concerned about the implications of 'information overload'. Scott (1997), for example, claims that as more information becomes freely available, we become less able to make judgements as to its validity. Instead of trusting what we are told, for instance by an 'expert', we are in a position of uncertainty. Traditional, scientific knowledge, such as that provided by medical practitioners, is replaced by a chaotic mass of information whose sources vary in reliability. Nettleton & Burrows (2003) demonstrate the vast amount of information available to anyone who performs an internet search on illnesses such as asthma and eczema. They argue that it is often difficult for consumers to judge the validity of these data. There is therefore the risk that trivial knowledge will undermine that

provided by medical experts. It is interesting to note here the similarities in Wessely's (1997) claim that greater access to information in the media has led ME sufferers to question the expertise of clinicians working in this field.

Related to the issue of the dissemination of knowledge is that of access to the internet. Writers have noted that CMC provides a greater level of social inclusion for people in minority groups, such as the chronically ill (Hardey, 1999) and those with incapacitating physical or speech difficulties (Bowker & Tuffin, 2004).

Hutchby (2001a; 2001b), however, questions the idea that information technologies have inherent properties that impose themselves on people with predictable results - for instance that CMC will lead to depersonalised behaviour, or that its capacity to provide large amounts of information will result in uncertainty or a lack of confidence in clinical expertise. Instead, he argues for a different way of conceptualising the relationship between society and technology. He proposes that technologies can themselves be shaped by human practices, within certain practical limits. He draws on Gibson's (1979) concept of 'affordances' to illustrate this proposition. This was developed in the psychology of perception to describe the ways in which humans, animals, insects, birds and fish relate to objects in the world. The same object, it is argued, has certain material properties, but will afford different uses to different species, and in different contexts. Thus, a rock might be perceived and used as a shelter by an insect or a missile by a human. The implications for CMC research are that we cannot assume *a priori* that it changes human interaction in specific ways, or that the influence is only in one direction. While CMC may impose some constraints on human activity, it can also enable new and creative forms of interacting as people appropriate the new technologies for their own purposes.

What is needed, then, is an examination of how CMC is used *in practice*, in order to examine its role in social interaction, the dissemination of knowledge and social inclusion. With regard to social interaction, Yates (2001) studied a corpus of data gathered from a variety of CMC media. His analysis of linguistic markers showed that the words 'I' and 'you' were used more frequently in CMC than in data gathered from a very large sample of general spoken and written English. Although he does not examine the interactional function of these pronouns, Yates concludes on the basis of their widespread use that CMC is not depersonalised. He also found a particularly high count for the verbal formulation 'I am' in video-conferencing and chatrooms. These kinds of interaction involved people from a large number of nations and societies. Yates suggests that such contextual issues must be taken into account, as well as the particular medium of communication. Fernback (2003) notes that online communication is not marked by uninhibited behaviour, but rather that conventions - often referred to as 'netiquette' - have evolved in response to some of the constraints of CMC. For example, the upper case is used to indicate a raised voice, and as such it is generally used sparingly.

In relation to the dissemination of knowledge, an analysis of illness narratives produced on 'home pages' (Hardey, 2002) reports that sufferers were transformed from consumers to producers of health care information. That is, their own experience became a resource for other people (as well as a means by which they might develop their own understanding of their experiences). Hardey suggests that this might reflect the development of a new relationship between medical expertise and lived experience of illness. In terms of access to information available via CMC, Nettleton & Burrows (2003) argue that the mere provision of internet facilities will not necessarily lead to a greater level of inclusion. For example, much depends on the *use* made of such technologies.

From the point of view of this thesis, there are also analytic issues involved in comparing internet with focus group data, an important aspect being the differences between written and oral communication. The internet data gathered were in textual form. However, some writers have suggested that despite this, CMC can have oral qualities. Yates (2001) makes the point that the terms 'written' and 'oral' refer to socially learned practices rather than mere modes of communication. 'Doing writing' may in some circumstances be similar to 'doing talking'. Research carried out before the use of word processing became widespread has shown that speakers have a narrower range of lexical use than writers (Chafe & Danielewicz, 1987). We might expect, then, that CMC, with its possibilities for easy correcting and reviewing, would display an even greater range than the written texts used to support this finding. However, Yates found this was not the case; CMC resembled oral vocabulary variance more than written. He suggests that it is not the medium but the social practices adopted by its users that affect their use of language. Instead of comparing it with either oral or written communication, we should consider CMC in its own right as a practice, or rather a number of practices. Similarly, Fernback (2003) concludes that CMC is a site of oral culture, though one that undoubtedly possesses print characteristics.

This review suggests that internet use may influence the kind of data that are collected, but that the nature of such influence should not be assumed in advance. Furthermore, issues arising from the use of the internet are best explored by analysing what happens in practice.

3. Schedules of questions

I made up a schedule of 13 questions. Of these, four were directly related to the research themes. Thus, I asked participants to describe their condition in order to see

how they constructed it. I asked how their illness had affected them as people in order to explore issues of identity. I asked what advice they would give to other sufferers, and how they themselves dealt with their illness in order to examine the ways in which they coped. A further 9 questions were asked in an attempt to generate general discussion that might have some relevance to this study. All of the questions can be seen in Appendix I.

4. Participants

There was therefore a total of 56 ME participants, of whom 49 were internet correspondents. The total number of stroke participants was 22. The breakdown of participants is as follows:

	Focus Groups	Internet
ME	7	
ME Chatline		38
ME Internet Personal Correspondence		11
Stroke - sufferers	12	
- carers	5	
Stroke Internet Personal Correspondence		10

5. Analysis

Discourse analysis is not one method, but rather an approach to data that is shaped by the particular epistemological standpoint of the researcher, the topic of investigation

and the type of material that has been collected. The methods of analysis I use in this thesis are rooted in the theoretical assumptions I have outlined above. These are that language has a social function, it is a medium of social action (Edwards, 1997) in that it is used to *construct* what is spoken or written about, and it reflects neither a pre-existing reality, nor the internal psychological processes of the interactants. Analysis therefore focuses on *how* it is that accounts are constructed, and the *functions* that such constructions might serve. To this end, I draw on methods of conversation analysis for the fine-grained examination of local interactional business, and also make use of some of the insights provided by narrative analysis. A broader analysis of patterns across the data enables me to relate discursive practices to the wider social context. I will discuss each of these approaches in turn.

Conversation analysis is informed by the ethnomethodological assumptions that there are systematic properties underlying social interactions, and that if we study such interactions closely enough we can see normative patterns in behaviour (Garfinkel, 1967). Thus, Sacks and his associates Schegloff and Jefferson (Sacks, 1979; Sacks, 1984; Sacks, Schegloff, & Jefferson, 1974) turned to naturalistic recordings of everyday talk and found that it is designed at a highly detailed level to respond both to the sequential context and to the interactional work that is being done. This has a special significance for the social constructionist claim that reality is not something that is constructed once-and-for-all, but is, rather, an on-going interactional achievement. Conversation analysis enables us to examine *how* facticity is worked up by participants at local and interpersonal levels.

The key focus of conversation analytic study is naturally-occurring dialogue, untainted by the imposition of researchers' own interests on what is said. It is, however, possible to draw on the principles and findings of conversation analysis in other

research contexts, and I will discuss this with reference to three characteristics of the ways in which data were collected for this thesis.

The first and most obvious is that participants' contributions were not part of naturally-occurring, everyday interactions. Rather, the data were gathered for the specific purpose of examining sufferers' views and experiences of two particular chronic illnesses. A schedule of questions was used in order to elicit discussion of the areas identified as important in the course of a review of the literature. This inevitably influenced the content of responses. To address this, attempts were made to focus on participants' concerns, for example by using open and general questions, and refraining from directing the topic of ongoing discussion to particular areas once the initial question had been asked.

Classic conversation analysis of naturally-occurring dialogue involves the compilation of a collection of examples of particular conversational phenomena. By studying such collections, it has been possible to demonstrate patterns that are normative in the sense that their disruption is accountable. For example, Sacks showed that certain types of utterance seem to call forth certain other types of utterance. One such 'adjacency pair' is invitation/reply to invitation. Adjacency pairs have quite systematic properties relating to the usual order in which they appear, and the kinds of response that are preferred. Such conversation analytic findings can be used as a resource for the analysis of non-naturally-occurring data, and can therefore help to shed light on the kinds of actions that might be taking place.

The second way in which data gathered in this research differs from the classical conversation analytic methodology is in the use of focus groups and one-to-one interviews. Kitzinger (1994; 1995) has noted that a key advantage of using focus groups to gather data is that participants interact, and even when this is not explicit in

the data, their talk is potentially directed towards an audience of other participants. Although such interaction cannot be described as 'natural', it nevertheless provides a rich context for the study of participants' views. For example, the variety of communicative actions is likely to be greater than in one-to-one interviews, and can include things such as jokes, teasing and arguing (Kitzinger & Barbour, 1999). In focus groups, participants are not always responding directly to the interviewer, and it is possible to examine the ways in which their constructions are interactively shaped. The potential to do this is extremely important in conversation analysis. It is crucial to ensure that findings do not stem from researchers' assumptions but instead are demonstrably oriented to by participants. Hutchby and Wooffitt (1998) refer to this as 'next turn proof procedure'. This involves the turn-by-turn analysis of talk, to see how it is that interactants take up what has just been said, and how their response in turn shapes what might come next. For example, it is not enough simply to denote a statement as constructing fact if it is not treated as such by other interactants. Where next turn proof procedures cannot be used to verify analytic conclusions, participants' self-repair can be examined for its orientation to the possible uptake of what was said, and what might have been said. Thus, in the detail of talk we can see how different versions of events are worked up, collaborated upon, treated as factual or undermined in different ways.

There is far less potential for such analysis in one-to-one interviews. A significant feature of the interview data in this research is that participants' turns are extended and conversational interaction is minimal. Hutchby & Wooffitt (*ibid*), however, suggest that the techniques of conversation analysis can still be a valuable resource for the study of data collected in this way. Researchers working within this tradition have, for example, systematically explored the use of particular conversational devices, and the possible functions they might have. Thus, Drew (1987) discusses the 'po-faced receipt of teases' as a device that works to counter the potential ascription of a deviant

identity. Data that have less obviously conversational properties can be examined, and better understood, with reference to such findings.

The third feature of the data gathered in this thesis, which is relevant to the use of conversation analysis, is that interviews were conducted via the internet and are therefore in written form. Oral communication is characterised by such features as overlaps, turn-taking devices, pauses and self-repair, all of which have been shown to be potentially significant in the analysis of talk-in-interaction. These features are absent in written communication, so that there are fewer conversation analytic resources on which to draw. However, it is still possible to read such data for properties that are not exclusively oral. For example, extreme case formulations can be used to present the best possible case for something in order to counter a cynical uptake (Pomerantz, 1986). These are potentially observable in written as well as verbal communication.

We can see, then, that conversation analysis provides some powerful resources which can be drawn upon to examine the data gathered for the research reported in this thesis. A conversation-analytically sensitive approach can shed light on participants' construction of illness categories, it can be employed to analyse the use of identity as an achievement and a tool (Antaki & Widdicombe, 1998b) and to explore issues of accountability that might arise from the ways in which the chronically ill person copes with his or her condition.

Another potential resource for the examination of data can be shown by reference to Riessman's (1990) exploration of the ways in which an MS sufferer managed to construct a positive identity in the face of disabling illness. She argues that narratives play a crucial role in helping individuals to make sense - for themselves and for others - of disruptive events such as the onset of serious and chronic illness. In an extension

of the usual boundaries of narrative analysis, Riessman examines stories not just for their linguistic content, but also for the *functions* they might serve. For example, a 'habitual narrative' tells of the general course of events over a period of time. Her research participant uses this genre to give an account of the reasons for his divorce. At other points, however, he produces a more specific story, a description of a particular event, and this serves to draw the hearer more fully into his world. It is therefore reserved for the telling of events that orient to particularly significant features of the speaker's identity. These narrative genres are used strategically, then, to provide a convincing illustration of the participant as a devoted husband and responsible worker. Riessman also draws attention to the fact that stories are necessarily selective renderings, and that accounts can be examined not just for the kinds of things they describe, but also for areas which are glossed over. A sensitivity to the action potential of narratives described by Riessman informed the analysis of data gathered for this thesis.

There remains the question of how we can relate findings to the wider social context. Schegloff (1992) distinguishes between two kinds of context that researchers might consider: the external, or distal, and the proximate. The former includes such things as social class, sex and ethnicity, categories that are routinely employed in a great deal of qualitative psychological research. The latter refers to things that relate only to the immediate features of the interaction being studied, and so might include the fact that data arose from an interview, or focus group, and the capacities in which people speak, for example as interviewer, ME or stroke sufferer, or carer. Schegloff argues that it is only the proximate context that should be provided by the researcher. Other features of context are of interest only at those times when they are made relevant by participants.

In conversation analysis, the burden of evidence for researchers' claims is on the demonstration of participants' understanding *as demonstrated in the data*. Analysis should not be motivated by researchers' *a priori* theories. This is a controversial issue. Radley & Billig (1996), for example, argue that talk about health and illness is ideological to the extent that it potentially perpetuates and renders 'natural' the social inequalities that are associated with ill-health. It also presents the sufferer with a particular type of dilemma. If he or she is to be accorded the entitlements that might be associated with ill-health - for example, sympathy, assistance or appropriate treatment - it is necessary to make the difficulties of illness manifest. At the same time, however, he or she has to display socially desirable qualities, such as a positive outlook, forbearance or strength of character. This, they argue, is the context in which research is carried out, and it should not be ignored. That is, participants can reasonably assume that the researcher, who is after all carrying out his or her work, is healthy. They will therefore orient to the moral requirement of providing an account of themselves that addresses issues of self-presentation and entitlement.

From a conversation analytic perspective, such an orientation is not discounted, but it could only be defended where it was identifiable in the data. We cannot assume in advance that participants will at all times respond with reference to these particular aspects of the research context, just as we cannot assume that they will necessarily orient to other characteristics such as the age, sex, or ethnicity of the researcher. Furthermore, in their discussion of the use of rhetorical devices that can work to convince a potentially sceptical audience, Hutchby & Wooffitt (1998) make the point that speakers' utterances may be designed to respond not to the interviewer but to cynicism in the wider community. This suggests that dilemmatic talk of the type described by Radley & Billig might be found even if the researcher was not deemed by participants to be a healthy individual enquiring into the lives of the ill. A sensitivity to the potential for accountability is therefore important at all times.

The issue of how research might be situated in a wider social setting divides discourse theorists, broadly speaking, into two schools of thought. Those whose work is informed largely by post-structuralist theory, as developed, for example, by Barthes (1977), Derrida (1976) and Foucault (1972), advocate the 'analysis of discourses'. Here, discourses are identified by the researcher through an interpretation of interactions, but are abstracted from their situated context. The adoption of a particular discourse offers particular implications for the interactant. For example, discourses can be related to the effects of power or ideology so that those people who adopt a certain discourse can use it to oppress those who do not, or perhaps cannot, use that discourse (Parker, 1992). This approach to analysis aims to expose the mechanics of disempowering ideologies and to give a voice to marginalised sections of society (Parker & Burman, 1993). The 'analysis of discourses', then, takes what Schegloff described as the external or distal context as a key to both analysis and action.

The alternative way to locate research in the wider social context, and the one that I use in this research, is proposed by Potter, Gill, Edwards & Wetherell (1990). It is rooted in the theories of conversation analysis (Sacks *et al.*, 1974), speech act theory (Austin, 1962), rhetoric (Billig, 1987), and the sociology of scientific knowledge (Gilbert & Mulkay, 1984). Potter and colleagues (1990) argue that discourses cannot be abstracted from their context in interaction. To do this, and to treat them as if they are independently-existing phenomena which cause certain ideological or power effects is to reify them in order that they can be used to support the researcher's own aims. They point instead to the usefulness of the 'interpretative repertoire' to make sense of the more broadly based social functions of certain constructions. These differ from 'discourses' in three important respects. First, they are examined as they appear in interactional context, and are not abstracted from what is said or written. Second, they are not linked to specific groups of interactants. That is, interpretative repertoires are thought of as available to a wide range of participants. For example, Gilbert and

Mulkay (*ibid*) found that both groups of scientists in their study drew on the two interpretative repertoires that they identified. This relates to the third point, which is that the same interpretative repertoire can be used to perform different interactional tasks. Interpretative repertoires can thus be thought of as a flexible resource for participants, and it is of particular interest here to see how they might be used by people with different chronic illnesses, and by participants who were recruited by the different means of focus groups, email chatlines and email one-to-one correspondence.

Before the analysis can be done, the data have to be transcribed. There are various levels at which transcription can be carried out, and the amount of detail provided by the transcription will depend on the various aims of the analyst. Potter & Wetherell (1987) note the requirement to balance the type of information that is being sought with issues such as the time taken to transcribe, and the readability of the final transcript. Thus, the process of transcription is unavoidably selective and can itself be thought of as a prior form of analysis (Ochs, 1979). I had a large amount of data from different sources, and one of my aims was to make some comparison between material collected in different ways. I therefore transcribed the focus group data using a modified version of the widely-used system developed by Jefferson (summarised by ten Have, 1999) that provides enough detail to allow me to explore the content and local organisation of constructions and accounts. This can be seen in Appendix II. I transcribed overlapping talk, silences and gross changes in emphasis and intonation. For the data collected by email, I copied and pasted the content into a separate file, which therefore had details of date and time sent, recipient email address and so on. I went through this file and copied just the date, time and content of the email, and at this point changed the participants' names. I retained the layout, in terms of new lines taken, new paragraphs, etc as far as possible. I also retained the original spelling and other features, such as capitalisation.

For each analytic chapter, I gathered together the responses to questions directly specifically at the relevant research theme. Thus, I collated responses to questions relating to illness constructions (chapters 3 and 4), identity (chapters 6 and 7) and coping (chapters 8 and 9). In the course of analysing the ways in which sufferers constructed stroke, I became aware of the potential importance of carers' contributions within the focus groups. I therefore collected extracts in which carers appeared to hold sufferers accountable for their illness, and also looked for instances in which such accountability was acknowledged even if not explicit in the text. For each chapter, I also went through responses to the more general questions to identify those data that appeared to be relevant to each analytic chapter and marked them as such on a printed copy of the transcripts. In accordance with Potter & Wetherell (1987), where there was any doubt about the relevance of any data, they were included rather than excluded. Since all of my data were on computer file, I then cut and pasted the marked sections on to a separate file, and printed this off.

Having gathered a large amount of data for each chapter, I read it over several times in order to get some idea of broad themes. Discourse analysis has famously been compared to riding a bicycle or sexing a chicken (Wetherell & Potter, 1992), in the sense that it is not something that is easy to describe in simple stages, and that to some extent one learns how to do it in a process of trial and error. Potter & Wetherell (1987) warn against reading for gist. However, it is extremely difficult in the initial stages to see anything beyond the content of what is said. They give some guidelines: look for patterns in the data, and consider the possible functions and consequences of such patterns. When looking for patterns, it is particularly important to also look for deviant cases. Clayman & Maynard (1995) compare deviant case analysis with Garfinkel's (1967) breaching experiments. In these experiments, departures from the usual pattern of events were used to highlight normative elements that were otherwise taken for granted. Thus, if a pattern is found, for instance that a question is normally

followed by a response, then when a response is not forthcoming, we might see an orientation to the normative question-response pattern in the form of hesitation markers, or some sort of accounting. In this way, deviant case analysis can support the existence of normative patterns.

Schegloff (1996) also provides some advice on where to start, and suggests that there are three aspects to an analysis of talk-in-interaction. First, it is necessary to look at the action(s) being accomplished. This should then be related back to the text to see that participants do indeed orient to the action(s) as described by the analyst. The third aspect involves an explication of how it is that the linguistic device used manages to produce the action(s) in question. I attempted to synthesise these guidelines and adopted the following strategy. When I thought that an action was being performed - such as constructing ME in a certain way - I would examine *why* I was reading the transcript in the way that I did, and try to relate that to what was happening within the text. For this, I found it useful to bear in mind what Edwards (1997) refers to as the 'could-have-been-otherwise' quality of talk. That is, every detail of what is said or written is potentially significant because it was said or written in that particular way, and at that particular time.

In the course of analysis, I found that the devices used in some stretches of text seemed to be far more obvious than in others, and that progress was not therefore as steady as I might have hoped. It was of some comfort to read Potter & Wetherell's claim that "often it is only after long hours of struggling with the data and many false starts that a systematic pattern emerges" (Potter & Wetherell, 1987: 168). Cowan (1997) makes the analogy of a 'tool kit' that can be used as a resource in analysis. The tool kit consists of rhetorical and linguistic devices, and systematic sequential patterns that other researchers have found commonly to occur in interaction. The idea is that if such a device or pattern is found, then the local text can be examined to

identify the kinds of actions that might be being performed. I began to index the various concepts, linguistic devices and patterns (for example, active voicing (Wooffitt, 1992), extreme case formulations (Pomerantz, 1986), devices used in fact construction (Potter, 1996) that I came across in my readings, so that I might be more familiar with the ways in which data can be analysed. I constantly referred back to this, re-read my own transcripts, and studied as many theoretical papers and texts as I could. The process of analysis was therefore somewhat recursive.

A potential issue of concern for anyone using an analytical approach that by its nature cannot be described in a set of 'how-to' rules, is that the results should stand up to scrutiny. Potter & Wetherell (1987) note four ways in which analytical conclusions can be validated. The first is that "a set of analytic claims should give coherence to a body of discourse" (Potter & Wetherell, 1987: 170). Second, participants' own orientations can be used to defend the analyst's claims. Third, if a pattern is found, then we might find that it brings with it new problems that have to be dealt with as part of the local interactional business. They give the example of turn-taking procedures, first described by Sacks and colleagues (1974). Powerful normative patterns that function to allow conversation to run smoothly bring with them the problem of how to *end* an interaction. Patterns that deal with this *secondary* problem support the existence of the patterns found to solve the primary problem. Lastly, an analysis has some validity to the extent that it is fruitful, or useful in helping us to understand an area of research. To this I would add that, unlike in other forms of qualitative analysis, discourse and conversation analysts do not paraphrase participants' contributions, nor do they take single examples of utterances out of context to make a case for a particular finding. All of the analytical process is explained and can be verified by the reader. In this particular piece of work, I had the additional validation check provided by regular meetings, discussions and feedback from my academic supervisors.

Before moving on to the analytic chapters, I would like to make it clear that I do not offer participants' constructions simply as versions of events to be deconstructed and therefore undermined. That is, I follow Heritage's (1984b) argument that when we show *how* something is constructed, and indeed *that* it is constructed, we do not imply that it is therefore without value or significance. This is a particular concern when dealing with the discourses and written texts of groups whose own version of events has had little voice in the traditional research literature. Furthermore, Wetherell (2001) makes the point that "results are not found they are *warranted* into being", and therefore this thesis itself can be seen as a work of construction. In the following chapters I warrant my interpretation of sufferers' constructions of ME (chapter 3) and then of stroke (chapter 4). Accountability and stroke is discussed in chapter 5. ME and stroke sufferers constructions' of identity are analysed, respectively, in chapters 6 and 7. Responses to their illness are examined in chapter 8 (ME) and chapter 9 (stroke).

CHAPTER 3

SUFFERERS' CONSTRUCTIONS OF ME

In Chapter 1, I discussed the ways in which ME has been described and defined in the literature. It is generally agreed that the main symptom is enduring fatigue. No physical cause has been found, and the most commonly reported risk factor is reported to be the co-existence of either physical or psychological stress (Levine *et al.*, 1999). This, and the fact that fatigue is a symptom of many psychiatric disorders, most notably depressive illness, has led some to doubt the physical basis of ME. Indeed, in the medical literature, the term 'ME' has been abandoned because it implies a specific physical abnormality which has not been supported in the research. That is, 'ME' stands for Myalgic Encephalomyelitis, which suggests muscle pain combined with inflammation of the brain and spinal cord. This term has been replaced by 'Chronic Fatigue Syndrome' or 'CFS'. A number of working groups have tried to produce a case definition of CFS, and one of the main difficulties they have had is in ascertaining the extent to which it might involve psychological or psychiatric problems.

The finding that stress is a risk factor in ME has led some researchers to look at the possibility that an examination of the personal characteristics of sufferers might shed light on this illness. Thus, it has been suggested that the hectic lifestyle prior to the

onset of illness, described by many ME sufferers, may be a contributing factor in this condition (Eichner, 1989; Riley *et al.*, 1990; Ware, 1992; Wessely & Powell, 1989).

There is no reliable evidence as to the cause of ME, but it is thought by some that the ways in which sufferers understand and respond to their condition might help *perpetuate* it (Sharpe *et al.*, 1996; Surawy *et al.*, 1995; Wessely *et al.*, 1989). The recommended treatment is therefore cognitive behavioural therapy - aimed at changing sufferers' perceptions of their illness - drug treatment for depression, and graded exercise programmes designed to demonstrate to sufferers that they are capable of gradually increasing their levels of activity without causing a worsening of their symptoms. These treatments are based on the underlying assumption that sufferers' beliefs about their illness are wrong. The aim of this chapter is to explore how people with ME construct this condition.

When asked to describe their illness, the ME sufferers in this study oriented to ME as a problematic condition. A preliminary analysis identified three analytic themes. First, a number of devices that were used to stress the seriousness of this condition. Second, participants worked to construct ME as an enigmatic illness. Finally, respondents used formulations that were oriented particularly to potential claims that ME has a psychological basis, and specifically that it might be a form of depression.

The extracts are coded to indicate their source. 'ICC' stands for 'Internet Chatline Communication, which means that the contents, although addressed to me, were also distributed throughout the membership of the ME internet support group, in such a way that participants could respond to each others' comments. 'IPC' indicates that this was an 'Internet Personal Communication'. These responses were emailed direct to me, and were therefore private correspondence. 'FG1' and 'FG2' denote focus groups 1 and 2, respectively.

All of the internet data are quoted with spelling and punctuation as in the original, including such features as line breaks, use of capitalisation, and apparent typographical errors. This was done by cutting and pasting the content of emails rather than re-typing them.

1. Constructions of ME as a serious illness

Participants in this research constructed their illness in terms of a set of symptoms, and one way in which this was done was by listing the features of ME. This can be seen in the following extract, which was an internet chatline response to my question "how would you describe having ME to someone who doesn't know anything about it?":

Extract 3:1 MEICCP58 Billy

27 It's still annoying that there's no proper description of the disease in
28 any literature, whereas really there is a very unique symptomatology.
29 Mainly the frequent fluctuation of signs, within hours everything can
30 change. The alcohol intolerance. (you look to others like you're a
31 chronic alcoholic and you haven't had, or desired, a drink in six
32 months). The IBS [Irritable Bowel Syndrome]. The memory loss.
33 Concentration gone. Can't absorb anything read. Emotional IQ
34 completely zeroed out. Fuzzy vision - it looks as if you're looking at a
35 two-dimensional screen, the 3D effect goes and the focus is difficult.
36 Vertigo or giddiness - things don't look steady. Odd attacks of
37 unaccountable backache or joint pain that may last days, weeks, then
38 just go. Can't get to sleep normally; wake up much too early in the
39 morning, so feel tired as a consequence. Night sweats. Muscles that
40 ache or hurt after minor exercise, like turning the car.

In extract 3:1, Billy uses a list construction to warrant the seriousness of his illness. This is particularly evident when compared with the grammatical style he uses at the start of this extract. He begins with a sentence that is both complete and fairly long: "It's still annoying that there's no proper description of the disease in any literature, whereas really there is a very unique symptomatology" (lines 27-28). In contrast to this, what follows has a list-like appearance. Thus, in line 29 he moves to the use of

phrases, and short sentences that lack part of a verb or a personal pronoun. For example, "Concentration gone. Can't absorb anything read. Emotional IQ completely zeroed out" (lines 33-34); "Night sweats. Muscles that ache or hurt after minor exercise, like turning the car" (lines 39-40). He also makes repeated use of the definite article where it would usually be left out - "the frequent fluctuation of signs" (line 29); "[t]he alcohol intolerance" (line 30); "[t]he IBS" (line 32); "[t]he memory loss" (line 32). The effect is to suggest that these are symptoms that are *generally* associated with ME, and this helps to construct the reality of symptoms as, literally, *definite* articles. In the following extract, we can see how George uses listing to construct ME as a serious illness.

Extract 3:2 MEICCP26 George

- 3 You feel profoundly tired physically and mentally for no good reason.
- 4 You get odd aches and pains (especially headaches and muscle
- 5 tension). If you overdo things, you feel absolutely shattered.

Jefferson (1991) showed that a three-part list is commonly used to orient to a common feature of each of the items in it. In extract 3:2, George's three-part list describes the symptoms of ME in terms of their debilitating nature. Thus, "You feel profoundly tired physically and mentally for no good reason" (line 3); "You get odd aches and pains (especially headaches and muscle tension)" (lines 4-5); "If you overdo things, you feel absolutely shattered" (line 5).

In extract 3:3, Alex, another internet respondent, also uses a list formulation:

Extract 3:3 MEICCP17 Alex

- 1 My sleep pattern has gone out of the window.
- 2
- 3 My muscles ache.
- 4
- 5 I'm not tired, I'm exhausted yet I haven't moved off the sofa.
- 6
- 7 I get 5 or 6 different types of headache.
- 8
- 9 My vision has deteriorated very quickly.

- 10
 11 I start to talk and forget in mid sentence.
 12
 13 Oh, I must not forget I suffer from IBS [Irritable Bowel Syndrome].

Here, Alex leaves a blank line between each symptom description, so that his account of ME gives the visual impression of a list. In line 13, he writes "Oh, I must not forget I suffer from IBS." To introduce this illness as an apparent afterthought, and at the *end* of a list, emphasises the importance of the symptoms that came before. Thus, Alex constructs ME as a serious illness.

We can see in the following extract how focus group participants collaboratively constructed ME by each contributing to the listing of symptoms.

Extract 3:4 FGME2

- 1 Jennifer: how would you describe having ME to someone who
 2 doesn't know anything about it?
 3 Rhona: hhh unbelievable
 4 Liz: aye
 5 Rhona: e::m tiredness (..) you get switched off
 6 Liz: aye
 7 Rhona: you can be sitting (.) no [not] even doing anything
 8 Jennifer: mm
 9 Rhona: and it's like somebody (..) switches you off and you
 10 have got to lie down (..) or you you fall asleep [unclear]
 11 Liz: your brain doesnae work properly either
 12 Jennifer: mhmm
 13 Rhona: fuzzy head
 14 Liz: aye
 15 Rhona: muscle and (.) joint pain

After Rhona's comment in lines 7-9 that "you can be sitting (.) no even doing anything [...] and it's like somebody (..) switches you off and you have got to lie down (..) or you fall asleep", Liz follows with "your brain doesnae work properly either" (line 11). Then, in lines 13 and 15 Rhona adds to the list "fuzzy head"; "muscle and joint pain." These last contributions are given with no introduction or explanation, and this adds to the impression of a list being produced.

We can see from the above extracts that listing is a useful device to construct ME as a serious illness with an accumulation of symptoms that illustrate the extent and range of problems faced by sufferers. In the following extract, Debbie makes use of vivid description to construct her condition as serious.

Extract 3:5 MEICCP2 Debbie

15 Constant thick head that sometimes hurts so badly that you could beg
 16 someone to hit you with a hammer as that would probably feel better.
 [...]
 36 Complete exhaustion where your eyes are rolling into the back of your
 37 head and your eyelids refuse to stay open and yet there is no way you
 38 can sleep.

Debbie's description here of a "[c]onstant thick head that sometimes hurts so badly that you could beg someone to hit you with a hammer" (lines 15-16) is vivid. Her choice of the verb "beg" also helps to suggest the desperate nature of such a request, and this helps to emphasise the extreme nature of the pain to which she refers. Later in the same email, she uses another visual image to construct the extent of exhaustion felt by the ME sufferer: "where your eyes are rolling into the back of your head and your eyelids refuse to stay open" (lines 36-37). We can see in the next three extracts how participants used analogy to similarly make vivid the serious impact of ME.

Extract 3:6 FGME1

3 Mandy: there is a definition that I've read of the (.) ME Action if
 4 you imagine (.) that you've got (.) severe 'flu (.)
 5 Claire: mhmm
 6 Mandy you've got a hangover (.)
 7 Jennifer: mhmm=
 8 Mandy so you've got the tummy and the head
 9 Jennifer: yeah
 10 Mandy and all the 'flu aches and pains (.) and then (.) if you
 11 imagine you've just run a marathon (.)
 12 Jennifer: mhmm
 13 Mandy you put all those together and you have ME

Extract 3:7 MEICCP1 Lynn

4 Remember your worst flu virus you had,now run a marathon,on top of
 5 that you have a migraine,feel dizzy,hurt from head to toe.Try to play
 6 chessblindfolded,and havent slept for a week.Wake up feeling ok,,,15
 7 minutes later are unable to even get out of bed with out help,every

8 muscleand joint feels like its on fire,and suddely find out you become
9 dyxlexic, Im sure there are other things ive forgotten.

Extract 3:8 ME|CCp1 Emily

9 I usually tell my friends that I feel like I have been out all night
10 drinking pints of vodka & tequilla slammers and then forced to run a
11 marathon on top of a dose of flu.

In extracts 3:6 and 3:7, the respondents call upon the reader or listener to imagine what it is like to have ME. This is done by comparing it to relatively commonplace experiences that most people would understand. Thus, in extract 3:6, Mandy invites us to "imagine (.) that you've got (.) severe 'flu (.) [...] you've got a hangover" (lines 4-6); and "imagine you've just run a marathon" (line 11). The common feature of this three-part list (Atkinson & Heritage, 1984; Jefferson, 1991) is that it comprises symptoms that most people would be able to appreciate, and many from personal experience. Similarly, in extract 3:7, Lynn asks the reader to "[r]emember your worst flu virus you had,now run a marathon,on top of that you have a migrain [*sic*]" (lines 4-5). This is the beginning of a longer list of the effects of ME. In both of these extracts, the use of analogy can be seen as an orientation to having the interlocutor empathise with the ME sufferer. In extract 3:8, Emily offers an account that suggests she has used this strategy more than once: "*I usually tell my friends that I feel like I have been out all night drinking pints of vodka and tequilla slammers and then forced to run a marathon on top of a dose of flu*" (lines 9-11; emphasis added). Here, the example of alcohol intake is extreme - not only drinking strong spirits by the pint when they would usually be taken in small measures, but mixing drinks which would add to the harmful effect. Similarly, in extract 3:7, Lynn's description is of "your *worst* flu virus you had" (line 4). Pomerantz (1986) has shown that extreme case formulations, such as "always", or "never" can be used to provide the strongest possible case for what is being said, in anticipation of a potentially cynical uptake.

By comparing ME symptoms to extreme forms of more everyday experiences, participants orient to the potential charge that their fatigue is similar to the kinds of tiredness commonly felt by other people, and is therefore not a serious condition.

In the following three extracts, we can see how participants used the categorisation of 'good' and 'bad' days to construct ME as a serious illness.

Extract 3:9 MEIPCp1 Sheena

- 1 I heard one description once which I thought was really good:
- 2 A bad day is like having a bad dose of 'flu with a hangover and also
- 3 feeling as if you've just climbed a couple of Munros²! A good day is
- 4 like the aftermath of 'flu when you just feel totally exhausted.

Extract 3:10 MEIPCp6 Dorothy

- 1 imagine Thatyou had to climb everest, then run a marathon, then swim
- 2 ten miles. To do all that gives you an idea of what it's like to start a
- 3 *good* day with ME. And then it gets worse. Much worse.

Extract 3:11 MEICCP2 Debbie

- 1 on really bad days I don't even remember what my own childrens
- 2 names and ages are or even how old I am anymore.

In the first extract above (3:9), Sheena describes two types of day that the ME sufferer might experience. She begins with a three-part list (Atkinson & Heritage, 1984; Jefferson, 1991) in which the common feature is that each circumstance would bring about physical debilitation of some sort: "A bad day is like having a dose of 'flu with a hangover and also feeling as if you've just climbed a couple of Munros!" (lines 2-3). This constructs ME as serious, and the effect is emphasised by the sentence that follows: "A good day is like the aftermath of 'flu when you just feel totally exhausted" (line 4). Thus, although a 'good' day compares somewhat favourably with a 'bad' day, it is nevertheless still portrayed as debilitating. The extreme case formulation (Pomerantz, 1986) "totally exhausted" helps to provide the strongest possible case for her claim and a useful defence against the possible suggestion that what she is

²A Munro is a mountain of 3,000 feet or more in height

describing is simply everyday tiredness. Lee (1987) has described the functions of the particle 'just'. In this case, it has an emphatic meaning, and this further helps to stress the level of exhaustion felt on a 'good day'.

In extract 3:10, Dorothy uses two devices that I have already discussed in this chapter. She employs a three-part list (Atkinson & Heritage, 1984; Jefferson, 1991) in which the common feature is that each pursuit would lead to extreme tiredness, and she also invites the reader to empathise with the situation of the ME sufferer: "imagine Thatyou [*sic*] had to climb Everest, then run a marathon, then swim ten miles" (lines 1-2). She then claims that "[t]o do all that give you an idea of what it's like to start a *good* day with ME" (lines 2-3). Here, a contrast is not explicit, but the categorisation 'good' day implies an alternative category of 'bad' day, and this is further suggested by the use of asterisks to stress the adjective 'good'. Thus, we can infer that a 'bad' day with ME is marked by even more severe symptoms, and that the illness is therefore serious. Debbie also uses one part of the 'good' and 'bad' day categorisation to similar effect. In extract 3:11, she makes the claim that "on really bad days I don't even remember what my own childrens [*sic*] names and ages are or even how old I am any more" (lines 1-2). For most people, knowing their children's names is something that they would take for granted and could hardly imagine forgetting. The effect of "my own childrens" is to make relevant her parenthood, and the seriousness of an illness that results in such lapses.

I have already noted that one feature of participants' analogies is that they invite the reader or listener to empathise with them, and this can be done by comparing ME to more extreme versions of activities that many people would know to be associated with fatigue, often from personal experience. In the following extracts, we can see that participants constructed ME as serious by describing sufferers' inability to perform mundane tasks.

Extract 3:12 MEIPCp2 Dorothy
24 Holding a pen or a book become thing to be proud of ;-)
25 Reading becomes something you can do only in short stints. Walking
26 becomes a trial.

Extract 3:13 MEICCp115 Gillian
8 When speaking you have to use tone, facial expression, nods of the
9 head, laughter, gesticulations, which just exhausts my muscles within
10 minutes.

Extract 3:14 MEICCp13 Lesley
57 standing is one of the most dangerous things one can do.

Extract 3:15 FGME2
816 Rhona if I stand for long periods (.) I don't know about
817 you
818 Liz: terrible
819 Rhona: that kills you
820 Liz: terrible

In extracts 3:12-3:15, we can see that internet and focus group participants constructed everyday activities as unusually demanding. Thus, in extract 3:12, Dorothy produces a three-part list (Atkinson & Heritage, 1984; Jefferson, 1991) that orients to the amount of effort involved in mundane tasks: "[h]olding a pen or book become [*sic*] thing to be proud of ;-) Reading becomes something you can do only in short stints. Walking becomes a trial" (lines 24-26). Gillian, in extract 3:13, uses a list formulation to emphasise the effort involved in talking to other people: "[w]hen speaking you have to use tone, facial expression, nods of the head, laughter, gesticulations, which just exhausts my muscles within minutes" (lines 8-10). In extract 3:14, Lesley describes standing as unexpectedly demanding - "one of the most dangerous things one can do" (line 57). In extract 3:15, focus group participants collaborate to similarly construct standing as unusually effortful. In lines 818 and 820, Liz evaluates standing for long periods as "terrible", while Rhona's comment is "that kills you" (line 819).

When participants construct mundane activities in this way, they stress the contrast between the difficulties they have, and the experiences of most other people, who would find all of these tasks quite straightforward and unremarkable. The effect is to construct their physical condition as serious. Another effect of this device is that it helps to defend against the potential charge that ME sufferers bring about their fatigue by overdoing things. This can be seen as an orientation to the possible interpretation of ME as an illness of 'high achievers', brought on by an unusually active and demanding lifestyle. In the next section, I will show how participants orient to the same issues when they construct ME as a mystery illness. First, however, I will discuss a more general feature of the extracts examined so far in this chapter.

A further notable feature of participants' constructions of ME as a serious illness relates to their use of pronouns and in particular differences between internet and focus group data. In two of the three focus group extracts discussed in this chapter, ME sufferers use the second person plural when describing what it is like to have this illness. Thus, in extract 3:4, Rhona states "you get switched off [...] you can be sitting no even doing anything [...] and it's like somebody switches you off or you fall asleep [unclear] your brain doesn't work properly either" (lines 5-11). Similarly, in extract 3:6: "if you imagine (.) that you've got (.) severe 'flu (.) [...] you've got a hangover [...] so you've got the tummy and the head [...] and all the 'flu aches and pains (.) and then (.) if you imagine you've just run a marathon (.) [...] you put all those together and you have ME" (Mandy; lines 3-13). The use of 'you' suggests that the symptoms described are generally associated with ME, and this helps to construct an identity for the illness itself.

We might tentatively suggest a pattern here, and one way of exploring this is to look at a case where the first person singular pronoun is used. This can be seen in extract 3:15 above, in which Rhona says "if I stand for long periods (.) I don't know about

you [...] that kills you" (lines 816-819). Here, we see a pronoun shift. She begins by using "I." There follows a short pause, and an insertion clause in which she explicitly seeks some sort of collaboration regarding the effects of standing - "I don't know about you." Liz takes this up as an invitation to provide an assessment, but does so selectively, in that she does not refer to her own experience. Instead, she uses no pronoun at all: "terrible." In Rhona's turn that follows, her claim is general rather than personal: "that kills you." It seems from this extract, then, that it may be somewhat problematic to use "I" when discussing the effects of ME as serious. Thus, when participants use the pronoun "you", it may function not just to suggest general features of ME, but also as a means of avoiding the use of the first person singular pronoun.

When those extracts taken from the internet are examined, it can be seen that "you" is quite commonly used. For example, in extract 3:2, George writes "[y]ou feel profoundly tired physically and mentally for no good reason. You get odd aches and pains (especially headaches and muscle tension). If you overdo things, you feel absolutely shattered" (lines 3-5). In extract 3:10, Dorothy writes "imagine Thatyou [*sic*] had to climb everest, then run a marathon, then swim ten miles. To do all that gives you an idea of what it's like to start a *good* day with ME" (lines 1-3). We can see in extract 3:1 that Billy also uses the second person plural pronoun - "you look to others like you're a chronic alcoholic and you haven't had, or desired a drink in six months" (lines 30-32). It is interesting that in this same extract, when describing symptoms that are quite specific, and so might reasonably be considered to relate to personal experience, Billy omits the pronoun where it would normally be expected. Thus, "[c]an't get to sleep normally; wake up much too early in the morning, so feel tired as a consequence. Night sweats. Muscles that ache or hurt after minor exercise, like turning the car" (lines 38-40).

So far, then, we have seen a similar pattern in data collected from different sources. There is one significant difference however, and this is in the use of the first person singular in internet extracts. Alex, in extract 3:3, makes repeated use of "my" and "I": "[m]y sleep pattern has gone out of the window. My muscles ache. I'm not tired, I'm exhausted yet I haven't moved off the sofa. I get 5 or 6 different types of headache. My vision has deteriorated very quickly. I start to talk and forget ... in mid sentence. Oh, I must not forget, I suffer from IBS" (lines 1-13). In extract 3:8, Emily similarly uses the first person singular: "I usually tell my friends that I feel like I have been out all night drinking pints of vodka and tequilla slammers and then forced to run a marathon on top of a dose of flu" (lines 9-11). In extract 3:11, Debbie writes "on really bad days I don't even remember what my own childrens [*sic*] name and ages are or even how old I am anymore" (lines 1-2). This last extract is quite explicitly personal in its description of the impact of ME.

In the example taken from focus group responses, we saw the pronoun shift from "I" to "you", and an inserted request for some sort of collaboration regarding the effects of ME. These suggest that the use of "I" might have been somewhat problematic. However, no such indications can be found in the internet extracts discussed above. Thus, while we can see a degree of similarity between the different sources of data, internet participants appear to have greater potential for flexibility in their use of pronouns. The second person plural can work to suggest that symptoms described are global. It can also function to distance the speaker from the views that are expressed. It may be more accountable to use the first person singular in the context of focus groups, where other interactants can possibly challenge what is said.

2. Constructions of ME as an enigmatic illness

ME sufferers in this research constructed their illness as enigmatic. This can be seen by drawing on extracts already presented in this chapter. For ease of reference, the original extract number appears in brackets:

Extract 3:16 (also 3:1) MEICCP58 Billy
30 The alcohol intolerance. (you look to others like you're a
31 chronic alcoholic and you haven't had, or desired, a drink in six
32 months).
[...]
36 Vertigo or giddiness - things don't look steady. Odd attacks of
37 unaccountable backache or joint pain that may last days, weeks, then
38 just go.

Extract 3:17 (also 3:7) MEICCP1 Lynn
6 Wake up feeling ok,,,,,15
7 minutes later are unable to even get out of bed with out help

Extract 3:18 (also 3:2) MEICCP26 George
3 You feel profoundly tired physically and mentally for no good reason.
4 You get odd aches and pains

Extract 3:19 (also 3:3) MEICCP17 Alex
5 I'm not tired, I'm exhausted yet I haven't moved off the sofa.

Extract 3:20 (also 3:4) FGME2
7 Rhona: you can be sitting (.) no [not] even doing anything
8 Jennifer: mm
9 Rhona and it's like somebody (..) switches you off and you
10 have got to lie down (..) or you you fall asleep [unclear]
11 Liz: your brain doesnae work properly either
[...]
29 Liz: em (.) it's just a weird weird thing it's no [not] one thing
30 and it's no [not] one thing (..) two days in a row
31 Jennifer mhmm
32 Rhona: you can feel differently couldn't you?
33 Liz: aye
34 Rhona: every day

In all of the above extracts, participants write or speak about ME as an enigmatic illness. Thus, in extract 3:16, Billy writes about "[o]dd attacks of *unaccountable* backache or joint pain that may last days, weeks, then just go" (lines 36-38; emphasis

added). Here, "just" is used in the deprecatory sense (Lee, 1987), in which what is described is downplayed in comparison to some implicit referent, or an alternative process. We might normally expect such pains to go after some sort of treatment, or period of rest. However, as Billy describes it, they 'just' go, and this draws attention to the lack of imputed reason for their disappearance. Lynn also writes about the inexplicable nature of her symptoms, and uses a contrast formulation to emphasise the serious nature of ME: "[w]ake up feeling ok,,,[sic] 15 minutes later are unable to even get out of bed with out help" (lines 6-7). By providing specific detail as to the time between these states, she stresses the sudden and dramatic onset of her incapacity. In extract 3:20, Liz makes the claim "em (.) it's just a *weird weird* thing it's no one thing and it's no one thing (..) two days in a row" (lines 29-30; emphasis added). In extract 3:18, George writes that "[y]ou get *odd* aches and pains (line 4; emphasis added). Immediately prior to this, he explicitly denies that there might be some identifiable cause: "You feel profoundly tired physically and mentally *for no good reason*" (line 3; emphasis added).

In the last two extracts above, participants use a contrast structure to explicitly formulate symptoms as *not* being the result of their prior actions or activities. Thus, in extract 3:19, Alex writes "I'm not tired, I'm exhausted yet I haven't moved off the sofa" (line 5). Here, "yet" signals the contrast between Alex's previous state of inactivity, and the exhaustion that he reports. Similarly, in extract 3:20, Rhona sets up a contrast between what she was doing prior to feeling fatigue, and the extreme nature of that fatigue: "you can be sitting (.) no even doing anything [...] and it's like somebody (..) switches you off and you have got to lie down" (lines 7-10). Rhona also emphasises her passive role in this by suggesting that the agent is external - "it's like *somebody* (..) switches you off." In extract 3:16, Billy writes that "you look to others like you're a chronic alcoholic and you haven't had, or desired, a drink in six months" (lines 30-32). As well as using a contrast formulation here, Billy specifically

orients to the possible charge that his symptoms are brought about by his own actions. He manages this by stating that not only has he *not* had a drink for six months, but that he has not even *desired* one. In doing this, he reconstructs his symptoms as *causing* his distaste for alcohol, rather than *being caused* by an excessive intake.

3. Constructions of ME as 'not psychological'

In this section, I will show how participants orient to the possibility that others might take sufferers' fatigue to be due to lack of motivation, or to depression. I will begin by examining part of a focus group discussion.

Extract 3:21 FGME2

689 Liz: when you say "cannae be bothered" (.) it sounds as if (.)
690 to me lazy
691 Rhona: aye
692 Jennifer: mhmm
693 Rhona: yeah
694 Liz: it it's (..) you know it's no [not] lazy it's (..) you just ()
695 havenae got the energy to do it .h (.) and that's what you
696 say "oh I cannae [can't] be bothered doing that" but it (.)
697 it's no [not] that it's (.) you haven't got the energy to get
698 yourself up out the chair (.) to do it (.) and (..) you just
699 cannae [can't] fathom out what what's going on

In extract 3:21, Liz uses an appearance/reality formulation to construct her incapacity as due to lack of energy rather than laziness. Potter & Wetherell (1989) have shown how this formulation can help to construct the reality of what is being claimed. It involves setting up a construction as the one that may appear to be obvious, then undermining it by producing the construction that is 'real'. An example of this can be seen in the first extract of section 2 (3:16), when Alex contrasted the appearance "you look to others like you're a chronic alcoholic" with the reality "you haven't had, or desired a drink in six months" (lines 30-32). Here, Liz makes a similar appearance/reality contrast: "when you say "cannae be bothered" (.) it sounds as if (.) to me lazy [...] it it's (..) you know it's no lazy it's (..) you just havenae got the

energy to do it" (lines 689-695). The appearance of ME is constructed as one in which the sufferer lacks the motivation to do something. With "it sounds as if", Liz orients to the interpretation that others might have of ME sufferers' inactivity. Immediately after this, there is what seems to be a repair. That is, we might expect in the context something like "it sounds as if you're being lazy." What Liz does is to pause briefly then say "*to me* lazy." She therefore actively positions herself as a person who understands this assumption of a lack of motivation. This works to construct Liz herself as impartial, making the same initial assumptions that any other observer might have done. In turn, this construction helps to strengthen the reality claim that follows. In the last lines of this extract, Liz also constructs ME as an enigmatic illness with her claim "you just cannae fathom out what's going on" (lines 698-699).

In the last two extracts, participants orient to the potential claim that ME is some form of depression, and in each they refer to the knowledge of a 'reliable witness' to support their claim.

Extract 3:22 FGME2

475 Liz: a:nd I mean before I went to the doctor (.) the last
 476 time before I was () diagnosed or () she agreed with
 477 me () I did say to my husband "look (..) do you think
 478 it's depression or do you think there's something wrong
 479 with me () do you think (.) I'm just making it all up or
 480 whatever" he says "no" he says "I live with you day to
 481 day and (.) and I know there is definitely something (.)
 482 wrong"
 483 Jennifer: mm=
 484 Liz it's no [not] depression I actually (.) suffered from
 485 depression (.) years ago (.) a:nd so I knew it wasnae
 486 [wasn't] depression

Extract 3:23 MEIPCp7 Dorothy

29 I called my husband into the Drs surgery and told him in front of the
 30 Dr what his dx [diagnosis] was. My husband laughed and said that
 31 there was no way I was depressed and that as his field of work was
 32 mental health he reckoned that he might have spotted the signs in his
 33 wife were they present.

In the above extracts, both Liz and Dorothy make relevant the status of 'husband' as witness to their condition. Sacks (1974; 1975) has noted that category entitlement can warrant claims to knowledge, and in this case, someone in the category of a husband, could be warranted with detailed knowledge of his wife. Potter (1996) also notes the usefulness of providing corroboration in rendering an account as factual. In extract 3:22, Liz describes a conversation she had "I did say to my husband "look (.) do you think it's depression or do you think there's something wrong with me" (lines 477-479). This sets up depression as *not* something wrong, which suggests that Liz herself associates depression with malingering. Wooffitt (1992) has shown that 'active voicing' can be used to construct the reality of the reported speech. So, when Liz quotes her husband, the account appears more convincing than if she had merely summarised what he had said in her own words. In her account, her husband does not simply say "no." He *also* makes relevant his close relationship with her: "I live with you day to day (.) and I know there is definitely something wrong" (lines 480-482). He therefore takes up Liz's formulation of 'something wrong' and so both confirms her first explanation and rejects the alternative one of depression.

In extract 3:23, Dorothy also calls on an 'expert witness' to support her claim that she is not suffering from depression. She also makes relevant the status of 'husband' and therefore allows us to infer the kinds of category entitlement described above. Thus, in line 29: "I called my husband [sic] into the Drs surgery", and in lines 30-31 where she reports his reaction to the doctor's diagnosis: "[m]y husband laughed and said that there was no way I was depressed." Laughter is a surprising reaction to a being told of a partner's depression, and this account formulates such a diagnosis as not only wrong but risible. Dorothy's husband's special knowledge is also made relevant in lines 31-32: "his field of work was mental health", and for a third time their relationship as a married couple is signalled: "he reckoned that he might have spotted the signs *in his wife* were they present" (lines 32-33; emphasis added). Thus, the

husband's credentials as a person with knowledge of depression, and as someone who has a close relationship with Dorothy, are used to expose the doctor's diagnosis of depression as inaccurate.

4. Summary

Participants in this research displayed sensitivity to potential implications that this illness is not serious, that it is brought on by over-activity, and that it is linked to depression. I have shown how respondents constructed their illness as serious. They did this by using three-part lists (Atkinson & Heritage, 1984; Jefferson, 1991), and longer list formulations. They used vivid descriptions. They constructed ME by analogy with everyday experiences that cause debilitating tiredness - such as having the 'flu or running a marathon. This allowed them to invite the non-sufferer to empathise with their situation. The categorisation of 'good' and 'bad' days was used to stress the level of exhaustion that is part of ME. In general, the use of extreme case formulations (Pomerantz, 1986) distinguished the symptoms of ME from 'normal' fatigue. Participants also described the difficulties they had in carrying out mundane activities. This descriptive strategy also enabled participants to orient to the potential charge that their illness was brought on by their previous levels of activity.

Some subtle differences were noted between focus group and internet participants' use of pronouns when constructing their condition as serious. It appeared to be potentially less problematic for internet respondents to use the first person singular, thus referring explicitly to personal experiences and views.

Participants constructed ME as an enigmatic illness. Such a construction emphasises their passive role in developing symptoms. Respondents also oriented to the potential accusation that their incapacity could be attributed to a lack of motivation, or to

depression. They used appearance/reality formulations (Potter & Wetherell, 1989) and active voicing (Wooffitt, 1992) of 'reliable witness' testimony to construct as real their claims that ME is not laziness, nor is it depression.

5. Discussion

In the literature review, I showed that there is open debate about what constitutes ME, or CFS. A fundamental issue relates to the extent to which this can be thought of as a physical, or a psychological illness. In this chapter, we have seen that participants constructed their illness as serious, as enigmatic, and as specifically not psychological. Similar results have been found by other researchers. Bland (1995), for example, found that participants used extreme case formulations to stress the serious nature of their illness. Horton-Salway (1998; 2001b) and Tucker (2004) record sufferers' use of corroboration and active voicing to construct their illness as physical. In Horton-Salway's (2004) discourse analysis of discussions between a psychiatrist and an ME support group, she shows that what is at stake is whether sufferers can be seen to 'know their own minds'. She concludes that their techniques of fact construction are rhetorically less powerful than one which refers to the 'doctors' category' of masked depression.

Kitzinger & Farquhar (1999) suggest that focus group interaction can encourage open conversation about difficult issues, although there is also the possibility of a kind of communal censorship. The latter is not a problem *per se* for research; indeed it can point up areas of sensitivity. Such actions can be studied by contrasting focus group with one-to-one interviews. In this thesis, internet communication provides a useful comparison, one that suggests that the construction of ME may be an accountable practice. Thus, the context in which data are gathered may be of some significance.

Traditional research into ME is based on the empiricist assumption that ultimately this illness can be defined, and then categorised as either physical or psychological. Definitions are provided by clinicians and researchers, and these can be compared with the illness attributions of those suffering from ME. In the case of this condition, it has been reported that sufferers' beliefs about their illness are faulty.

A social constructionist approach to the ways in which people talk about their illness has a different starting point. It does not assume that so-called beliefs, attitudes or attributions are reflections of particular, private mental states. Rather, they are regarded as situated, communicative productions designed to perform particular rhetorical tasks (Potter, 1997; Potter & Wetherell, 1987; Wetherell & Potter, 1992). Horton-Salway (1998; 2001b) notes that the rhetorical and interactive nature of illness accounts has been ignored in cognitivist approaches. ME sufferers' descriptions of their illness has been taken at face value as evidence for theoretical interpretations of the cause of this condition. Thus, sufferers' apparent pre-occupation with its seriousness, or its enigmatic nature, has been used to support the use of cognitive behavioural therapy to change 'dysfunctional' beliefs (Wessely, 1996). Sufferers' accounts might, however, stress the seriousness and mysterious nature of ME *precisely* to counter claims that it is not a legitimate, physical illness. This has important implications for the ways in which ME might best be treated.

Stroke has a more legitimate status as a physical illness than does ME. In the next chapter, I will show how stroke sufferers constructed their condition.

CHAPTER 4

SUFFERERS' CONSTRUCTIONS OF STROKE

In Chapter 1, I provided an outline of the ways in which stroke has been described and defined in research carried out from a number of different perspectives. In the medical literature, the emphasis is on the neurological deficits brought about by particular types of stroke, and how these can vary with the location of brain injury. Thus, the consequences of stroke are predominantly viewed in terms of biological impairment. However, the mapping of brain damage to neurological deficit has been shown to be problematic in two particular areas. Working from a conversation analytic perspective, Manzo and colleagues (1995) challenged the view that linguistic difficulty is simply the result of left hemisphere damage. In their analysis of interactions between stroke sufferers and their partners, they showed that communicative 'dysfluency' was instead a function of sufferers' disempowered status.

The second medically problematic area, in the sense that it cannot be mapped to specific injury, is the symptom described as 'anosagnosia'. This refers to the sufferer's apparent failure to acknowledge the dysfunction brought about by his or her stroke. In the absence of a biological explanation, the problem has been attributed to psychological factors. For example, anosagnosia has been described as a cognitive

deficit - a problem with the sufferer's thought processes. From the perspective of cognitive psychology, the knowledge that sufferers (and non-sufferers alike) have of illness takes the form of cognitive schemas that relate separately to five distinct categories of information (Leventhal & Benyamini, 1997). Among these are illness identity and its consequence. Failure to recognise the damage caused by illness could, from this perspective, be related to the distortion or absence of relevant schemas. Anosagnosia has also been described as a coping mechanism designed to protect self-image, and a form of psychoanalytic denial (Pimm, 1997). The stigma attached to the loss of bodily functions has also been linked to the tendency of some stroke sufferers to conceal their 'real' level of impairment (Bendz, 2000).

Some researchers, working from a psychosocial rather than medical perspective, have also found that stroke sufferers have a problematic relationship with dysfunctional parts of the body. As Bendz (2000) describes it, these body parts were objectified, and no longer seen as integral to the sufferer's personality. Ellis-Hill and colleagues (2000) similarly found the stroke sufferers in their study experienced a 'self-body split'. They, and other researchers, also found another fundamental effect of stroke is the disruption it can cause in the sufferer's life (Becker, 1993; Ellis-Hill *et al.*, 2000; Glass & Maddox, 1992).

In this chapter, rather than address the 'problem' of competing theories as to the impact of stroke, or the extent to which 'real' injury is acknowledged by sufferers, I analyse accounts of people who have had a stroke, in order to see how they themselves construct its effects. Thus, I aim to focus on participants' concerns and not prior theory.

In my preliminary analysis, I was struck by focus group participants' initial hesitancy in responding to my question in which I asked them to describe stroke. A similar

effect was found in the internet data. Further analysis of subsequent extracts showed how stroke sufferers orient to the problems of describing this condition to people who have never suffered stroke. This is discussed in the first section. In extracts examined from later in the course of the focus groups, and in internet correspondence, I found that participants constructed the effects of stroke in terms of loss of ability, and the stroke itself as unpredictable. This is discussed in the second section.

Extracts are coded as follows. 'FG' denotes 'focus group', and 'DS' indicates that the participants were part of the 'Different Strokes' support group. 'IPC' stands for 'internet personal communication', which, in the case of stroke sufferers, was purely on a one-to-one basis. Those names in italics refer to carers who participated in the focus group sessions. My own name is underlined.

1. Orienting to the question

The same question was put to the two focus groups, and to the internet correspondents: "how would you describe your situation - having had a stroke at a young age - to someone who doesn't know anything about it?" In each case, this was the first question that was asked

Extract 4:1 FGDS1

1 Jennifer: how would you describe your situation () having had a
2 stroke at a young age () to someone who doesn't know
3 anything about it?
4 Harry: [trying to speak] mm mm
5 Jennifer: yeah?
6 Norman: yes?
7 Harry: mm mm
8 *Kirsty*: what way would you des- describe
9 Harry: [trying to speak and pointing at himself]
10 *Kirsty*: feeling having a stroke?
11 Harry: [unclear] I dunno

Harry's reply to my question - "I dunno" does not come until line 11. This suggests that he is having some difficulty in replying, an interpretation that can be supported by the interaction and vocalisations that take place between lines 4 and 11. The concept of adjacency pairs is relevant here (Sacks, 1992). Sacks showed that when a question is asked, a response is expected. That is, the pairing of question-response is normative, and this can be seen in an analysis not just of the extent to which such pairings take place, but also in interactions in which the response is not forthcoming. The rules of adjacency pairing suggest that a *delay* in producing the response can indicate some kind of interactional problem. We can see an orientation to this problem in lines 5, 6, 8 and 10. Both my "yeah?" in line 5 and Norman's "yes?" in line 6 have a rising intonation, and might be interpreted as minimal continuers designed to encourage Harry's attempts to speak. Kirsty, a carer, reformulates the question in lines 8 and 10 - "what way would you describe [...] feeling having a stroke." By partially repeating the question, she treats Harry's failure to produce a timely response as due either to a failure to understand the question, or to remember it. This also works to give him more time to formulate the response, as well as providing a more recent question with which his response can be less problematically paired. Before my analysis of the last line of this extract, I will turn to the initial response from the second focus group, which is similarly characterised by its hesitancy:

Extract 4:2 FGDS2

1	<u>Jennifer</u> :	okay (.) right the first question I've got (.) is how would
2		you describe your situation (.) that is having had a stroke
3		at a young age to someone who doesn't know anything
4		about it ?
5		(7)
6	Brian:	what like (.)
7	<u>Jennifer</u> :	just how would you describe it to someone that doesn't
8		know anything about what it's like having had a stroke
9		or [[unclear]]
10	Brian:	[it's like] your worst nightmare realised

Here, the question is initially met with a 7-second pause (discussed in more detail below) before Brian requests some clarification: "what like." As in the last extract, this request for clarification also functions to give participants more time to answer, and the opportunity to repair any interactional problems caused by the initial delay between question and answer. Brian's response - "it's like your worst nightmare realised" - does not appear until line 9, after my reformulation of the original question.

Jefferson (1989) shows that speakers' usual tolerance level for pauses in interaction is something between 0.8 and 1.2 seconds. This can be demonstrated by the typical response to a more lengthy pause, which is that more than one party will 'take the floor' at the same time. A 7-second pause is, therefore, remarkably long, and the fact that no-one spoke before this time suggests that the question may not have been an easy one to answer (this was the only instance of a pause of such length in either of the focus group sessions). It is worth noting, however, that there are likely to be particular interactional difficulties when speakers have impaired speech, a symptom that can result from stroke. We have to consider the possibility that adjacency pairing might be delayed to some extent by verbal difficulties, rather than as a result of difficulties with the question itself. However, if we look at extracts taken from once participants had begun to talk, we can see how they orient to the problematic nature of providing a description of stroke. To turn back to the last line of extract 4:1, after Harry's efforts to provide a reply, and his carer's reformulation, he provides an answer in line 11: "I dunno." This further suggests that the task of describing this condition is a difficult one. We can also see participants orient to the provision of a description of stroke as something problematic in the following extract, which is a continuation of extract 4:2 above:

Extract 4:3 FGDS2

9 Brian: it's like your worst nightmare realised
10 Jennifer: mhmm
11 Brian: .hhh you know (.) you don't () cos my stroke was quite
12 (.) it was quite eh (.) it built up and then it just .hh (.)
13 and then I fell into a coma

Extract 4:3 is characterised by the hesitant nature of Brian's description of stroke. It begins with his response to my initial question, and takes the form of a simple analogy - "it's like your worst nightmare realised." This analogy does give an indication of the seriousness of stroke, emphasised by the extreme case formulation - "your *worst* nightmare realised." Pomerantz (1986) demonstrates that extreme case formulations can be used as a rhetorical device to forestall hearers' potential doubts as to the reality of what is being stated. Thus, Brian treats the serious impact of stroke as something that others might not appreciate. The assessment that follows, however, is characterised by its incompleteness. Thus, we can see in lines 11-13 a series of unfinished utterances, separated by pauses, beginning with a long (3 second) intake of breath, followed with "you know (.) you don't () cos my stroke was quite (.) it was quite eh (.) it built up and then it just .hh (.) and then I fell into a coma." The hesitant nature of this account suggests that my question could not be straightforwardly answered, that, at the least, describing stroke is a hard thing to do. This is implicit in the next extract:

Extract 4:4 DSIPCp1 Derek

1 Please find attached a response to your 1st question. I would
2 not be offended if you felt the style/tone was not suitable and
3 would be open to some guidelines. This is the first time in
4 nearly 10 months that I have actually tried to explain certain
5 issues.

In extract 4:4, taken from internet correspondence, Derek writes five lines before he embarks on a response to my question (the response itself will be examined later in this section). There is a disclaimer as to the appropriateness of what follows - "I

would not be offended if you felt the style/tone was not suitable and would be open to some guidelines" (lines 1-3). This suggests a sensitivity to the ways in which his response might be taken up, an impression that is strengthened by his subsequent explanation for any potential inadequacies in the response - "[t]his is the first time in nearly 10 months that I have actually tried to explain certain issues" (lines 3-5). This leaves open the question of why it might be that Derek has not attempted an explanation for such a long time. We are left to infer that it is not easy to produce an account of stroke. In the lines that follow, analysed later as extract 4:8, I will show how Derek's description of stroke invites the reader to empathise with the difficult problems that he faces.

In the next extract, there is specific reference to the problems sufferers have in portraying stroke to non-sufferers.

Extract 4:5 FGDS1

67	Norman:	to describe to somebody () having a stroke is (.) I mean
68		we all agreed when we saw the film that it's you <u>can't</u>
69		tell a person [what it's like having a stroke]
70	Steve:	[no no no that's] [right aye
71	Norman:	[if they've] never had one
72	Steve:	aye
73	Norman:	[it's like]
74	Yvonne:	[aye]
75	Norman:	it's like they equate it to like a woman telling her man
76		that she's had a <u>baby</u> the guy wouldn't be able [to
77		understand]
78	Steve:	[aye aye
79		aye]
80	Yvonne:	to appreciate it
81	Norman:	wouldn't be able to
82	Steve:	aye
83	Norman:	and the effects I would say i::s (.) everything comes to a
84		stop

In extract 4:5, Norman does provide an assessment of what it is like having had a stroke: "and the effects I would say i::s (.) everything comes to a stop" (lines 83-84). Before making this assessment, however, he makes the claim that "you can't tell a

person what it's like having a stroke" (lines 68-69). This allows us to infer that what follows is not to be treated as a definitive account of stroke. That other people would not understand is presented as consensual: "we all agreed when we saw the film" (line 68; presumably a film about the effects of stroke shown to the people in this support group), and by reference to an external source: "it's like *they equate it* to a woman telling her man that she's had a baby" (lines 75-76; emphasis added). We might infer that 'they' refers here to the producers of the film referred to earlier. Thus, Norman works up an account in which he gives the impression that the difficulties in explaining stroke to others is something that has already been discussed and agreed not just within the group, but beyond its confines. This helps to make real the claim that "you can't tell a person what it's like having a stroke." In the last line of this extract, Norman's use of an extreme case formulation (Pomerantz, 1986) - "everything comes to a stop" orients to the possibility that hearers will not appreciate the severity of the effects of stroke. In the following extract, Eric also orients to the views that other people might have of stroke:

Extract 4:6 FGDS2

76	Eric:	yeah all strokes are different=
77	Brian:	aye=
78	Eric:	they're all different as well .hh and people think they
79		hear that somebody's had a stroke they (..) immediately
80		imagine well .h they've lost the () the use of one side
81	Brian:	[aye]
82	<u>Jennifer</u> :	[mhmm]
83	Eric:	and that's it you know (.) there's a lot more to it than
84		that yeah () a lot more

This extract begins with Eric's claim "yeah all strokes are different" (line 76), then uses an 'appearance/reality' device to contrast what people *think* stroke is, with what it is *really* like. Potter & Wetherell (1989) show how speakers can use this device to establish factuality where what is being claimed runs counter to what people would normally understand to be 'true'. While this device works to suggest that non-sufferers' appreciation of stroke is limited - "people think they hear that somebody's

had a stroke they (..) immediately imagine well .h they've lost () the use of one side [...] and that's it you know" (lines 78-83), the reality with which this is contrasted is, however vague - "there's a lot more to it than that yeah () a lot more" (lines 83-84).

The last two extracts of this section can be contrasted with those we have seen so far, in which participants provide vague, hesitant or incomplete descriptions of stroke.

Here, we can see how the use of vivid analogies is designed to enable the non-sufferer to visualise the effects of this condition:

Extract 4:7 DSIPCp4 Charles

17 To someone with no experience of stroke then it's difficult to
18 portray the loss of full functionality to one side(generally) of
19 your body, the only way I can describe it is to imagine having
20 one of your hands tied behind your back and the corresponding
21 side's leg weakened to maybe half functionality where you can't
22 kick or trap a football and to have to do everything one handed
23 without thinking about it.

Extract 4:8 DSIPCp1 Derek

1 Please find attached a response to your 1st question. I would
2 not be offended if you felt the style/tone was not suitable and
3 would be open to some guidelines. This is the first time in
4 nearly 10 months that I have actually tried to explain certain
5 issues.
6
7 Imagine looking at a friend's hand, focus on the thumb, the
8 nail, the knuckle, the creases, hairs, blemishes, color, really get
9 to know it as if it is yours... Now try and move your friends
10 thumb without you touching or saying anything, just use your
11 mind.

In each of the above extracts, the reader is invited to imagine what it is like having had a stroke. Both Charles and Derek invite the reader to put her- or himself in the place of the stroke sufferer, and in each case this involves a vivid and detailed description. Thus, in extract 4:7, Charles does not just say that one hand does not function, he suggests that we imagine what it would be like if it was tied behind the back. He illustrates the partial loss of function in the leg by suggesting that we imagine being

unable to "kick or trap a football" (line 22). Derek provides an even greater level of detail when he asks us to imagine looking at a friend's hand - "focus on the thumb, the nail, the knuckle, the crease, hairs, blemishes, color" (extract 4:8, lines 7-8) - and trying to move it solely by the power of the mind. By providing this level of detail, Charles and Derek design their accounts to enable the reader to empathise with some of the difficulties they face. This implies that otherwise the reader might not be able to understand this condition. In both extracts, we can see an orientation to the difficulties participants have in describing their condition to other people. I have already discussed this in relation to extract 4:8 (the first 5 lines of which comprise extract 4:4). In extract 4:7, Charles prefaces his account of stroke by claiming that this is not an easy thing to do: "it's difficult to portray [...] the only way I can describe it is" (lines 17-19).

We can see in these two extracts, then, that participants construct stroke as something that is hard to define, an orientation that has been found in previous extracts. However, whereas in other cases participants gave hesitant, incomplete and vague responses to my questions, Charles and Derek resolve the difficulty by constructing stroke through analogy. It is notable that the former accounts were largely from focus group data, and that the latter responses were communicated via the internet. Vivid and detailed assessment such as that provided in extracts 4:7 and 4:8 may be more vulnerable to challenge in the context of focus groups in which differently affected sufferers, and their carers, are present. However, in the context of one-to-one emails, such considerations may be less relevant. It is also notable that the descriptions here portray the difficulties that stroke sufferers have in undertaking quite mundane tasks, a device that I will return to at the start of the next section.

So far, we have seen that focus group participants were hesitant in their initial response to my question "how would you describe your situation - having had a

stroke at a young age - to someone who doesn't know anything about it?" Analysis has shown that when they did provide a response, participants inferred that stroke is complex and hard to describe. They achieved this by providing an incomplete or vague account of their condition, and referring explicitly to the inadequacy of that account. Respondents also referred, explicitly and implicitly, to the inability of non-sufferers to understand what stroke is like. There is a contrast between the vague and incomplete accounts provided by sufferers describing their own experiences direct, and the detailed accounts given when they invite non-sufferers to imagine what stroke is like.

In the next sections, I will refer to those descriptions that were produced after an initial, hesitant, start in the focus groups. I also analyse extracts taken from later discussions and emails. Two issues emerged from my analysis. The first is that stroke was constructed in terms of a loss of ability. Second, participants constructed stroke as unexpected. I will now discuss each of these issues in turn.

2. Constructions of stroke in terms of loss of ability

Participants used two rhetorical devices to construct the effects of stroke in terms of loss of ability. The first involved using mundane activities to give some indication of the level of loss. The second was the use of story-like accounts to demonstrate the ways in which stroke incapacitates the sufferer.

I referred briefly to the use of mundane activities in extracts 4:7 and 4:8, in which participants invited the reader to imagine what it is like having had a stroke, using the examples of moving one's thumb and trapping a football. In the following extracts, taken from later email correspondence, we can see that respondents used various examples from everyday life to construct the effects of stroke in terms of loss of

ability. The presentation of extract 4:11 may seem somewhat unusual. As with all the email correspondence, it is pasted exactly in the form sent to me, with no 'corrections'.

Extract 4:9 FGDS2

616 Euan: just () you know realising that things you could do
617 easily before () are now so difficult
618 Jennifer: yeah
619 Euan: like reading and comprehending things are now
620 Brian: mhmm
621 Euan: really really difficult

Extract 4:10 FGDS2

623 Euan: you do things a lot slower because you just can't do
624 things at the same rate
625 Jennifer: mhmm
626 Euan: say things which (.) you used to be able to do before
627 which were so easy
628 Eric: yeah (...) I think [confidence takes a]
629 Euan: [like like I don't have] enough energy
630 to read through the paper each day=
631 Brian: mm=
632 Euan: before I get I get tired after about (.) a couple of pages
633 Brian: mm
634 Euan: and it means you miss most of the things (.) in the paper

Extract 4:11 DSIP Cp3 Tim

9 the stroke also leaves me
10 feeling pretty useless in many ways, I cant take my children out
11 as I used to I dont go out with my wife to the pub or out for
12 meals anymore it seem,s you have to change your whole way
13 of life

In each of the above extracts, participants make a general claim about the effects of stroke, and follow this with examples of the difficulties posed by mundane activities. Thus, in extract 4:9 Euan makes the general claim that "things you could do so easily before () are now so difficult" (lines 616-617) and in extract 4:10 that "you do things a lot slower" (line 623). These are followed by more specific examples, relating to reading and comprehending. Similarly, in extract 4:11, Tim's general claim - "the stroke also leaves me feeling pretty useless in many ways" (lines 9-10) is followed by

specific examples of how it has affected his life: "Icant take my children out as I used to I dont go out with my wife to the pub or out for meals anymore" (lines 10-12). In all three extracts the inability to perform mundane, everyday activities is used to illustrate the seriousness of stroke, in that these are activities that most of us could manage with very little difficulty. The severity of stroke is also conveyed by the use of emphasis in extracts 4:9 and 4:10. Thus, Euan describes the things he used to be able to do before "so easily" (extract 4:10, line 627), and now "so difficult [...] really really difficult" (extract 4:9, lines 617 and 621).

In the following extract, one of the focus group participants describes a situation in which she *is* able to perform everyday activities, but by making this performance noteworthy, she achieves the same ends.

Extract 4:12 FGDS1

946	Yvonne:	I stay on my own and <u>I</u> like it (..) because (.) at least I
947		can do things you know wee silly stupid things like
948		make a cup of coffee now
949	<u>Jennifer:</u>	mhmm
950	Yvonne:	I can bring through half a cup of coffee and (..) I was
951		fair away with myself the other day I was smiling away I
952		made myself a bit <u>toast</u> for the first time
953	Ian:	yeah
954	Yvonne:	I thought "oh this is great" and it tasted <u>brilliant</u> you
955		know

In extract 4:12, Yvonne describes her ability to perform an everyday activity: "I can [...] make a cup of coffee now" (lines 946-948). She describes this activity as "wee silly stupid." These adjectives serve to minimise the importance of being able to make a cup of coffee. However, this can be contrasted with Yvonne's subsequent assessment, in which a usually unremarkable activity is made special by a description of her delighted reactions: "*I was fair away with myself the other day I was smiling away I made myself a bit toast for the first time [...] I thought "oh this is great" and it tasted brilliant "* (lines 950-954; emphasis added). In this extract, then, the contrast

between a seemingly insignificant ability and the high level of achievement that it now represents for Yvonne helps to construct stroke in terms of *loss* of ability. By describing a specific event, Yvonne draws on the narrative potential of a story noted by Riessman (1990). That is, the story can be used to illustrate significant features, in this case the level of achievement implied in carrying out an everyday activity. In the following two extracts, we can see further examples in which participants used stories to construct stroke in terms of a loss of ability.

<p>Extract 4:13</p> <p>166 Norman:</p> <p>167</p> <p>168</p> <p>169</p> <p>170</p> <p>171</p> <p>172 Ian:</p> <p>173 Steve:</p> <p>174 Jennifer:</p> <p>175 Norman:</p> <p>176 Jennifer:</p> <p>177 Norman:</p> <p>178</p>	<p>FGDS1</p> <p>and and () one day I mean literally when I had this stroke (.) I woke up on the bed and I said "mm that wasn't too good I think I'm gonna call the doctor now" I got off the bed () and went straight across the <u>room</u> and hit the <u>wall</u> and it's like or the wardrobe because (.) I <u>thought</u> I could still walk</p> <p>[mm]</p> <p>[aye]</p> <p>[yeah]=</p> <p>but I couldn't</p> <p>yeah</p> <p>and I couldn't even <u>crawl</u> (.) and I literally had to slide to the floor to go to the phone</p>
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In extract 4:13, Norman provides an account of what happened when he had his stroke. This has a number of story-like properties. Thus, it begins in the way that many of our culture's stories begin - "one day", it depicts events in chronological sequence, and provides a level of detail that allows the hearer to visualise what happened: "and and one day I mean literally when I had this stroke (.) I woke up on the bed and I said "mm that wasn't too good I think I'm gonna call the doctor now"" (lines 166-168). Here, Norman quotes his own reaction to this event. Wooffitt (1992) suggests that the use of 'active voicing' - the provision of reported speech or thoughts - works to construct what is said as an accurate reflection of events. Norman then describes the difficulty he had in making this call to the doctor: "I got off the bed and went straight across the room and hit the wall and it's like or the wardrobe" (lines 169-170). Hitting the wall or the wardrobe is a highly unexpected consequence of

walking across the room. Thus, Norman sets up a contrast between what he intended to do, and what he was capable of doing, and this helps to emphasise the loss of abilities that resulted from his stroke. This can also be seen in the following: "I thought I could still walk [...] but I couldn't [...] and I couldn't even crawl (.) and I literally had to slide to the floor to go to the phone." (lines 170-178). In the next extract, we can see how Norman again uses an account in which a contrast formulation is used to emphasise the loss of abilities brought about by his stroke.

Extract 4:14 FGDS1

101 Norman: and I was physically fit and everything and very capable
102 of doing almost anything and they said "right do this
103 and this" (.) and I just looked at them and (.) I said "I
104 don't know how to [do that"]
105 Steve: [mm]
106 Norman: and they said "can you plea-" I said "can you go
107 through it (.) even more slowly than that describe what
108 the first thing that happens" cos I just didn't have a clue
109 there was nothing that I knew about walking any more

Here, Norman accounts for his inability to walk, and specifically not knowing how to walk - "I just didn't have a clue there was nothing that I knew about walking any more" (lines 108-109). In the account, which precedes this claim, Norman uses a story-like account and a contrast formulation to emphasise his inability. Thus in lines 101-102, he makes a claim about his physical condition prior to his stroke that contrasts with the account that follows. Thus, he claims that prior to his stroke, he "was physically fit and everything and very capable of doing almost anything." Here, a 'softened' extreme case formulation - "almost anything" is deployed. Edwards (2000) suggests that this can be used to orient to the rhetorical weakness of the extreme case, and here it would be more defensible for Norman to claim that he was capable of "almost anything" than "anything." Thus, his claim is delicately designed to counter the possible response that he is exaggerating his pre-stroke abilities. Norman follows this with a contrasting account of what happened after his stroke, and he uses active voicing (Wooffitt, 1992) to construct this as factual. The people he

refers to here are rehabilitation physiotherapists: "and they said "right do this and this" (.) and I just looked at them and (.) I said "I don't know how to do that."" (lines 102-104). As well as providing a contrast with his pre-stroke abilities, Norman contrasts what he could do with what the physiotherapists expected him to do, and this works to demonstrate the lack of understanding that even healthcare professionals can have of the problems faced by stroke sufferers.

Story-like accounts are therefore used to provide a vivid portrayal of the effects of stroke, and of the loss of ability that can result. Specific stories work particularly well to draw the hearer into the world of the speaker (Riessman, 1990). Their chronological sequencing provides the opportunity to use contrast to highlight the difference between sufferers' previous capabilities, and the restrictions that follow stroke. Participants also used examples of mundane activities to emphasise the loss of ability brought about by stroke.

3. Constructions of stroke as unpredictable

Participants used two devices to construct the stroke as unpredictable. They told narratives in which their doctors initially failed to recognise this event, and they used 'before and after' constructions to construct stroke as something unanticipated and out of the ordinary.

In the next two extracts, Norman produces an account in which he illustrates the initial problems that medical staff had in ascertaining that he had suffered a stroke:

Extract 4:15	FGDS1
233 Norman:	I think what's also tragic I mean a lot of these people
234	say things about their doctors () but it's a genu- I mean I
235	my wife works (.) she's a medical (.) mm eh a practical
236	em eh a practice manager so she <u>works</u> with the doctors

237 and I'm friends with a lot of the doctors (.) and most
 238 GPs haven't really got a clue I mean [they]
 239 *Kirsty:* [that's] [[unclear]
 240 Norman: [revised]
 241 their whole way that they work after my case because
 242 *Jennifer:* mm
 243 Norman: they didn't know that I'd had a stroke () and he wa:s (.)
 244 probably the most experienced doctor they had in that
 245 practice () and he didn't realise he gave me pills for ear
 246 balance problems and all that
 247 *Jennifer:* yeah
 248 Norman: and em he only came I phoned he only came two hours
 249 later gave me a list [prescription] and that was at lunch t
 250 time and only about five o'clock at night he came back
 251 and and saw me again and [unclear] "I don't understand
 252 what's happened to this bugger"

Extract 4:16 FGDS1
 789 Norman: I mean I had two consultants and they they're pretty
 790 good at [hospital 2] and they really were struggling
 791 [slight laugh] I mean they apologised to me afterwards
 792 when they they finally sorted it cos they took me back
 793 there () after I'd been to [hospital 1] for a while (.) and
 794 e::h Dr Y who was a consultant for the geriatric ward
 795 came back and apologised because (.) he says "you only
 796 get one of these a lifetime
 797 *Kirsty:* mm
 798 Norman: and you're it "
 799 *Kirsty:* mm
 800 Norman: cos they just didn't have a clue what was wrong with me

In extract 4:15 , Norman's central claim is in line 243: "they didn't know that I'd had a stroke"; in extract 4:16, it can be seen in line 800: "they just didn't have a clue what was wrong with me. In both accounts, Norman constructs the medical personnel involved as highly capable clinicians. Thus, in extract 4:15, Norman follows his claim by providing information about the GP's level of experience that also allows us to infer that *none* of the other doctors in his practice would have realised that he had had a stroke: "and he wa:s (.) probably the most experienced doctor they had in that practice" (lines 243-244). Prior to making this assessment, Norman provides an account that helps to establish the assessment as factual, based on relevant experience: "my wife works (.) she's a medical (.) mm eh a practical em eh a practice manager so she works with the doctors and I'm friends with a lot of the doctors" (lines 235-237).

Norman's central claim is followed by an account that constructs his GP's failure to realise what had happened. He describes how his doctor thought initially that the problem was relatively minor: "he didn't realise he gave me pills for ear balance problems" (lines 245-246). He uses active voicing (Wooffitt, 1992) to enhance the facticity of his GP's comments when he came to visit for a second time "I don't understand what's happened to this bugger" (lines 251-252).

In extract 4:16, Norman similarly works to stress the level of expertise of the doctors concerned. His central claim is the upshot of an account provided in lines 789-798. In this account, Norman makes relevant the doctors' status as experienced clinicians, and the reputation of the hospital he was in: "I mean I had two consultants and they're pretty good at [hospital 2]" (lines 789-790). Sacks (1974; 1979) suggests that category terms, such as consultant, can be used to make available certain inferences about people or things belonging to the category. In this case, we would expect that someone described as consultant could be regarded as expert in medical matters. Norman also makes relevant the fact that there was not one, there were *two* consultants, and furthermore that those at this particular hospital are "pretty good." The claim that follows is, therefore, surprising: "they were really struggling" (line 790). Norman accounts for this by twice referring to the doctors' acknowledgement of this state of affairs - "I mean they apologised to me afterwards" (line 791); "Dr Y who was a consultant for the geriatric ward came back and apologised" (lines 794-795). In both extracts, Norman provides a level of detail that helps construct the reality of his account. His description of the doctors' confusion in extract 4:16 is constructed as one with which they themselves would agree, and not just Norman's personal opinion. As in extract 4:15, Norman uses active voicing (Wooffitt, 1992) to enhance the credibility of the doctor's statement: "you only get one of these in a lifetime [...] and you're it" (lines 795-798). This emphasises the rarity of Norman's condition, and hence its unexpected nature. The story in extract 4:15 also works to

illustrate the difficulties Norman's GP had in discovering what had happened to him. We can infer from these accounts that Norman's stroke was both unpredicted and unpredictable.

In the next two extracts, participants used 'before and after' formulations to construct the unpredictability of stroke:

Extract 4:17	FGDS1
216 <i>Kirsty</i> :	it just hits you so sudden doesn't it?
217 <i>Steve</i> :	aye I [know aye I know]
218 <i>Yvonne</i> :	[you couldn't describe it]
219 <i>Steve</i> :	that's what I eh (.) [when it]
220 <i>Yvonne</i> :	[I'd been] to the [<u>bingo</u> that night]
221	and
222 <i>Kirsty</i> :	[that's I think]
223	[that's]
224 <i>Steve</i> :	[when I]
225 <i>Yvonne</i> :	drove back to <u>Edinburgh</u>
226 <i>Kirsty</i> :	mhmm
227 <i>Steve</i> :	mm
228 <i>Yvonne</i> :	got in my hall and that was me

In extract 4:17, Yvonne tells a story following on from Kirsty's comment "it just hits you so sudden doesn't it?" (line 216). In her narrative, Yvonne describes what she was doing prior to her stroke. She had had a social evening out - "I'd been to the bingo that night" (line 220) - something that someone would not be likely to do if he or she felt very unwell. She drove her car back - the emphasis in "drove back to Edinburgh" (line 225) can be heard as inferring that this was out of town, again something that she would have been unlikely to have undertaken if she had had any inkling that she was about to have a stroke. Thus, Yvonne's story helps to construct her stroke as unpredicted. It is interesting to note Yvonne's description of the moment when she had her stroke: "got in my hall and that was me" (line 228). As we have seen in earlier extracts, this constitutes a somewhat vague account of what happened.

In the following extract, Eric also uses a 'before and after' construction to describe the effects of stroke:

Extract 4:18 FGDS2
38 Eric: I think you go through .h your life em doing just doing
39 things .h as normal I mean Lorna although is .hh the the only
40 carer here you go through life you just (.) things just go and
41 then you evolve and .h and you just do things then suddenly
42 this stroke hits you and you .h everything comes to a dead halt

Extract 4:18 can be divided into two parts. In lines 38-41, Eric works up a description of ordinary life. Lee (1987) writes that the particle 'just' can be used in a deprecatory sense, indicating that what it refers to is somewhat trivial in comparison to an alternative referent that can either be explicit or implicit. Where it is implicit, it suggests that there is an alternative which is in some way more important or more significant. In this case, then, the repeated use of 'just' serves to suggest that life before stroke is ordinary and unremarkable - "I think you go through .h your life em doing *just* doing things .h as normal [...] you go through life you *just* (.) things *just go* and then you evolve and (.) you *just do* things" (lines 38-41). This works to set up a contrast between life before the stroke, and the sudden impact of this condition. The description is also marked by its imprecision and incompleteness - "just doing things" (lines 38-39); "things just go" (line 40); "you just do things" (line 41), and by an impression of movement - "you go through (.) your life" (line 38); "you go through life" (line 40); "things just go and then you evolve" (lines 40-41). In the remainder of the extract, the stroke takes the active part of the verb - "this stroke hits you" (line 41), and the description, portraying a sudden stop that contrasts with the previous impression of movement, is not lengthy and vague, but short and precise: "then suddenly this stroke hits you and you .h everything comes to a dead halt" (lines 41-42).

The 'before and after' construction was, then, used to emphasise the unexpected nature of stroke. The same effect was achieved by the use of story-like accounts describing the difficulties that experienced doctors had in diagnosing stroke. If the sufferer was thought to be at all likely to have a stroke, we might assume that clinicians would have recognised this fact sooner.

4. Summary

In this chapter, I have shown that stroke sufferers in the focus groups were hesitant in providing an answer to my question "how would you describe your situation - having had a stroke at a young age - to someone who doesn't know anything about it?"

While some hesitancy might be attributable to speech difficulties, it has been demonstrated that there are other possible explanations. Stroke is hard to describe; and other people cannot really understand what it is like. Participants oriented to these points, and also went on to construct the effects of stroke in terms of a loss of ability, and the stroke itself as unpredictable. It was noted that more vivid assessments were provided in internet communications, and that this may be because they were less open to challenge by other people. Mundane activities and story-like accounts were used to illustrate loss of ability. Unpredictability was constructed by means of 'failure to diagnose' narratives, as well as 'before and after' devices.

5. Discussion

We can see, then, that stroke sufferers did not themselves construct stroke solely in terms of the neurological deficits it can bring about. Neither did they construct stroke in terms of distinct cognitive schemas relating to its identity and effects. The participants in this research did not demonstrate a denial of injury, but they did at times display hesitancy in constructing the effects of stroke. This was shown to be

suggestive of an orientation towards the likely failure of non-sufferers to understand stroke. While respondents may have had some linguistic problems, these did not prevent them from providing accounts that were delicately crafted to construct stroke in terms of the loss of ability it can bring about, and in terms of its unpredictability. This can be seen in both the verbal interaction of focus groups, and the written communication in email correspondence, although it appears that accountability may have been a greater issue in focus group discussions. There are implications for the ways in which research is carried out into the effects of stroke on the sufferer. Most studies have used a quantitative methodology to measure functional losses and this has formed the rationale for rehabilitative treatments that do not always focus on sufferers' own concerns (Kirkevold, 2002).

Other researchers (Bendz, 2000; Ellis-Hill *et al.*, 2000) have found that stroke sufferers experienced their condition in terms of a self-body split, in which the body becomes objectified. The perspective of this thesis is that such accounts might be examined not just for their content, but also for their rhetorical function. Such a construction might serve, for example, to avoid the stigma associated with bodily incapacity. That is, the notion of the self-body split might be used to orient to accountability issues. Billig (1987) has shown the importance of argumentation in interaction. That is, any one construction is rhetorically designed to counter a number of other possible constructions. In this research, carers of some of the stroke sufferers participated in the focus groups, and this meant that issues of situated accountability could be explored further. This is described in chapter 5.

CHAPTER 5

ACCOUNTABILITY AND STROKE

Research into chronic illness suggests that people can potentially be held accountable for being unwell and for their role in getting better. This was highlighted by Parsons (1951) in his classic exploration of the relationship of the sick person to society. A fundamental assumption of his thesis is that the notion of patient motivation - not just to get better, but also to be ill in the first place - is crucial. Thus, falling ill is a potentially warrantable state of affairs.

In the case of stroke, Pound and colleagues (1997) explore the ways in which this condition has been named and described over the years. They suggest that sufferers' lifestyles have historically been implicated in stroke and that stroke has been seen in terms of a punishment for such lifestyles. Thus, they cite references to "the stroke of God's hand" and "the stroke of justice." In more recent times, medical researchers have identified a number of risk factors for stroke, and these can be used by GPs to estimate the likelihood that particular individuals might suffer this condition (Coppola *et al.*, 1995). The lifestyle factors that are directly implicated in stroke are smoking and taking little exercise. In addition, people with high blood pressure - a condition which itself is related to lifestyle factors such as dietary intake - are at risk. Furthermore, there is research that suggests an association between personality factors

and susceptibility to stroke. Finally, the majority of sufferers are over the age of 65. Therefore, to have a stroke at a younger age might be more accountable because it is less easily explained by current medical research.

In chapter 4, I showed how stroke sufferers constructed stroke as complex, hard for others to understand, unpredictable, and in terms of the loss of abilities it brings about. An interesting feature of the stroke data is that carers contributed to the focus group discussions, and in this chapter, my aim is to examine the ways in which their presence might shed some light on the possible functions of sufferers' constructions of stroke. Preliminary analysis suggested two possible functions of these constructions. First, to construct stroke as unpredictable can serve to counter the potential charge that sufferers were in some way accountable for having had a stroke. A discussion of this can be seen in Section 1. Second, to construct stroke in terms of loss of abilities can be seen to orient to the problem of distinguishing the effects of stroke from laziness. To construct stroke as complex and hard for others to understand can serve the same function. This is explored in section 2.

1. Accounting for having had a stroke

In this section, I examine the 'stroke as unpredictable' construction. In chapter 4, I demonstrated that participants used two particular devices to do this. They told narratives in which medical professionals initially failed to produce an accurate diagnosis of what had happened, and they used 'before and after' stories to construct stroke as something unanticipated and out of the ordinary. If it can be demonstrated that doctors could not recognise the event of stroke, and that the sufferer had no prior symptoms of note, then we can infer that the sufferer would not have been in a position to prevent this occurrence. Thus, the 'stroke as unpredictable' construction might be used to absolve the sufferer from responsibility for his or her condition. I

therefore examined the data further to see whether this interpretation was something to which participants oriented. First, I analysed responses to a question that I had posed about the possible causes of stroke. Second, I reasoned that participants were more likely to orient to issues of accountability when in the presence of carers who might challenge sufferers' constructions, so I re-examined all of the focus group data to see whether the *carers* who were present constructed stroke as an accountable issue. This led to my third line of enquiry, which was to explore whether internet participants used accountability devices relating to the cause of stroke. This group was of particular interest here because they emailed me on a one-to-one basis and therefore did not orient to the presence either of other sufferers, or of carers, although what they wrote can perhaps be seen as part of the wider social context in which stroke sufferers construct their condition. I will discuss each of these three stages of analysis in turn.

1.1 Constructions of the possible causes of stroke

The extracts discussed in this section were all taken from the response to my question: "do you have any ideas about how it is that people get strokes at a young age?"

Extract 5:1 FGDS1

1453	Yvonne:	cos they've been buggers in their lives no? [general laughter]
1454		
1455	Steve:	no [not] me no eh [laughs]
1456	Kirsty:	to me it's a lot (.) to me it's (..) the luck of the draw to tell you the (.) know what I <u>mean</u> it's (.) people smoke
1457		they say "oh smoking's not (.) good for you" but
1458		well I've never [smoked so]
1459	Ian:	
1460	Kirsty:	[and this] know what I mean it's (.)
1461		people that have never smoked in their life and died of
1462		lung cancer

In extract 5:1, we can see that there are two separate accounts offered to explain what might cause stroke. First, Yvonne's response "cos they've been buggers in their lives no?" (line 1453) explicitly suggests that stroke sufferers are in some way to blame for

their condition. The second account is provided by Kirsty, a carer, and her interpretation is non-blaming: "it's (..) the luck of the draw" (line 1456). Each account, therefore, orients to the possibility that the sufferer might be held accountable for having had a stroke.

An interesting feature of this extract is the stroke sufferers' response to these accounts. In line 1455, Steve follows Yvonne's claim with "no me no eh [laughs]." This can be seen as a somewhat po-faced receipt of a tease, a conversational device that was first observed by Drew (1987). Steve's laughter shows that he does recognise that Yvonne is being humorous, but he nevertheless begins his response with a denial. Drew suggests that the tease ascribes a deviant identity to the recipient, and that one way of resisting such an identity is to provide a po-faced response. In this case, the ascription of the identity "buggers" (line 1453) can be considered deviant.

Ian provides a similar response to Kirsty's account, before she has even finished. After her initial claim that having a stroke can be attributed to bad luck, Kirsty uses the case of smokers as an illustrative example. Thus, she states that "they say "oh smoking's not (..) good for you" but" (line 1458). We might expect, following Kirsty's original claim, that her example would illustrate the role of luck in illness, and that her use of "but" might signal such a construction. However, it is at this point that Ian produces a denial, using an extreme case formulation (Pomerantz, 1986) for emphasis: "well I've *never* smoked" (line 1459). While Kirsty's construction would not be seen as a tease, it *is* treated as one that might ascribe a deviant identity to the stroke sufferer - especially with her reference to smoking, which has been linked with stroke.

We can see from this extract, then, that responsibility for stroke is oriented to in respondents' accounts, and furthermore that stroke sufferers orient to the potentially

deviant identity that might be ascribed to them when the cause of stroke is being constructed. In the following extract, an internet respondent orients to the possibility that he might be held responsible for having had a stroke:

Extract 5:2 DSIPCp21 Frederick

- 1 Not really. I think the doctors don't know themselves. They
2 offer all sorts of explanations, but if they really knew I
3 wouldn't have had one.

Here, Frederick's reply to my question - asking if he had any ideas about what might cause stroke - is "[n]ot really" (line 1). This denial is followed by an account that constructs stroke as something that is poorly understood by the medical profession, and therefore, as I have argued in Chapter 4, unpredictable. Frederick also orients to the possibility that *he* might be held responsible for his condition, and he does this by laying the blame elsewhere: "if they really knew I wouldn't have had one" (lines 2-3).

The next extract is taken from the second focus group, and in it we can see that participants orient to the accountability that might arise from being a young sufferer of stroke.

Extract 5:3 FGDS2

- 1359 Jennifer: do you have any ideas about how it is that people get
1360 strokes at a young age?
1361 (4)
1362 Brian: all the old people said to me "you're gey [very] young to
1363 have a stroke young laddie" [laughs]
1364 Eric: [laughs]
1365 Brian: I know (.) old wives' tale (..)
1366 Eric: it's the other way round
1367 Euan: I think (.) both Brian and Eric sort of sort of illustrate
1368 what happens with a lot of stroke survivors is that () we
1369 all become usually quite knowledgeable about (.) our ()
1370 brain injury
1371 Jennifer: mhmm
1372 Euan: mhmm
1373 Brian: yeah
1374 Euan: like Brian there just can't remember the full (.) technical
1375 detail of it
1376 Jennifer: mm
1377 Euan: the full name of it he's al- he's almost right

1378 Brian: mm
 1379 Euan: it's something like encetoph- encetalophy or
 1380 Jennifer: mm
 1381 Brian: no progressive multi-focal oh neurgh [[unclear]]
 1382 Eric: [I didn't want to
 1383 know] I didn't want to know
 1384 Brian: [laughs] I still can't say it [laughs]
 1385 Eric: I think ehm the doctors have sai- said .hh you're your
 1386 own you are your own doctor if you feel off-colour then
 1387 you should go to your doctor .h (4) mm? and that's the
 1388 (.) for the (.) young people if there's something wrong
 1389 well .hh we all we all think we're invincible

My question "do you have any ideas about how it is that people get strokes at a young age?" is followed by a 4-second pause, which indicates that this question might be problematic. A 'standard' pause would normally be in the range of 0.8-1.2 seconds (Jefferson, 1989). The remainder of the extract will be examined in three sections. First, in lines 1362-1364, there is an insertion sequence referring to the young age at which Brian had his stroke. In the next section, from lines 1365-1384, participants provide warrants for their claim to knowledge about stroke. Finally, in lines 1385-1389, Eric orients to issues of responsibility for seeking appropriate medical attention when necessary. This is discussed in full below.

In the insertion sequence, lines 1362-1364, Brian uses active voicing (Wooffitt, 1992) to illustrate the reaction that old people had to his condition: "you're gey young to have a stroke young laddie" (lines 1362-1363). Brian's adoption of a slightly tremulous tone, as if impersonating an old person's voice, and some rather old-fashioned colloquial terms - 'gey' and 'laddie' - serve to characterise this statement as somewhat humorous. Indeed, Brian, and then Eric, proceed to laugh. Brian's claim that follows - "I know (.) old wives' tale" (line 1365) constructs this account as one that is not based in fact but folklore. Thus, Brian orients to his young age as a phenomenon that some people might find unusual, and at the same time he undermines that view as one that should not be taken seriously.

In the next section of this extract (lines 1365-1384), participants work up a claim to knowledge which, can be seen to orient to some of the features of the 'old wives' tale'. Euan uses a general, medical term "brain injury" (line 1370), which can be contrasted with the lay term "stroke" used by the old people. This is followed by a joint attempt to produce the correct medical term: "it's something like encetoph-encetalophy or" (Euan; line 1379); "no progressive multi-focal oh neurgh [unclear]" (Brian; line 1381). Medical knowledge of the condition might be considered to have more warrant than an "old wives' tale." However, Euan and Brian are patently having some difficulty in providing the medical terminology. It is at this point that Eric interjects "I didn't want know I didn't want to know" (lines 1382-1383), which is followed by Brian's turn "[laughs] I still can't say it [laughs]" (line 1384). These claims *reframe* their failure to produce the medical term. We are left to infer that Eric might have known, had he wished this, and that Brian does know but is unable to enunciate it. In accounting for their inability to use the correct clinical term, they bolster the claim to knowledge that the use of such terminology implies.

In the last section of this extract (lines 1385-1389), Eric re-oriens to the original question with the claim that "if you feel off-colour then you should go to your doctor" (lines 1386-1387). This oriens to a potential accountability on the part of the person who is unwell, and the 4-second pause that follows suggests that such an orientation is problematic. Eric's account that follows - "if there's something wrong well .hh we all we all think we're invincible" (lines 1388-1389) - serves to mitigate this accountability in two ways. First, he uses the general form 'we' to suggest that stroke sufferers are not the only people who do not attend the doctor when they perhaps should. Second, he suggests that this can be put down to feeling invulnerable, and this constructs the identity of the stroke sufferer in a relatively positive light.

The following extract can be seen as an exception to the ones discussed so far, in that no blame is inferred and no accounting is offered.

Extract 5:4 DSIPCp21 Ana

- 1 The causes of stroke in younger people include head
- 2 injury, brain tumour, infection(encephalitis or cerebral
- 3 abscess), congenital vascular malformations e.g. aneurysms
- 4 and AVM [Arterio-Venous Malformation], and familial
- 5 hypercholesterolaemia.

Here, Ana provides a list of possible causes of stroke. There is nothing in this account to suggest that sufferers might be held responsible for their condition. It differs from the previous extracts in two ways. First, Ana draws on specialist medical terminology, and does not refer to lifestyle factors that have been implicated in stroke, such as taking little exercise and smoking, but instead physical events over which the individual could not be expected to have any control. This in itself may avoid the need for further accounting. Second, she refers, in line 1, to "[t]he causes of stroke in younger people" in general, and does not discuss her particular case. Thus, her account is presented as one that is both objective and warranted by medical knowledge.

We can see from the above extracts that participants generally did orient to the causes of stroke as problematic. By imputing particular causes, participants allow certain inferences to be made regarding the extent to which the sufferer might be held responsible. Stroke sufferers oriented to the potentially deviant identities that were offered in accounts of the cause of stroke. Clinical terminology was used to validate claims to knowledge about stroke, and in the one extract in which there was no evidence of accountability for stroke, the respondent drew solely on general medical causes.

1.2 Constructions of the causes of stroke in sufferer-carer interactions

The extracts in this section come from focus group data, and in particular interactions involving carers - who were close relatives or spouses of the sufferers - and the people who had had a stroke. It is notable that these people did hold stroke sufferers accountable. The extracts shown here are of interest because they provide the opportunity to examine sufferers' responses when they are explicitly held accountable for their stroke, and not just when responding to my question about its possible causes.

In the following three extracts, carers construct stroke sufferers as responsible for their stroke in terms of their lifestyle choices:

Extract 5:5 FGDS2

576 Eric: don't know why I had a stroke in the first place
577 Lorna: you like being in control
578 Eric: oh yes
579 Alison: oh yeah
580 Lorna: well definitely from what you've said [looking at Alison]
581 Alison: definitely
582 Eric: definitely yes (.) oh yeah (...) but I would have taken the
583 view before the stroke that I could have run this hospital
584 you know

Extract 5:6 FGDS2

1046 Lorna: [looking at Brian] did you think you deserved it? (...)
1047 had you been leading a wild (.)
1048 Brian: yeah
1049 Lorna: cos you're the youngest in the group [laughs]
1050 Brian: ah (..) aye I was I wasn't meant to be born I was I was a
1051 mistake my mother and father
1052 Eric: [[laughs]]
1053 Brian: [it was though] YOU DON'T HAVE SOMEONE
1054 WHEN YOU'RE FORTY-FIVE you don't have a child
1055 when you're forty-five
1056 Eric: [very quite] [unclear]
1057 Brian: that's cos I was being dragged all round the world with
1058 my father

Extract 5:7 FGDS2

1407 Jennifer: and what would you (.) say would be the warning signs
1408 (.) to look out for?

1409 *Lorna:* I would say stress running around running ragged not
 1410 taking a break
 1411 *Alison:* [mhmm]
 1412 *Jennifer:* [mm]
 1413 *Lorna:* ehm (.) diet () lack of exercise
 1414 *Jennifer:* mhmm
 1415 *Eric:* yeah [[unclear]
 1416 *Lorna:* [and it's not in] the year or so beforehand it's
 1417 *Alison:* [yup]
 1418 *Lorna:* [away] back it's right throughout
 1419 *Alison:* yup
 1420 *Euan:* eating your lunch at your desk [sort of thing mhmm]
 1421 *Alison:* [years ago my mum] told
 1422 him that years and years ago
 1423 *Eric:* yeah (.) [I think it's]
 1424 *Alison:* [cos he never would] take a lunch break he
 1425 never ate from () when he left in the morning till he
 1426 came in at night
 1427 *Lorna:* yeah
 1428 *Alison:* the whole day you know and ["well" my mum used to
 1429 say "you're gonna make yourself ill"] little did we know
 1430 *Lorna:* [I'm sure that would cut
 1431 down on the number]
 1432 *Jennifer:* mhmm
 1433 *Eric:* yeah I think there's a category of person I think that
 1434 *Alison:* yup
 1435 *Eric:* you can identify high risk people (.)

In extract 5:5, Lorna's claim "you like being in control" (line 577), coming straight after Eric's claim "don't know why I had a stroke in the first place", appears to be offered as an account of why Eric had his stroke. Lorna does not just suggest that his stroke is attributable to a personal characteristic, she also infers some volition on Eric's part in her use of "you like." Thus, she holds Eric responsible for his condition.

In extract 5:6, Lorna's questions, aimed at Brian, imply that he might be to blame for his stroke. Thus, she asks "did you think you deserved it?" (line 1047) and her next question asks for information about Brian's lifestyle prior to the stroke: "had you been leading a wild (.)" (line 1048) - the sentence is incomplete, but we might assume from common usage that the missing word is "life." By asking these questions, Lorna makes Brian accountable for his stroke.

Extract 5:7 begins with my question - which referred to an earlier reference by Lorna (one of the carers) to "warning signs" - "and what would you (.) say would be the warning signs (.) to look out for?" (lines 1407-1408). We might expect the response to this to be concerned with physical symptoms that suggest something is wrong. However, what Lorna does is provide a list of behaviours that might be thought to precipitate stroke - "stress running around running ragged not taking a break" (lines 1409-1410). She follows this up in line 1413 with "diet () lack of exercise." Thus, she uses features of the stroke sufferer's lifestyle, over which he or she presumably has some control, to suggest responsibility for this condition. Furthermore, she refers back to a vague time in the past: "and it's not in the year or so beforehand it's [...] away back it's right throughout" (lines 1416-1418). Taking up this construction, Alison uses extreme case formulations (Pomerantz, 1986) and active voicing (Wooffitt, 1992), from someone we can infer has the category entitlement of a reliable witness - her mother. These devices help reinforce this biographical account of her partner (Eric) as indeed marked by these behaviours. An illness of some sort is constructed as something that was foreseen some time ago: "years ago my mum told him that years and years ago [...] cos he *never* would take a lunch break he *never* ate from () when he left in the morning till he came in at night (lines 1421-1426; emphasis added). Here, Alison uses the 'habitual narrative' genre, which Riessman (1990) described as a useful strategy when making a case for the way in which a situation might have developed over time. It functions well to suggest that Eric's stroke was attributable to his lifestyle. Alison does not just make Eric accountable for his stroke, she makes it clear that he was warned and so cannot claim ignorance of the dangers of his lifestyle. Thus, we can see in this extract that sufferers are held accountable in terms of their behaviours prior to having had a stroke.

In the first two extracts above, the initial response of the stroke sufferer in question is to provide an agreement token. Eric's response to Lorna's claim that he likes being in

control is "oh yes" (extract 5:5, line 578); Brian's response to her suggestion that he might have deserved his stroke is "yeah" (extract 5:6, line 1049). An analysis of subsequent turns, however, shows that both sufferers orient to the potential charge that is being made, in that they each provide an account that is subtly designed to deflect personal responsibility for their stroke. In extract 5:5, Eric's "oh yes" (line 578) is recycled by Alison (Eric's wife) in line 579 - "oh yeah." Lorna upgrades the agreement token with "well definitely from what you've said." This upgrade suggests that Lorna does not treat the agreement tokens provided so far as sufficient. Lorna's reference to something that Alison had previously said is used to warrant her claim. There are two aspects to this warrant that make it particularly difficult to challenge. The first is that no details are given. Potter (1996b) points out that details can be examined and questioned, whereas to provide a vague account can work to resist such a response. The second relates to the first - in order to challenge this, Alison would have to ascertain what it was that she had said to Lorna. This could be problematic in the presence of her husband, as well as the other participants. Alison's response is to recycle Lorna's assessment - "definitely" (line 581) but with no reference to any prior conversation. Eric recycles this upgraded assessment, but follows it with a reiteration of his and Alison's original, weaker agreement tokens: "definitely yes (.) oh yeah" (line 582). He then provides an illustrative example relating to the topic of control: "but I would have taken the view before the stroke that I could have run this hospital you know" (lines 582-584). To have felt competent enough to have run a hospital has far less negative connotations than were implied by Lorna's claim at the start of this extract - "you like being in control" (line 577). This suggests that the desire for control is general, and we might infer from this that it is not always appropriate. It also implies that this relates to Eric as a person and is therefore something for which he should take responsibility. Eric's formulation, however, suggests specific competence in a particular setting, and furthermore that he was hard-working. These

are socially acceptable qualities. Thus, Eric's account works to deflect personal culpability.

We can see a similar pattern in extract 5:6. This begins with Lorna's inference that Brian's way of living might have contributed to the onset of his stroke - "had you been leading a wild (.)" (lines 1046-1047). 'To lead a wild life' is a fairly common idiomatic expression. Drew & Holt (1989) have noted that such formulations can be hard to challenge because they are vague and they refer to some shared, common-sense knowledge about the world. This particular expression implies an excessive lifestyle which is likely to lead ultimately to harmful consequences. Brian provides an agreement token - "yeah" (line 1048) and Lorna's response is to provide an account for her inference - "cos you're the youngest in the group [laughs]" (line 1049). Thus, she makes relevant the age difference between Brian and the other young stroke survivors. This works to make him even more accountable, in that it is far less common to have a stroke at a younger age than an older age. In the turns that follow, Brian responds subtly to the charge that his stroke is related to the excessive lifestyle of a younger person. Lorna ended her turn with laughter, which might have worked to downgrade her previous remarks to a tease or joke. However, Brian does not orient to this but instead to the serious nature of her allegations. He begins with another agreement token, and follows it with a claim that casts him in a completely passive role - "ah (..) aye I was I wasn't meant to be born I was I was a mistake my mother and father" (lines 1050-1051). Eric takes this up as a joke, but while he is laughing Brian continues "it was though" then in a loud voice he provides an account that justifies his claim - "YOU DON'T HAVE SOMEONE WHEN YOU'RE FORTY-FIVE" (lines 1053-1054). His use of "you" here allows him to suggest that what he is saying is part of some shared, general knowledge. By referring to the relatively late time in life at which his parents had him, Brian allows us to infer that, although he is younger than the others, they may have similarly aged parents. This lessens the

difference between him and the older stroke sufferers in the group. Further more, it moves the focus from Brian to his mother and father. It is notable that when he recycles his claim in lines 1054-1055 - "you don't have a child when you're forty-five", he refers to "a child" and not "someone", and thus is able to stress the dependent nature of the relationship. Finally, Brian provides an upshot of the fact that his birth was not planned: "that's cos I was being dragged all round the world with my father" (lines 1056-1057). Thus, he suggests that his "wild" lifestyle was characterised by a great deal of travelling when he was extremely young, and had little choice in the matter. The latter can also be inferred by the passive use and lexical choice of the verb in "I was being dragged." Brian's response therefore also works to minimise personal responsibility for the onset of his stroke.

In extract 5:7, carers construct the stroke sufferer as a busy and active person. This might be seen as a less blameworthy construction than one that, for example, involves having led a wild life, which we saw in extract 5:6. Indeed, one of the stroke sufferers collaborates in the carers' construction: "eating your lunch at your desk that sort of thing mhmm" (line 1420). It is also interesting to note Eric's response. He agrees, and does so with reference to characteristics of the stroke sufferer: "yeah I think there's a *category of person* I think that [...] you can identify *high risk people*" (lines 1433 and 1435). Thus, Eric implies that personal characteristics contribute to the chances of suffering stroke. In this case the personal characteristics in question would normally be considered in a positive light. When this is not the case, participants' responses are subtly designed to reduce personal responsibility for their stroke.

In the next two extracts, accountability for stroke rests on the sufferer's success or failure in seeking the appropriate medical attention on time, an issue that was oriented

to by Eric in extract 5:3, when he suggested that "if you feel off-colour then you should go to your doctor" (lines 1386-1387).

Extract 5:8 FGDS2

1469 Sharon: I actually didn't feel well before my brain haemorrhage
1470 and I went to my doctor and he sent me for an eye test
1471 cos I said I was getting headaches [and he]
1472 Jennifer: [mhmm]
1473 Sharon: said "go and get you and get your eyes tested and go and
1474 do this and this and this" .hh and it didn't even seem to
1475 occur to him there was something serious coming

Extract 5:8 is taken from slightly later in the same transcript as extract 5:7. Here, Sharon produces a narrative in which she describes a visit to her doctor prior to her stroke. This type of specific story can be used to highlight significant features of the lead-up to her stroke (Riessman, 1990). By claiming "I *actually* didn't feel well", Sharon suggests that such symptoms are unusual in the run up to a stroke. This allows us to infer that stroke sufferers might not normally have any 'warning signs'. Sharon notes that she did go to the doctor, "and it didn't even seem to occur to him there was something serious coming" (lines 1474-1475). Thus, she constructs her stroke as unpredictable, while at the same time making relevant the fact that she did seek medical attention prior to it. This allows her to avoid the potential charge that she might have been in a position to do something to avoid her stroke.

Extract 5:9 FGDS2

1119 Euan: you know my stroke could probably have been avoided
1120 which is annoying=
1121 Alison: well yeah
1122 Eric: I'm the same [yeah]
1123 Lorna: [and] you've only got yourself to blame
1124 Eric: I'm the same (.) no?
1125 Jennifer: what kind of things (.) would [prevent it]
1126 Eric: [well like] higher blood
1127 pressure [or]
1128 Lorna: [it] runs in the family
1129 Eric: my mum
1130 Lorna: he would have gone to doctor when he had a headache
1131 that he doesn't normally have
1132 Jennifer: mm
1133 Lorna: [you know he would]

1134 Euan: [when I bashed it] on a on a when I was fixing a shelf
 1135 for you
 1136 *Lorna:* on his desk was the doctor's tele- the GP surgery's
 1137 telephone number (.) and it was there for how many
 1138 days before you had your stroke? because I said to you
 1139 "you've still got your headache I think you should make
 1140 an appointment"
 1141 *Jennifer:* mm
 1142 *Lorna:* and it's (.) probably STILL sitting on the desk
 1143 *Jennifer:* mhmm
 1144 Euan: but [but]
 1145 *Lorna:* [not] willing [to take a little bit of [unclear]] advice
 1146 Euan: [if if if my my headache was] nothing
 1147 to do with my stroke
 1148 *Lorna:* yes it was (.) it was all related your blood pressure was
 1149 (.) gently soaring (..)
 1150 Euan: but it takes (.) but you (.) getting an appointment at the
 1151 GP is actually quite hard

Extract 5:9 is long, but is offered in its entirety in order to provide context for the points that will be discussed. At the beginning, Euan makes a claim: "you know my stroke could probably have been avoided" (line 1119), and Lorna's response is to make Euan fully accountable for his stroke: "and you've only got yourself to blame" (line 1123). In the rest of the interaction, Lorna provides evidence for this claim, and this focuses on Euan's failure to consult his doctor for the headache he suffered prior to his stroke. This failure is made accountable by her claims that Euan had the GP's telephone number on his desk, and Lorna had advised him to make an appointment.

It is interesting to note that Euan neither agrees nor collaborates with Lorna's construction of him as accountable. Instead, he produces defensive statements that orient to her specific claims. Thus, Lorna claims that to prevent his stroke "he would have gone to the doctor when he had a headache that he doesn't normally have" (lines 1130-1131). Thus, she constructs his headache as unusual and therefore one that merited a clinical consultation. Euan counters this with "when I bashed it on a on a when I was fixing a shelf for you" (lines 1134-1135). In the context of this interaction, we might assume that 'it' refers to his head. Here, Euan constructs his

headache as having an identifiable cause, and therefore presumably not something to worry about. Lorna's claim that "on his desk was the doctor's tele- the GP surgery's telephone number" (lines 1136-1137), makes relevant the fact the Euan had easy access to this information, and from this we can infer that he is accountable for not making the necessary call. Euan does provide an account for his failure to arrange a consultation: "but it takes (.) but you (.) getting an appointment at the GP is actually quite hard (lines 1150-1151).

In the extracts discussed so far, participants' responses were delicately crafted to counter implications that they might be personally liable for their stroke. When carers constructed sufferers as active and busy people whose lifestyle might in some way have contributed to their condition, participants colluded somewhat in this construction. Another type of accountability to which participants oriented was a failure to seek appropriate medical attention prior to their stroke. Stroke sufferers quoted here did attempt to counter implications of responsibility in this case.

1.3 Internet participants' constructions of the possible causes of stroke

We have seen how, in interactions between carers and stroke sufferers, the latter are held responsible for their stroke. In this section, I will show that one-to-one internet participants also treat the cause of stroke as accountable:

Extract 5:10 DSIPCp1 Kenneth
1 I had a stroke(caused by an unusual accident), at the age of 48.
2 my circumstances are probably greatly different than most.

Extract 5:11 DSIPCp10 Ana
1 My stroke was due to an aneurysmal haemorrhage (no
2 prior history of problems).

In both extracts here, respondents insert a claim in parentheses which serves two functions. First, it says something about what might have brought on the stroke. Second, it constructs the stroke as unpredictable. Thus Kenneth's claim about his stroke is that it was "caused by an unusual accident" (extract 5:10, line 1). In extract 5:11, Ana inserts a claim that suggests there was no precipitating incident: "no prior history of problems" (lines 1-2). Kenneth's use of the adjective "unusual" helps to emphasise that this event was something out of the ordinary, and Ana's claim similarly constructs her stroke as something that could not have been foreseen. Putting a remark in parenthesis is a useful emphatic formulation. It allows the writer to add information as an aside, and it has the effect of separating it from the rest of the text, therefore drawing particular attention to it.

In these extracts, then, we can see some orientation to the problematic issue of accounting for the cause of stroke. This suggests that responsibility for having a stroke is a concern for sufferers even when such a possibility is not explicitly constructed in interaction.

2. Accounting for level of disability

My analysis of the data in chapter 4 suggested that sufferers oriented to accountability not just for having had the stroke in the first place, but also to the possibility that their disability might not be entirely attributable to their condition. In this section, I will begin by discussing two extracts in which I show that stroke sufferers do orient to the views that other people have of their level of disability. I will then examine a further two extracts in which carers refer both implicitly and explicitly to the laziness of stroke sufferers.

Extract 5:12 FGDS1

278 Eric: and e:m () there's I think as Lorna says from the
279 outside outside ehm (..) it doesn't () show if anything's
280 happening you know my doctor said to me that eh (.)
281 from the outside I look perfectly normal (.) and we met
282 (.) eh George and (...) what's the wife's name (.) she's
283 about that height ehm George B and his wife (..)
284 *Alison*: oh God I cannae [can't] [remember]
285 Eric: [yeah] .h we met them anyway
286 and she said "oh you're back to normal again" I said "am
287 I hell"
288 *Jennifer*: mm
289 Eric: because they can't see what's happening inside you
290 know

Extract 5:13 FGDS1

405 Norman: I I went to the fire brigade (.) eh rehabilitation place that
406 they've got em (.) in Yorkshire () and the physios
407 would and the physio she's going and the physios
408 would turn around and say "well do this" and "do that"
409 and they'd say "what are you doing that for?" and I had
410 to turn round and tell her "look I'm scared stiff (.) you
411 know I'm gonna fall down and hurt myself here and I I
412 know what I can do (.) it looks easy for you and [the]
413 Ian: [mm]
414 Norman: trouble is we look normal

In both extracts 5:12 and 5:13, participants orient to the views that others have of them, specifically that they do not appreciate the extent of the stroke sufferer's disability. The stroke sufferers talking here produce a narrative that works up to a claim that external appearances do not reflect the reality of their condition. Riessman (1990) notes the strategic value of producing a specific story to highlight essential features of what is being talked about. Thus, in extract 5:12, Eric's upshot on outside appearances is that "they can't see what's happening inside you know" (lines 289-290), and in extract 5:13, Norman claims that "the trouble is we look normal" (lines 412-414). Prior to these claims, both Eric and Norman provide an account in which they use two devices that Potter (1996b) shows are useful in constructing a particular version of events as factual. Thus, they use detailed narrative in which information is provided relating to people and places - "and we met (.) eh George and (...) what's the wife's name (.) she's about that height ehm George B and his wife" (extract 5:12,

lines 281-283); "I I went to the fire brigade (.) eh rehabilitation place that they've got em (.) in Yorkshire" (extract 5:13 lines 405-406). They also use active voicing (Wooffitt, 1992) - "oh you're back to normal again" (extract 5:12, line 286; "they'd say "what are you doing that for?" and I had to turn round and tell her "look I'm scared stiff" (extract 5:13, lines 409-410).

In extracts 5:12 and 5:13, then, stroke sufferers contrast appearances with reality to suggest that their account is the more valid one, and in addition they use detailed narrative, and active voicing (Wooffitt, 1992) to construct as fact that their disability is due to the effects of stroke. The use of these devices suggests that stroke sufferers' inability to perform tasks is an accountable issue. In the next two extracts, we can see how this is explicitly formulated in interactions between sufferers and carers.

Extract 5:14 FGDS2

636 *Lorna:* but you've (.) dropped lots of things that you used to do
 637 as well
 638 *Euan:* mhmm
 639 *Lorna:* you would do it I think if you were asked (.) like (.) do
 640 that extra wee bit of (.) tidying up in the garden that you
 641 might have done voluntarily before (..) you j- the
 642 whether that's energy or just (..) whatever you just don't
 643 do it now
 644 *Sharon:* mm
 645 *Eric:* I think it's a bit of both () really
 646 *Lorna:* yeah
 647 *Eric:* I think it's .h energy
 648 *Alison:* I mean Eric will say I'll ask him the the the same thing
 649 "yeah I'll do that for you" [but it doesnae [doesn't]
 650 happen]
 651 *Euan:* [I always got ideas of] things
 652 I want to be doing but (..) never get them done
 653 *Eric:* energy and motivation [yeah]
 654 *Lorna:* [mhmm]
 655 *Alison:* yeah I've wondered about that as well whether that's (.)
 656 the stroke or whether it's just that they have well (.) it
 657 doesnae [doesn't] (.) "I cannae [can't] be bothered" you
 658 know whether it's (.) being lazy or whether it's (.) the
 659 stroke

Extract 5:15 FGDS1

1003 *Emma:* but I've I have found and I've found this with my father
 1004 and I've found it with her (.) and she she must admit this

1005		if she's gonna be honest (.) if you're there (..) and
1006		you're [unclear] she would let you run back and forward
1007		[unclear] she'll do on her own if there's nobody there
1008	<i>Kirsty:</i>	aye
1009	<i>Emma:</i>	and if you're there the more you do for them
1010	<i>Ian:</i>	yep
1011	<i>Emma:</i>	the more they'll expect they'll expect you to do

In extracts 5:14, and 5:15, Lorna and Alison, and Emma, carers of Eric, Euan and Yvonne respectively, construct stroke sufferers as unwilling rather than unable to carry out tasks. They use a number of rhetorical devices to achieve this. The first relates to lexical choice; Lorna's use of verb in "you've (.) *dropped* lots of things that you used to do" (extract 5:14, line 636) suggests that Euan has actively opted not to do these things, rather than that he is incapable. Second, she makes a conditional claim: "you would do it I think if you were asked" (line 639). Similarly, Emma claims that "she'll do on her own if there's nobody there" (extract 5:15, line 1007). These claims make activity conditional on a prior state of affairs, and suggest that the sufferer has some control over what he or she can do. Alison develops Lorna's construction by claiming that she *does* ask Eric to do things, that he agrees but still fails to act, and she uses a third device, active voicing (Wooffitt, 1992), to construct her account as factual: "I mean Eric will say I'll ask him the same thing "yeah I'll do that for you" but it doesnae happen" (lines 648-650).

Emma makes an explicit claim to truth with "she must admit this if she's gonna be honest" (lines 1004-1005), which leaves us to infer that if Yvonne does *not* agree with her, then it is Yvonne who is not being honest.

In extract 5:14, Lorna followed up a 'before and after' contrast of Euan's activities with a partially incomplete assessment: "whether that's energy or just (..) whatever you just don't do it now" (lines 642-643). Alison similarly ends her account with an assessment: "whether it's (.) being lazy or whether it's (.) the stroke" (lines 658-659).

In both cases, the carer suggests that there is some uncertainty as to the reason for sufferers' failure to carry out tasks. However, these assessments can be seen in the context of previous constructions of stroke sufferers as unwilling to help out, and hearers are therefore likely to draw the inference that stroke sufferers are being lazy. This has two rhetorical functions. First, carers manage indirectly to infer a construction that might otherwise be thought of as unkind on their part. Second, the hearer is more likely to see a construction as factual if he or she was the one to make it. Emma's assessment, at the end of extract 5:15, is more direct. She uses the pronoun "them" to construct stroke sufferers, in general, as lazy - at least when other people are around: "the more you do for them [...] the more they'll expect they'll expect you to do" (lines 1009-1011).

It is interesting to note the stroke sufferers' responses to implications that they are lazy. They do not counter this by, for example, attributing their failure to carry out tasks to the effects of stroke. Instead, in extract 5:14, they reframe their failure to carry out activities. Thus, Lorna's initial assessment - "whether that's energy or just (..) whatever" (line 642) - left open the possibility for alternative explanations. Alison, another carer, reformulated this in more negative terms: "whether it's (.) being lazy or whether it's (.) the stroke: (lines 658-659). Eric, however, claims "I think it's a bit of both () really" (line 645). He recycles the first part of her assessment - "I think it's .h energy" (line 647) - and in his next turn he continues "energy and motivation yeah" (line 653). When Alison gives her account of Eric's failure to do things even when asked, something that might be construed as laziness, this is overlapped by Euan's claim: "I always got ideas of things I want to be doing but (..) never get them done" (lines 651-652). Here, Euan defends against any inference that he is not motivated to do things, but he does not actually provide an account of why the things never get done. Specifically, he does not draw on the possible inference

that this is due to laziness. Thus, Eric's and Euan's accounts represent a less damaging assessment of their failure to carry out tasks.

In extract 5:15, it is interesting to note that Yvonne does not offer any comment, far less a defence against Emma's construction of stroke sufferers as lazy (and does not do so in the lines following the extract). This may be a reflection of the rhetorical strength of Emma's construction. Ian's "yep" in line 1010 is ambiguous. It may, on the one hand, represent agreement. Using the techniques of conversation analysis, Pomerantz (1984) has shown that an assessment is commonly paired with either an agreement or disagreement, and that the former is the normatively paired response. Interaction runs more smoothly when the preferred response is provided; this can be seen in the pauses and accounting that take place when the response is of the dispreferred type. When an assessment is followed by an agreement, this can also provide the signal that the previous speaker's turn is complete. Emma, Kirsty and Norman orient to this in the next line, in which Emma finishes her sentence and Kirsty and Norman take the floor. Thus, Ian's agreement might be considered a way of drawing a close to Emma's damaging claims. Norman's claim reframes the failure to carry out tasks when someone else is there to do them, in terms of the problems the sufferer might have in performing such tasks in front of other people - "it's it's embarrassment" (line 1013). This works to deflect personal blame from the stroke sufferer.

3. Summary

In this chapter, I have considered two areas in which stroke sufferers can be held accountable: for having had the stroke in the first place and for the extent to which their disability prevents them from carrying out tasks. In responses to my question about the possible causes of stroke at a young age, participants oriented to issues of

accountability, and they were sensitive to the negative implications this might have for their identity. Responsibility for having suffered a stroke was constructed by carers here in terms of sufferers' previous lifestyle choices and their failure to seek appropriate medical care prior to the event. While the sufferers quoted here did attempt to counter claims relating to the latter, they colluded somewhat with carers' construction of stroke sufferers as busy and active people (pre-stroke), despite the implication that this may have contributed to their condition. However, when the personal characteristics inferred were less positive, participants constructed a subtle and effective defence in which personal liability was minimised.

Some internet participants also oriented to issues of accountability, although none was explicit in the interactional context. Some stroke sufferers also oriented to others' views on the extent to which their incapacities were due to the effects of stroke. Indeed, carers here constructed sufferers as, at times, lazy. Stroke sufferers here reframed this account in terms that were personally less damaging.

4. Discussion

Parsons (1951) drew attention to some of the social implications of being unwell, in particular the sick person's motivation to be in that situation. In this chapter, we have seen that sufferers and carers treat both the cause of stroke and their subsequent incapacity as accountable. The stroke sufferers in this study attended to the potential negative identity that might arise from the imputed causes of their stroke. Pound and colleagues (1997) trace the history of stroke and suggest that there have always been moral undertones relating to the lifestyle factors that are thought to be involved, which have been described as smoking, having high blood pressure, being over 65 and taking little exercise (Coppola *et al.*, 1995). Stroke sufferers here did orient to the potential impact of each of these factors, in focus groups where carers also

participated. In the extracts shown, respondents who had suffered stroke constructed themselves as active and busy people prior to their stroke. In extracts from internet participants' responses, we also saw an orientation to accountability. This suggests that accountability might not just derive from the immediate social context, but that it might be explained by wider social and cultural factors. Research suggests that there is a stigma associated with being chronically ill (Goffman, 1963). Thus, people with long-term conditions might have to attend to potentially negative identity implications associated with their illness. This is the focus of the following two chapters.

CHAPTER 6

ME SUFFERERS' CONSTRUCTIONS OF IDENTITY

Research into chronic illness suggests that people suffering from such conditions experience some sort of disruption to their sense of self. In order to make sense of this disrupted self, the person with chronic illness may modify his or her 'life narrative' to preserve some feelings of continuity (Corbin & Strauss, 1985; Corbin & Strauss, 1987; Riessman, 1990; Williams, 1984). In addition, research suggests that there is a stigma attached to having a chronic condition.

For people with ME, identity implications arise from the uncertain medical status of this illness. We have seen, in chapter 3, that participants in this study constructed ME as serious, as enigmatic, and specifically not psychological.

In this chapter, I will discuss participants' responses to my question "in what ways would you say that having ME has affected you as a person?" Preliminary analysis led to the identification of two broad types of response, and chapter sections are organised accordingly. First, I will examine responses in which participants wrote or spoke about the effects of ME as a change for the worse. In the second section, I will show how some participants employed both 'positive' and 'negative' categorisations

of the impact of ME. I will also discuss responses that described the changes brought about by this condition in terms of a change for the better.

1. Effects of ME as a change for the worse

I will begin by showing how respondents in this research used 'before and after' constructions to emphasise the losses they suffered as a result of their illness. An example of this can be seen in the following extract:

Extract 6:1 MEICCP77 Alex

9 I was a very active person with a very good social life who
10 enjoyed nothing more than going for long walks with my wife
11 and the dog or visiting the pub with friends for a few drinks
12 and hopefully a quiz.
13
14 The garden was my pride and joy. Indeed the year before I
15 developed ME I transformed my then fiancées (now wife)
16 garden from a bare patch of grass to an oasis of colour
17 complete with ponds, flower beds, borders and even a
18 bench. Every day people passing would stop and admire the
19 changes in the garden.
20
21 I was a very ambitious person with hopes and dreams for my
22 future. Part of this was a complete career change and I had
23 already begun the initial stages of this when the illness struck.
24
25 Suddenly everything came to a grinding halt. The energy I had
26 always had and taken for granted was no longer there, even the
27 simplest task left me feeling totally drained. My body ached
28 from head to toe, I had almost constant headaches and other
29 symptoms too numerous to mention. The visits to the pub had
30 to go, I became totally intolerant of alcohol and the smell of
31 cigarette smoke or perfume turns me into a gibbering wreck.
32
33 I am now a virtual recluse, most days the only people I see and
34 speak to are my wife and daughter. Friends I once had regular
35 contact with have all but disappeared. I look at my garden and
36 I can see all the jobs that need to be done and in my mind I
37 form a plan of action but in reality very little actually gets done.

Extract 6:1 can be divided into two sections. In lines 9-23, Alex describes his life prior to falling ill with ME. In the rest of the extract, he gives an account of the impact this illness had on him. In the first part, Alex makes the claim that he was a "very

active person with a very good social life" (line 9). This is followed by an account, warranting this claim, of the things he used to do: "going for long walks with my wife and the dog or visiting the pub with friends for a few drinks and hopefully a quiz" (lines 10-12). This account helps to construct as a fact that Alex used to be an active and sociable person. There is another aspect of this account that is of some interest. The activities that Alex describes are mundane, everyday activities. They are things that ordinary people do, and by referring to them, Alex constructs himself as an ordinary person. Sacks (1984) noted that 'being ordinary' does not describe a state, or an 'average' person, but instead is an *accomplishment* that has continually to be worked at in the course of interaction. Alex's description in lines 10-12 can be seen, in Sacks' terms, as 'doing being ordinary'. However, he also makes relevant information that suggests the *extent* of his participation in these activities. Thus, he describes "going for *long* walks" (line 10; emphasis added), and "visiting the pub with friends for a few drinks *and hopefully a quiz*" (line 12; emphasis added). We can see a similar formulation in lines 14-19, where Alex provides a narrative description of his love for gardening - another quite mundane activity. He constructs a vivid contrast between the description of the garden before and after his intervention - he transformed it "from a *bare patch* of grass to an *oasis* of colour complete with ponds, flower beds, borders and even a bench" (lines 16-18; emphasis added). The visual contrast invoked here suggests a particularly high level of achievement. By listing the features of the newly created garden, and describing these in the plural, Alex similarly emphasises the contrast with what was there before. He also provides an external, and therefore objective, warrant for his achievements: "[e]very day people passing would stop and admire the changes in the garden" (lines 18-19). Alex's description of his involvement in mundane activities, combined with a marking of the extent to which he participated, enables him both to construct himself, pre-ME, as an ordinary person *and* as someone who put an extra level of effort into his hobbies. The claim that

follows in lines 21-22 - "I was a very ambitious person with hopes and dreams for my future" - constructs Alex as someone with high aspirations.

Hutchby & Wooffitt (1998) show how, in their verbal descriptions of paranormal experiences, people prefaced their description of a psychic event with a mundane 'state formulation', of the type 'I was just doing X (mundane activity) when Y (paranormal event)'. They suggest that this construction works to defend against a sceptical reappraisal of the psychic experience. That is, there is nothing in the immediate context of the paranormal claim that might help to 'explain away' the event. In this extract, Alex prefaced his description of the ways in which ME has affected him as a person with a series of claims that construct *him* as ordinary, as well as active and motivated. This construction works to defend against the possible accusation that there is something different about him *as a person* that might explain his ME. By constructing himself as hard-working and motivated, he also counters the possible accusation that he is lazy rather than ill. All of this provides an inferential context for the second section of this extract, in which Alex describes the effects of ME. Here, he uses extreme case formulations to emphasise the seriousness of this illness - "even the *simplest* task left me feeling *totally* drained. My body ached *from head to toe*" (lines 26-28; emphasis added); "I became *totally* intolerant of alcohol" (line 30; emphasis added). Pomerantz (1986) noted that extreme case formulations can be used to provide the strongest possible case for what is being claimed, and that this orients to the possibility of a challenge from interlocutors as to the validity of the claim. In this case, it is notable, given the description of Alex's activities and level of motivation pre-ME, that he has been seriously incapacitated by illness. His description of his post-ME state is systematically designed to provide a contrast with the claims made in lines 9-23. Having characterised himself as "a very active person" (line 9), he describes in lines 25-26 his loss of energy. Whereas, in line 11, he had noted his previous liking for visiting the pub with friends, he notes in lines 29-30 that such a

pastime is now intolerable. In lines 35-37 he notes his inability to carry out the work that should be done in the garden. The effect of this 'before and after' structure is to emphasise the seriousness of ME by providing specific examples in which previous abilities are compared with current incapacity.

In the following two extracts, both in response to my question about how ME has affected the sufferer as a person, participants work to accomplish 'being ordinary' as their pre-illness state:

Extract 6:2 MEICCP73 Lynn

12 I miss things like reading,going to
13 the pictures,having discussions with friends, playing
14 chess,backgammon.My home used to be a hive of
15 activity,people dropping round,for a meal,wine,catering for 10
16 people was easy then,and i loved doing it,dinner parties arent
17 just about eating,I guess my social life suffered the most. LOL [laugh
18 out loud] im lucky if i see more than 2 people a week now,and of of
19 those is normally the postman,Shopping becomes a
20 pain,,sainsburys 30 mins home, thats the extent of my weekly
21 outings,smile. Personality,changes,Yes i suppose it does,you
22 feel cut off from the average working,fit,person.

Extract 6:3 FGME2

862 Jennifer: in (.) what ways would you say that having ME has
863 affected you as a person?
864 Liz: oh (..) completely different person .hh e:m hh
865 housework h (.) I was never hh (.) one for (.) polishing
866 day and night but my (.) my house was always clean
867 and tidy and (.) the work was done and it wouldnae
868 [wouldn't] pile up .hh but (..) that that's the least of it
869 (.) we went dancing three times a week
870 Jennifer: mhmm
871 Liz: a::m (..) parties (.) dances (.) we loved dancing (.)
872 e:m (.) walking (.) you just cannae do it now (.) .hh

In extract 6:2, an internet chatline communication, Lynn uses a list formulation to recount the things she misses (lines 12-14) as a result of having ME. In chapter 3, I showed how listing could be used to construct ME as serious, by illustrating the extent and range of problems faced by sufferers. Here, listing is used to denote the extent and range of activities in which Lynn can no longer participate. In extract 6:3, Liz

similarly provides a three-part list (Atkinson & Heritage, 1984; Jefferson, 1991): "parties (.) / dances [...] / walking" (lines 871-872). She also uses a three-part list to describe the extent to which she was able to do housework before she had ME: "my house was always clean and tidy / and (.) the work was done / and it wouldnae pile up" (lines 866-868). A three-part list is a rhetorical device often used to orient to a common feature of the items listed (Atkinson & Heritage, 1984; Jefferson, 1991). Here, it suggests that Liz was sociable and active, and was able to keep ahead of her housework. Again, the kinds of pursuits to which she refers are mundane, and this helps to construct Liz as ordinary as well as active and hard-working. In Lynn's case, although the list is longer, the items have certain similarities. That is, "reading, going to the pictures, having discussions with friends, playing chess, backgammon" (lines 13-14) relate to everyday, mundane activities, and they help to construct Lynn as an ordinary person. The extent to which she enjoyed seeing people is evoked by her detailed description of the social activities that took place in her home, and that involved her in a good deal of work. She notes that she used to cater happily "for 10 people." This level of detail serves to construct her claim as factual, and to mark her achievement at this ordinary activity as extra-ordinary. It also forms a basis upon which comparisons can be made with her life since she had ME.

In line 17, extract 6:2, Lynn begins the contrasting account of her life now, and a direct comparison is made in terms of the number of social encounters she has - "im lucky if i see more than 2 people a week now, and of of [*sic*] those is normally the postman" (lines 18-19). The first 'of' in line 18 appears to be a typographical error, and it seems likely that it should have read "one of." That Lynn's social activities are now quite restricted is conveyed by her account of the number of people she is now likely to see in a week - 2, one of whom is there to deliver her mail and whose visit would therefore not normally be considered a social one.

Liz, in extract 6:3, does not provide a contrasting account. She does, however, imply that she is no longer able to take part in the activities she speaks about, and she does this by referring to them in the past tense - "my house was always clean and tidy and (.) the work was done and it wouldnae pile up [...] we went dancing three times a week" (lines 866-869). By specifying the frequency, Liz constructs this claim as factual (and also constructs her level of participation as high). Liz also marks the changes brought about by ME in her claims at the beginning and the end of her account. Thus, in line 864 she makes the claim, in regard to the ways that ME has affected her, that she is a "completely different person." Having listed the activities in which she used to take part, she ends her claim "you just cannae do it now" (line 872). Thus, Liz constructs herself pre-ME as ordinary, active and sociable, and she allows us to infer that her illness has prevented her from participating in the mundane activities that she describes.

In both of these accounts, participants describe an ordinary life before being ill. They refer to their inability now to perform mundane tasks as a contrast to the level of activity they enjoyed before. There is an extent to which such a formulation can also help to construct these sufferers *in the present*. Dingwall (1976) described ordinariness in terms of a cultural imperative, all the more important when some aspect of a person's life might be considered to be deviant. Illness is one such circumstance. He noted that being ordinary does not describe a state of affairs inherent in the individual, but rather an interpersonal achievement. In order to claim ordinariness, he argues, one needs to understand what 'ordinary' is, and be able to 'do' it. In the extracts above, Lynn and Liz describe their present situation as one in which they are *not* able to perform everyday activities. However, by referring to mundane activities, they demonstrate their cultural competence. That is, they know what constitutes ordinariness. Furthermore, by stressing how much they miss such everyday activities, they align themselves with the ordinary person in the here and now.

In the final extract of this section, Tricia *begins* her response by describing her situation now, and this provides an inferential context for a description of her life before ME. The effect is similar to that in the extracts already discussed. That is, it sets up a 'before and after' contrast between her pre- and post-ME states:

Extract 6:4 MEIPCp19 Tricia

1 To all who knew me before there is little resemblance between the
2 sick, housebound and often bedbound I am now and the busy
3 career person with a large home, student children, a wide circle of
4 friends and many interests like running a Guide Company,
5 teaching elocution, demonstrating crafts to women's groups and
6 church activities.

In extract 6:4, a one-to-one internet communication, Tricia uses a three-part list (Atkinson & Heritage, 1984; Jefferson, 1991) to describe how she is now - "sick, housebound and often bedbound" (line 2). This is then contrasted with the person she was before, the description of which takes the form of a list. In this list, which runs from lines 2-5, Tricia describes everyday activities involved in work, family life and social life. This constructs the pre-ME Tricia as an ordinary person who is also extremely active and hard-working. Her references to running a Guide Company, demonstrating crafts to women's groups, and church activities also help to construct Tricia as a 'good citizen', and thus attends to identity work. By framing the 'before and after' ME contrast as one that would be apparent "[t]o all who knew me before" (line 1), Tricia constructs the reality of the detrimental effects of this illness.

2. 'Positive' and 'negative' categorisations of ME

Some participants responded to my question by constructing the different effects of ME as either 'positive' or 'negative' for the sufferer. This can be seen most clearly in the following extract, which is long, but has largely been left intact to allow for an analysis of the way in which it is structured:

Extract 6:5 MEIPCp17 Jim

- 2 Let me first start with the negative sides, and then the
3 positive ones:
4
5 - Lack of energy influences in a big way what I can or rather
6 cannot do.
7 - Lack of finances has got a similar effect.
8 - I lost my fulltime, wellpaid job because of the illness [sic]
9 - I lost many friends because I was unable to keep up with them
10 - The illness caused a lot of other health problems eg Flu and
11 Cystitis.
12 - I can no longer enjoy a prper [sic] holiday, because of lack of energy
13 and finances.
14 - Finding parttime employment is hard as nobody want a crippled
15 person
16 - I need other people to do a lot of jobs for me, which forms an
17 extra financial burden.
18 - I cannot travel 'home' as often as I did to see my relatives in
19 Holland.
20 - Socialising is difficult because of lack of energy and money.
21 - It is difficult to have hobbies as energy is lacking
22 - I need a lot of extra rest and sleep, often mid-day.
23 - The continuous battle over money matters with the Benefits
24 Agency is a nightmare!!!
25 - I often feel guilty that I cannot offer my family what other people
26 have.
27
28 - Thru the illness I have learned a lot about myself (and other
29 people).
30 - My spiritual development has increased
31 - I am more in tune with myself and Mother Nature.
32 - I can now appreciate the little things in life more.
33 - I have become closer to my family.
34 - I have found who my true friends are (not many, though).
35 - I've gained a lot of knowledge about Medicine.
36 - I have learned how to cope with stress.
37 - I am now a different person (for the better, I believe)....

In extract 6:5 Jim uses a list formulation to describe first, in his terms, the "negative sides" then the "positive" (lines 2-3). Each point is prefaced with a dash, and takes its own line, and this gives his response the visible appearance of a list. It can be seen at a glance that there are far more 'negative' than the 'positive' effects (the latter are separated from the former by a blank line at line 27). In the 'negative' list, Jim refers to the ways in which ME has affected his level of activity, his ability to work, and his social life. We can infer a certain amount of information about Jim's life prior to ME from the detail that is provided in this first part. Thus, "I lost my fulltime, wellpaid

job [...] I lost many friends [...] I can no longer enjoy a proper [*sic*] holiday" (lines 8-12) imply that these are all things that he had before he had ME. This information can provide an inferential context in which to assess the detrimental impact of this condition. This is similar to the ways in which respondents in section 1 constructed the effects of ME as a change for the worse. They constructed themselves as active, hard-working and sociable people prior to the onset of ME. They also constructed themselves as 'ordinary' people, and 'doing being ordinary' can function to defend against the suggestion that there might be something different about ME sufferers that causes them to have this illness.

To provide nothing but a long list of its negative effects could leave Jim open to the accusation that he is a 'complainer', with the potential inference that the symptoms of his illness are exaggerated. The provision of a list of 'positive' effects functions to counter such potential accusations. Furthermore, we can see that this second list refers to *non-physical* changes rather than those to do with physical accomplishments and active socialising. Thus, Jim implies that the negative effects of ME are limited to the physical. Moreover, Jim's gloss in the last line - "I am now a different person (for the better I believe)" allows us to infer that the non-physical changes resulting from this illness have had a positive effect on his identity.

In the following extract, Tracey also constructs the effects of ME in two opposing categories:

Extract 6:6 MEICCP76 Tracey

- 3 Disabled - I am not not able to do many or most of the things I
4 did before including drive, walk, party, drink, work etc. So
5 ME has slowed me down and added frustrations to my life
6 which were not there before.
7
8 Enabled - It has also had a profound effect on the pace my life
9 is carried out which really and truly is an improvement. I have
10 time to watch and think, time to spend with my husband and
11 share the simple things of life and delight in them. I am no

12 longer in a hurry to conquer the world or be in control of
13 everything around me. I have always appreciate the wonderful
14 world in which we live but now I have time for that
15 appreciation. I am a calmer and more contented person despite
16 the ME

In her response, Tracey categorises the ways in which she has been influenced by ME as 'disabled' and 'enabled'. Within each category, she uses a list formulation to describe the effects this illness has had. The disabling effects are all related to reduced levels of physical activity, ability to work and to socialise (lines 3-4). Those effects that are categorised as 'enabling' relate to non-physical pursuits that result from a slower pace of life. Tracey provides a gloss in lines 15-16, similar to that offered by Jim in extract 6:5: "I am a calmer and more contented person despite the ME." Thus, like Jim, she constructs the negative changes wrought by ME as physical, and non-physical changes as having positive identity implications.

So far in this section, we have looked at responses in which sufferers counterbalanced the negative effects of ME with the positive. In the following extract, I will examine Debbie's construction of the positive effects of ME.

Extract 6:7 ME|CCp73 Debbie

27 Its not all bad though -it has taught me to see the smaller
28 things in life and to take pleasure from them and also to listen
29 to others as they may be able to help or I may be able to help
30 them even if it is only with a few small words, things that
31 maybe I wouldn't have noticed in my life before DD [dreaded disease].
32 I must admit though that although I am thankful for these small
33 things, I would like to have my life back and to be able to do
34 the most mundane of things again.

Extract 6:7 comes after a long account of the difficulties Debbie has encountered as a result of having ME, and this is signalled by her claim in line 28: "[i]t's not all bad though." This formulation, therefore, follows the 'negative' balanced by 'positive' construction discussed above (although Debbie does not *explicitly* categorise the

effects in this way). In the last lines of her response, Debbie rejects the possible claim that she stands to gain more from her illness than she loses by it: "although I am thankful for these small things, I would like to have my life back and to be able to do the most mundane of things again" (lines 32-34). This suggests that to speak in positive terms about the impact of illness is something that has to be carefully managed. This can be seen in the next two extracts.

Extract 6:8 MEICCP74 Gillian

4 On the whole having ME has been a life changing, positive
5 experience (although I think I've learned all I need to in 6 years
6 so please can I get better now?!!)

Extract 6:9 MEICCP76 Lesley

1 I can empathise with Gillian as in my case, too, I think it has
2 had a positive effect, and I feel more at peace. It has made me
3 stop and evaluate what is important in life.
[...]
27 All this isn't to say I wouldn't appreciate the chance of being
28 well again - all the more so with a new perspective on life!!

Both Gillian in extract 6:8, and Lesley in extract 6:9, referred explicitly to only the positive consequences of having ME. However, Gillian's assessment begins "[o]n the whole" (line 4). This expression allows us to infer that the positive assessment that follows can be seen in a context that is not entirely benign. Thus, some counterbalancing of negative and positive effects is implied. Lesley's response refers to this account - "I can empathise with Gillian" (line 1), which sets up their constructions as similar. Furthermore, Lesley writes "*I think* it has had a positive effect" (lines 1-2; emphasis added). Thus, like Gillian, she allows us to infer that her account of the positive aspects of the experience of having ME is dependent on her cognition, and not a fact relating to the illness *per se*. In both accounts, the positive assessment is followed by an explicit reference to the writer's desire to recover. Thus, Gillian writes "I think I've learned all I need to in 6 years so please can I get better

now?!!" (extract 6:8, lines 5-6). Lesley's response (extract 6:9) is positive throughout, although only the first three lines are shown here. At the end of her response, she also refers to her desire to recover: "[a]ll this isn't to say I wouldn't appreciate the chance of being well again - all the more so with a new perspective on life!!" (lines 27-28). Thus, in both these extracts a positive account of ME is set within an implied context that is not completely benign, and it is followed by a claim that constructs the sufferer as someone who is keen to get better. This shows an orientation to the potential charge that the sufferer is malingering, and that to construct the effects of ME in a positive light involves some delicate interactional work.

It is notable that the extracts in which participants described ME in positive terms were exclusively from data collected via the internet. I found no such examples in the focus group response to my question about the effects of ME on the person. It is possible, then, that the source of data might be significant. For example, it may well be problematic to claim to have benefited from an illness when in the presence of other sufferers. Speakers may run the risk of being challenged. Moreover, by downplaying the effects of their illness they may undermine the very basis on which the group is formed, which is to provide support to people with ME.

3. Summary

So far, we have seen that when participants described the effects of ME as a change for the worse, they used a 'before and after' contrast formulation in which they compared their lives before and after the onset of this condition. This allowed them to emphasise the losses brought about by their illness. Detailed descriptions were used to construct a 'before ME' identity that characterised them as doing ordinary things, but at a particularly exacting level. This functioned as a defence against the potential implication that the sufferer is either lazy or unmotivated. Participants used list

formulations and extreme case formulations (Pomerantz, 1986) to stress the impact of ME.

Some respondents categorised the effects ME had on them as positive or negative. While the negative effects were described in terms of reduced physical activities, leading to restrictions in work and social life, the positive effects related to *non-physical* changes, and the construction of the person with ME as a "better person" than before. Respondents who wrote in positive terms about ME, and did not explicitly counterbalance these effects with the negative ones, nevertheless inferred that the impact was not entirely beneficial. Furthermore, they followed their positive assessments with an explicit reference to their desire to recover. This works to defend against the possible claim that they are profiting from their illness - and might therefore be malingerers. It was noted that positive assessments were found only in internet data, and the possibility raised that the source of data might be a significant factor in the ways in which sufferers can construct their illness.

4. Discussion

The literature on the effects of chronic illness and identity suggests that it leads to a disruption of the sufferer's sense of self. In order to deal with this, the research suggests, the sufferer may re-construct his or her life story so that some sense of continuity of self is preserved. From a social constructionist perspective, these notions are of particular interest because of the possible rhetorical functions they might have. Thus, an account of how the self has been lost, or how illness has disrupted one's life might work to construct that illness as serious, or to construct the sufferer as a particular type of person - the type who does not, for example, easily give in to illness.

An analysis of responses to my question "in what ways would you say that having ME has affected you as a person?" showed that ME sufferers in this research used 'before and after' contrast formulations to emphasise the negative changes brought about by their illness. Similar formulations were also noted by Bland (1995) and Horton-Salway (1998; 2001a; 2001b), who concluded that they work to construct ME as a serious, physical condition. Horton-Salway argues that this construction shows an orientation to blame and accountability, in that if 'serious and physical' are successfully accomplished, the sufferer can avoid the negative identity implications of malingering. Participants responding via the internet did also refer to some positive effects of ME, and this suggests that the context in which research is carried out may be of some significance.

In this research, participants did attend to the identity implications of constructing the effects that ME had on them. They constructed pre-illness selves as involved in everyday activities, and thus accomplished 'being ordinary'. Bland (1995) reports similar findings, and notes the importance of such an accomplishment in countering potentially problematic identity ascriptions associated with chronic illness. Participants in this study also stressed the extent to which they participated in ordinary activities prior to becoming ill. This enabled them to construct a positive pre-illness, and current, identity which worked to counter the potential charge that they were the sort of people who would give in to illness. Respondents also worked to construct the positive, non-physical effects this illness had on them, and thus oriented to identity issues.

It is notable that stroke sufferers also used 'before and after' formulations to construct their condition in terms of loss of abilities, and that they also constructed an ordinary pre-stroke existence. The next chapter examines the ways in which these respondents constructed the effect their illness had on identity.

CHAPTER 7

STROKE SUFFERERS' CONSTRUCTIONS OF IDENTITY

In this chapter, I will show how participants oriented to identity issues in their responses to my question "in what ways would you say that having had a stroke has affected you as a person?" I have noted at the start of chapter 6 that research into chronic illness suggests that people suffering from such conditions experience some sort of disruption to their sense of self. In order to make sense of this disrupted self, the person with chronic illness may modify his or her 'life narrative' to preserve some feelings of continuity (Corbin & Strauss, 1985; Corbin & Strauss, 1987; Riessman, 1990; Williams, 1984). Research also suggests that people with chronic illness experience a changed relationship with the body, and that this in turn can affect their sense of identity. In addition, research suggests that having a chronic condition can have negative implications for the sufferer's identity. The literature on stroke suggests that sufferers do indeed experience a sense of disruption of the self, and that the body can become objectified, leading to a lowering of feelings of self-esteem.

In preliminary analyses, it was found that some respondents constructed themselves as having changed their outlook as a result of their stroke. Another theme that was identified was that participants oriented to issues of self-presentation when writing or

talking about the ways in which stroke had affected them. These observations are discussed in detail in sections 1 and 2. These analyses led to an exploration, shown in section 3, of the stigma of stroke observed in accounts of non-sufferers' reactions to this condition, and of the effects this has on the ways in which sufferers talk and write about stroke and personal change. In the final section, I explore the issue of identity change that arose in focus groups made up of both stroke sufferers and carers.

1. The changed outlook of stroke sufferers

In this section, I will analyse two internet, one-to-one responses for the devices that are used to construct the ways in which stroke has changed participants' outlook.

Extract 7:1 DSIPCp12 Ana

1 Having had a stroke has affected me profoundly:
2
3 My value systems have altered i.e. there are different
4 priorities I consider important. I place less importance on
5 ideas of 'morality', 'goodness', etc and more on the basic
6 principle that people are more important than ideas.
[...]
32 I am very aware of a sense of time being precious, and
33 feel grateful at every birthday and try to live life more for
34 the present.

Extract 7:2 DSIPCp12 Barry

1 I think my haemorrhage has changed me for the better.
2
3 After the actual seriousness of my illness had sunk in, I
4 decided not to take things for granted again. My friends, family
5 all rallied round to help me recover, so I am forever in their
6 debt.
7
8 I learned that you can't let little things in life get you down, and
9 that every day is a new experience. My mother gets upset if the
10 car breaks down for example, and she has to walk to work.
11 Whereas I would look at it as "thank goodness the car broke
12 down at home, and not out in a lonely place late at night". I
13 know that's a weird example, but I look at the best in each
14 situation. I take each day at a time, I don't get stressed out as
15 much. I always try and smile, no matter how hopeless the
16 situation. I think "if I didn't laugh about it and smile and be
17 kind to others - I'd go mad!" It's certainly better than feeling

18 sorry for myself and shut myself away, a sad fact that a lot of
19 stroke sufferers do.

Both Ana and Barry begin their response with a claim regarding the change brought about by their condition: "[h]aving had a stroke has affected me profoundly" (extract 7:1, line 1); "I think my haemorrhage has changed me for the better" (extract 7:2, line 1). They then each provide an account of the ways in which they have changed, and in each case they construct their response to stroke in positive terms. After Ana's claim in line 3 - "[m]y value systems have altered", she draws a contrast between ideas and people, the latter being more important to her now. She thus constructs herself as a person who now values others more than abstract concepts. Similarly, in extract 7:2, Barry makes a claim - "I learned that you can't let little things in life get you down" (line 8), then describes a hypothetical situation in which he contrasts the reaction his mother typically has, and the way in which he would react: "[m]y mother gets upset if the car breaks down" (lines 9-10); "[w]hereas I would look at it as "thank goodness the car broke down at home"" (lines 11-12). The contrast helps to construct his own response as positive, and his use of active voicing (Wooffitt, 1992) helps to construct the reality of this outlook. In his evocation of this potential problematic situation, Barry also manages to cast himself as *active* in his response. It is the way that *he* would look at it that makes the experience less upsetting.

Barry uses idiomatic formulations to construct facticity (Drew & Holt, 1998) when he describes the way he approaches life now: "you can't let little things in life get you down" (line 8); "every day is a new experience" (line 9); "I look at the best in each situation" (lines 13-14); "I take each day at a time" (line 14). Ana also draws on idiomatic formulations - "I am very aware of a sense of *time being precious*, and [...] try to *live life more for the present*" (lines 32-34; emphasis added).

2. Identity work

Ana and Barry's construction of the positive change brought about by stroke helps them to construct an *identity* that is positive, and for which they can take credit. In the following extracts, we can see the identity work that participants do when writing or talking about the effects of stroke:

Extract 7:3 DSIPCp13 Ana

19 I am probably less tolerant of some behaviours e.g.
20 rudeness and other sorts of bad manners, dishonesty, etc,
21 and more tolerant of others e.g. eccentricity.
22
23 My moods can be changeable and I can be irritable, this
24 is noticeable not because it's necessarily abnormal, but
25 because I was so calm and placid before.

In extract 7:3, Ana describes the ways in which her tolerance levels and her mood have changed as a result of stroke. Some of these changes are positive, and some negative. When she describes what might be considered to be the more negative impacts, she uses a number of linguistic devices as moderators. For example, she writes "[m]y moods *can* be changeable and I *can* be irritable" (lines 23-24; emphasis added). She notes that she is "*probably* less tolerant of *some* behaviours" (line 19; emphasis added). When she describes her changeable moods, Ana writes that "this is noticeable not because it's necessarily abnormal, but because I was so calm and placid before" (lines 23-25). She moderates the negative implications of her occasional irritability by constructing it as an attribute that is only evident in contrast to her previously placid nature. We can also note the use of "so" to emphasise positive attributes - "so calm and placid" (line 25). When Ana writes about more positive traits, she does not use moderators. In her description of how she reacts to different behaviours she writes that she is "more tolerant of others" (line 21). Thus, she moderates only those identity attributes that are potentially negative, and she emphasises positive identity attributes. Furthermore,

Ana constructs herself as a reasonable person. Her list of behaviours of which she is now less tolerant - "rudeness and other sorts of bad manners, dishonesty, etc" (line 20) are ones for which such a reaction is quite excusable.

We can see a similar orientation to the construction of a positive identity in the following extract.

Extract 7:4 FGDS1

853 Jennifer: can anybody say in what in () what wa:ys would you
854 say that having had a stroke has affected you as a
855 person?
856 (...)
857 Yvonne: impatient (.) e:h
858 Jennifer: what make it has made you impatient
859 Yvonne: mhmm
860 Jennifer: yeah?
861 Yvonne: [very quietly] aye (...)
862 Norman: yeah it's [unclear]
863 Ian: it's maybe
864 Norman: one of the things that trauma and shock bring on
865 Ian: yeah maybe you should ask the carers rather than the .h
866 the sufferers of that [laughs]
867 Yvonne: that's right

Extract 7:4 is taken from the beginning of the response in focus group 1 to my question about the ways in which stroke has affected the sufferer as a person. There is a three-second silence (shown in line 856) before Yvonne's response "impatient (.) eh" (line 857). Jefferson (1989) suggests that a silence of this length may indicate that what has been said is problematic, or that providing a response is problematic. Yvonne's response suggests a negative change, the impact of which is lessened because she provides minimal detail. She does not, for example, say that she herself is more impatient, and my response to her (line 858) constitutes a request for such clarification. Her agreement is minimal - "mhmm" (line 859); [very quietly] "aye" (line 861), followed by another three-second silence. The lengthy pauses and minimal agreements suggest that there are interactional difficulties in providing a response to my question about the effects of stroke. Norman orients to Yvonne's discomfort with

his assessment in lines 862-864: "yeah it's [unclear] [...] one of the things that trauma and shock bring on." Here, he provides a plausible reason for impatience. With "one of the things", he also suggests that this is a general reaction. This makes Yvonne less personally culpable for what might be considered to be a negative attribute.

In chapter 5, I discussed the self-presentational issues that might affect stroke sufferers in groups made up not just of other sufferers, but also of carers. I showed that it was more problematic to take credit for successful recovery in such circumstances than it was for participants who responded in writing on a one-to-one basis. I would argue that it is similarly difficult to construct oneself in a positive light when there are people present who might challenge such a construction. This echoes the findings of chapter 6, in which I noted that it was only in the internet communication that participants gave a positive account of ME. Thus, the method of capturing data may be of some significance in the constructions that are provided.

Problems can also arise when participants construct the effects of stroke on the self as negative. This extract ends with Ian's suggestion that the carers might be the best arbiters of any change, and this can be seen as an orientation to their presence in the group. In the next section, I will analyse extracts in which stroke sufferers orient to the views that non-sufferers have of their condition.

3. The stigma of stroke

In the first part of this section, I will show how, in orienting to issues of self-presentation, participants construct others' reactions to their stroke.

Extract 7:5 DSIPCp13 Ana

14 I am more assertive than before, perhaps as a result of
15 better awareness of what it feels like to be ignored, and

16 feeling that I am responsible for whether I am understood
17 and my feelings acknowledged.

Extract 7:6 DSIPCp12 Frederick

4 It has taken a big part away from me in terms of self realisation
5 (i.e. I won't be able to do what I wanted to achieve before and
6 I'm not even able to see myself the way I was before). This is
7 not self generated, but a reflection of how society looks at
8 disabled people. I don't fit the profile of any other group in the
9 hierarchy in our macho society. Personally I find that I have
10 more time to reflect on life and spiritual values have overtaken
11 material ones.

In extract 7:5, Ana characterises herself as more assertive, a trait that would normally be considered positive in terms of its impact on identity. This is followed by an account that is designed to construct this change as one for which *she* can take credit, resulting perhaps, as she claims, from "better *awareness* of what it feels like to be ignored" (line 15; emphasis added) and "feeling that I am *responsible* for whether I am understood and my feelings acknowledged" (lines 16-17; emphasis added). Extract 7:6 begins with Frederick characterising the effects of stroke in terms of a negative change in his personal attributes - "I won't be able to do what I wanted to achieve before and I'm not even able to see myself the way I was before" (lines 5-6). This claim is potentially damaging in terms of self-presentation, and Frederick orients to this by following it with an account that attributes the claim as "a reflection of how society looks at disabled people" (lines 7-8). Thus, he is explicit about the impact of other people's reactions to his stroke. Frederick implies that he belongs in the category of 'disabled people' by default, because he does not "fit the profile of any other group in the hierarchy in our macho society" (lines 8-9). The categorisation 'disabled' is therefore constructed as one that is externally imposed - and, we might infer, not one that he would necessarily choose. The negative social impact can be contrasted with Frederick's personal response that is constructed as both active and positive: "[p]ersonally I find that I have more time to reflect on life and spiritual values have overtaken material ones" (lines 10-11).

In the last two extracts of this section, I will show how participants use the example of other disabled people to counter others' attributions that are damaging to their identity:

Extract 7:7 FGDS2

655 *Alison:* yeah I've wondered about that as well whether that's (.)
656 the stroke or whether it's just that they have well (.) it
657 doesnae [doesn't] (.) I cannae [can't] be bothered you
658 know whether it's (.) being lazy or whether it's (.) the
659 stroke
660 *Jennifer:* mhmm
661 *Alison:* [it's sometimes] like that
662 *Eric:* [it's very easy] (.) eh I can understand how people who
663 have got eh .hh hip problems or whatever back problems
664 whatever .hh they just sit because it's it's very easy just
665 to sit there and just say .hh "ah it's too much effort" .h
666 you know

Extract 7:7 follows a discussion in which carers and stroke sufferers accounted for the stroke sufferers' failure to carry out everyday tasks. Lorna, a carer, "wondered" whether it was due to a lack of energy or "whatever", and this extract begins a few lines later. Alison's turn takes the form of an indirect question about the extent to which Eric's immobility can be explained by his condition - "I've wondered about that as well [...] whether it's (1) being lazy or whether it's (.) stroke" (lines 655-658). Eric's turn begins "it's very easy" (line 661), then, rather than saying immediately what it is that is very easy, he inserts a claim. The claim is that he understands how other people "just sit" because it is too much effort to do otherwise. Eric's inserted claim provides an indirect means of countering Alison's challenge. It does this in three ways. First, by claiming to understand these other people, Eric suggests that he has some empathy with them. From this, we might infer that his problem is similar to theirs; indeed, the issue to which he refers is immobility. Second, he attends to self-presentational issues by constructing himself in a positive light - as someone who understands. Furthermore, Eric's understanding can be contrasted with Alison's failure to work out what is going on. Third, he provides a warrant for the behaviour

of these other people. That is, they may "just sit", but they are identified as having good reason to be immobile - hip and back problems.

The first four lines of extract 7:7 were discussed in chapter 5, extract 5:15, in which I argued that sufferers were held accountable for the extent to which their apparent disability was due to the effects of stroke. In conversation analysis, a significant feature of interaction is the way in which utterances are designed *in response* to the sequentially previous turn. It is in the design of next turns that we can see how speakers themselves make sense of what is going on. Hutchby and Wooffitt (1998) have called this 'next turn proof procedure'. This analysis of Eric's turn shows that he does indeed orient to the potentially damaging attribution of laziness. The indirect nature of Eric's response to Alison's challenge is what renders it rhetorically powerful. He does not provide a straightforward account that would give an indication of how much of his inability might or might not be attributable to stroke, and instead makes a claim that would be hard for Alison to counter. His 'understanding' is an internal event, therefore difficult to refute. He refers to a hypothetical group of people, and therefore his attitude towards them could not easily be challenged on the basis of actual behaviour. Furthermore, the attributes of the group to which he refers provide a reasonable warrant for their behaviour. We can see, then, that to claim understanding of other people's problems can work as a device to counter the stigmatic responses of other people to those with stroke. A further example comes from a one-to-one internet communication:

Extract 7:8 DSIPCp13 Colin

5 Having a stroke has made me more confident in myself, mainly
6 due to the pride I have about how I've recovered so far. It has
7 also meant that I've learnt to discount many of the opinions
8 people have of me. I've also been able to understand a lot of
9 the problems physically disabled people face.

In extract 7:8, Colin claims that stroke is responsible for a positive change in his personal attributes: "[h]aving a stroke has made me more confident in myself" (line 5). He also writes that "[i]t has also meant that *I've learnt to discount* many of the opinions people have of me" (lines 6-8; emphasis added). His claimed response to these opinions suggests that they are negative, invalid or unacceptable to Colin. We can also infer from the prior and subsequent context that these opinions are related to the fact that Colin has had a stroke. That is, this is preceded by a claim about the effect stroke has had on him, and it is followed by his claim "I've also been able to understand a lot of the problems physically disabled people face" (lines 8-9). This claim can be seen as an orientation to providing a defence against the stigmatic responses of others, and it does so indirectly in a similar way to that discussed in extract 7:7. First, he implies an empathy with other physically disabled people that allows us to infer that he has encountered similar problems. Second, it helps to construct a positive identity for Colin - he is understanding and knowledgeable. Third, there is some warrant provided for the problems faced by the people to whom he refers - they are "physically disabled."

4. The problem of change

In this last section, I will examine the issues that arise for stroke sufferers when they are asked, in a focus group made up of sufferers and carers, about how stroke might have changed them. I will show that sufferers orient to the implications of change for the extent to which they might be held accountable for having suffered a stroke.

Extract 7:9 FGDS2

567	<i>Alison:</i>	but as far as Eric's concerned before it this () very
568		strong forthright person and was invincible
569	<i>Lorna:</i>	mhmm
570	<i>Alison:</i>	nothing would ever happen to him you know (,) and I
571		think that's yup () and that's why (...) I would say well
572		[possibly]
573	<i>Lorna:</i>	[but]

574 *Alison:* the same
 575 *Lorna:* but that's maybe why they've made such a good
 576 recovery?
 577 *Alison:* well (.) possibly as well
 578 *Eric* don't know why I had a stroke in the first place
 [...]
 582 *Eric:* .h but I would have taken the view .hh before the stroke
 583 that I could have run this hospital you know .h I could
 584 have been the .h the (.) manager of the place you know
 585 but eh .hh now I just [blows out 'pwrr'] couldn't care
 586 less
 587 *Jennifer:* mhmm
 588 *Alison:* [that's not true that's not true to say you couldn't care
 589 less]
 590 *Euan:* [I could still I could still do I could still but I keep falling
 591 asleep] [[laughs]]
 592 *Eric:* [[laughs]]
 593 *Alison:* because you could care less and that's what's bugs you=
 594 *Eric:* that's the frustration yeah

Extract 7:9 can be divided into two sections. In the first, ending at line 578, Alison, Eric's wife and carer, constructs his identity prior to his stroke. In the second, ending at line 594, Eric and Alison construct his post-stroke identity. I will analyse each of these in turn.

In lines 567-568, Alison describes Eric before his stroke as: "this very strong/ forthright person/ and was invincible." This three-part list (Atkinson & Heritage, 1984; Jefferson, 1991) works to construct Eric's sense of invulnerability, an interpretation that can be supported by the claim that follows: "nothing would ever happen to him you know" (line 570). Having constructed Eric as invulnerable, Alison then appears to suggest that this might have been what caused his stroke: "and I think that's yup () and that's why" (lines 570- 571) The 3-second pause that follows, and the hesitancy markers "well" and "possibly" suggest that what Alison is saying is problematic - as it would be to suggest that a sense of invulnerability could account for Eric's stroke. Lorna, another carer, provides an account in which these attributes can be seen in a more positive light: "but that's maybe why they've made such a good recovery?" (lines 575-576). By prefacing this with "but", she signals that this

explanation is an alternative to the one that she understands Alison is making.

Alison's response - "well (.) possibly *as well*" (line 577; emphasis added) is a mild agreement that also implies that her own explanation is different to Lorna's, and still stands. Eric's response - "don't know why I had a stroke in the first place" (line 578) shows that *he* orients to Alison's talk as an account of why he had his stroke. Thus, we can see in this section of the extract that Alison has constructed Eric as having a sense of invulnerability, that this characteristic might be attributed as the cause of his stroke.

In lines 582-586, Eric uses a contrast formulation to construct the extent to which he has changed as a result of his stroke. He claims that, whereas before his stroke he would have taken the view that he could have run the hospital (in which the focus group was held), now he couldn't care less. With this claim, he constructs the change as one of motivation rather than, say, inability. That is, he does not say that he *could not* run the hospital now, but effectively that he is not at all interested in doing so. This allows for the inference that he might still be *able* to run the hospital. The construction is designed to deal with the delicate interactional problem of constructing change. It allows him to lessen the negative impact on identity while acknowledging the effects of stroke. Similarly, Euan constructs *his* potential inability to run the hospital as due to *fatigue* rather than inability: "I could still I could still do I could still but I keep falling asleep" (lines 590-591). Alison directly challenges Eric's claim: "that's not true that's not true to say you couldn't care less [...] because you could care less and that's what's bugs you" (lines 588-593). Eric's response to this challenge is not to defend his earlier claim, but rather to agree: "that's the frustration yeah" (line 594). Thus, he appears to contradict what he has just said. The apparent contradiction here can be explained if we consider the *actions* that are being performed in each turn. With his first claim, Eric is orienting to the charge that his sense of invulnerability might have caused him to have a stroke. When Alison challenges this,

she does not orient to any inference that Eric might still be capable of running the hospital, but to the potentially damaging implication that he lacks motivation. Thus, to agree with her construction is to maintain a positive identity.

We can see in this extract, then, how Eric deals with the difficult interactional problem of responding to Alison's suggestion that his stroke might be attributable to his feelings of invulnerability. On the one hand, if this were the case, and he wishes to avert future strokes, then he *should* change with regard to this characteristic. However, it follows that by constructing his sense of invulnerability as changed, he runs the risk of lending credibility to Alison's theory. Furthermore, to have a sense of invulnerability might reasonably be considered a positive characteristic, and so any change might bring with it problems of self-presentation. On the other hand, if Eric constructs himself as *unchanged* by his stroke, this might imply that his condition is not serious enough to warrant his incapacity (which, as we have seen in extract 7:7, and in chapter 5, is an accountable issue). He also risks being held accountable for any potential future recurrence. What he does here is to construct himself as changed and at the same time orients to potentially damaging implications for his identity.

5. Summary

In this chapter, I have shown that participants oriented to self-presentational issues in their response to my question "in what ways would you say that having had a stroke has affected you as a person?" Throughout, we have seen the positive identity work that is done by stroke sufferers. Those who responded via one-to-one internet communication constructed change in positive terms, as an active response to stroke. Thus, the method of data collecting may have a significant impact on the constructions that are available to participants. Both internet and focus group participants designed their responses to moderate the potentially negative identity implications of change

brought about by stroke. That identity issues are particularly salient can be seen in participants' construction of others' response to stroke as stigmatising. For those speaking in focus groups in which carers were present, there were particular interactional difficulties surrounding the construction of change, and these were oriented to in a way that helped to maintain a positive identity.

6. Discussion

In chapter 6, I discussed the social constructionist perspective on traditional theories which describe the effects of illness on the self in terms of disruption. Briefly to recap, the approach taken in this study is that accounts describing illness in such a way might fruitfully be examined for their rhetorical function. They might, for example, work to construct the condition as serious, and the sufferer as legitimately ill. In this research, participants who had suffered stroke did not talk or write about a disrupted self. This is not to suggest the notion of the disrupted self is less valid - indeed, the perspective taken in this research is that constructions are worked up in, and in response to, the local context, so a degree of inconsistency across contexts is to be expected. Participants did, however, work in other ways to construct a positive identity.

Issues of self-presentation are important. In the traditional research, one of the reported effects of chronic illness is also a changing relationship with the body (Corbin & Strauss, 1987; Bury, 1988; Lupton, 1994), and this is something that has been found in people who have suffered stroke (Bendz, 2000; Ellis-Hill *et al.*, 2000). A social constructionist perspective on the body focuses on how we represent it in our interactions and on the rhetorical functions such representations might have. To speak in terms of a body that is separate from the self might, for example, work to counter the stigma that is associated with being ill. That is, the self need not be held

accountable for bodily incapacity. Traditional research also suggests that negative views about the body are mirrored by negative feelings about the self (Keppel & Crowe, 2000). This suggests that the body and the self are not separate. However, from the social constructionist perspective, such apparent inconsistency can be understood if we consider the possible functions of this kind of account. To attribute negative self identity to an unhealthy body might, for example, be used to counter the stigma of problems that arise in the mind. Thus, a social constructionist perspective and a consideration of issues of self-presentation can provide some insight into findings from traditional research perspectives.

In the remaining two analytic chapters, the focus moves to the ways in which participants deal with the kinds of issues that arise from their illness.

CHAPTER 8

SUFFERERS' CONSTRUCTIONS OF RESPONSES TO ME

In this chapter, I will examine the ways in which participants with ME spoke or wrote about how they dealt with ME. Much of the research into chronic illness is centred on the ways in which people 'cope'. In chapter 1, I discussed some of the distinctions that have been made between different types of coping, some being held to be superior to others. In the particular case of ME, some researchers have suggested that there may be an association between fatigue and 'avoidance coping', which signifies a failure to confront the illness (Afari *et al.*, 2000). In this study, I was interested to know whether 'coping' was a concept that *participants* would deploy. For this reason, I avoided using the terms 'cope' or 'coping' and instead used the following two questions in an attempt to generate discussion around this issue. These were:

1. "Can you describe how you dealt with your condition when you first knew about it?"
2. "What advice would you give to someone who has just developed symptoms of ME?"

Another concern of mine was that, in the literature, there are moral implications underlying the notion of 'coping', and that participants may well be aware of the inference that some coping strategies are thought to actually exacerbate illness. By

avoiding terms related to coping, I hoped to get a clearer idea of the issues that arose for participants. If, for example, there were ways of coping that were considered better than others, this would more fruitfully be explored by examining how sufferers frame this. I hoped that by asking separate questions about how they dealt with their illness, and what they would advise others to do, that this would shed some light on the ways in which they thought the illness could best be managed.

A preliminary analysis of the data revealed four themes and this is reflected in the organisation of this chapter. First, sufferers' *initial* response to ME was constructed here as one of surprise. Second, participants in this study constructed resting as an appropriate way of managing this condition. Third, accounts were provided of participants' other attempts to get better. Last, respondents described the kinds of support they got from other people. This is relevant because it highlights some of the issues that participants orient to when they talk about how they manage their illness.

1. Constructions of initial response to ME

In the extracts that follow, participants constructed their initial reaction as one of surprise at discovering they had ME, and at its likely duration. In the first extract, for example, Rosemary constructs herself as knowing very little about her condition when she was first diagnosed with post-viral fatigue syndrome³:

Extract 8:1 FGME1

2013 Rosemary: eh my first reaction was em (.) really complete
2014 misunderstanding and disbelief e:m cos I got diagnosed
2015 very early on () it was just a matter of I had a chest
2016 infection or a virus and was given three lots of
2017 antibiotics they didn't do any good () and then my
2018 doctor said "you have post-viral fatigue" and I more or
2019 less said "oh what's that" (.) and she said it would may

³Post-viral fatigue syndrome is one of the terms that has been used to describe ME. A discussion of the naming of this condition can be found in Chapter 1, p27

2020		take some time and I remember <u>distinctly</u> I said "I've had
2021		ten days off work already [what do you mean?]
2022	Evelyn:	[[laughs]]
2023	Rosemary:	[laughing] more time?" [laughs] and without any inkling
2024		it would be <u>years</u> and not another few days

Here, Rosemary uses three devices to construct her initial reaction to the doctor's diagnosis as one of surprise. First, she makes a direct claim: "my first reaction was e:m () really complete misunderstanding and disbelief" (lines 2013-2014). Second, Rosemary uses active voicing (Wooffitt, 1992) to lend credibility to a narrative account of her diagnosis and her reaction to it. For example, in lines 2017-2019 "and then my doctor said "you have post-viral fatigue" and I more or less said "oh what's that."" Her use of "oh" is the third device used to convey her surprise. Heritage (1984a) has shown that the preface "oh" can be used to signal a change in the speaker's locally current state of knowledge about what is being discussed.

A further aspect of this account is that it is designed to show that not only was she surprised, she also underestimated the likely duration of her condition. Thus, Rosemary uses a repair in lines 2019-2020 when describing the doctor's advice as to the possible duration of her illness: "she said it would *it may* take some time" (emphasis added). The repair has two effects. First, "it may" suggests less certainty about the timeline of this condition than "it would." Second, since this is the information that is reported to have been given to Rosemary at the time, it suggests that Rosemary herself was unsure at this point about the possible duration of her illness. She makes a direct claim to not being aware when she notes that her response was made "without any inkling it would be years and not another few days" (lines 2023-2024). She also uses active voicing (Wooffitt, 1992) to convey her surprise at even this slight possibility of her illness being protracted, with her comment "I've had ten days off work already what do you mean? [...] [laughing] more time?" (lines 2020-2023). This is framed as a response that she remembers distinctly (line 2020),

which helps to construct her account as a true version of what happened.

Furthermore, her laughter (line 2023) suggests that she found the doctor's suggestion ridiculous.

We can see, then, in extract 8:1, that Rosemary works to construct her initial reaction to the doctor's diagnosis as one of surprise. She also constructs her initial assessment of her condition as one that underestimated its duration. There is one final point of interest that can be observed in this extract. When Rosemary expresses her disbelief about the likely duration of her illness, she does so in terms of the precise number of days of absence from her employment: "I've had ten days off work already" (lines 2020-2021). There are other ways that her disbelief might have been formulated - for example, that she had felt unwell or was unable to carry out other sorts of activities or interests. What Rosemary does here is to construct herself as someone who is aware of the exact time she has had off work, and for whom this is an issue of some concern. She therefore constructs herself as motivated to work. In the following extracts, we can see an orientation to the same issue.

Extract 8:2 MEICCP44 Tracey

27 relatives began to suggest possibility of ME - still thought this
28 was not likely - wouldn't happen to me!! carried on working
29 pushing myself as hard as I possibly could, Spending hours
30 not at work in a state of utter exhaustion and inactivity.

Extract 8:3 MEIPCp7 Dorothy

4 I was told by many folks if I didn't take things easy I would come
5 to a standstill. I believed my illness would be short lived and that I
6 could work my way out of it. I thought because I had, and still do
7 have, a very positive attitude that this would help me to get better.
8
9 So I came to a standstill.

In extracts 8:2 and 8:3, Tracey and Dorothy use a contrast formulation to construct, respectively, surprise at the diagnosis of ME and an underestimation of its possible

duration. They do this by first expressing the views of other people on their illness. Thus, Tracey writes that "relatives began to suggest the possibility of ME" (extract 8:2, line 27), and Dorothy notes "I was told by many folks if I didn't take things easy I would come to a standstill" (extract 8:3, lines 4-5). In both extracts, the views of other people are then contrasted with the sufferer's own view. In Tracey's case, she constructs her disbelief regarding the possibility that she might have ME: "still thought this was not likely - wouldn't happen to me!!" (lines 27-28). Dorothy then constructs her assessment of her condition in terms of its likely duration: "I believed my illness would be short lived" (line 5).

The contrast formulation provides an inferential context for the accounts that follow. Tracey uses contrast and extreme case formulations (Pomerantz, 1986) to compare the level of effort she put in at work with her complete incapacity the rest of the time: "carried on working pushing myself *as hard as I possibly could*, Spending hours not at work in a state of *utter exhaustion and inactivity*" (extract 8:2, lines 28-30; emphasis added). Dorothy similarly contrasts her positive beliefs about her ability to recover with what actually happened - "[s]o I came to a standstill" (line 9).

In each of these extracts, the contrast formulation also works to construct participants as motivated to work. Tracey refers explicitly to the extent to which she pushed herself at work. Dorothy refers to the way she thought about her illness, rather than, for example, the actual activities she carried out: "I *believed* my illness would be short lived and that I could work my way out of it. I *thought* because I had, and still do have, a very positive *attitude* that this would help me to get better" (extract 8:3, lines 5-7; emphasis added).

It is also notable that Dorothy uses the same expression twice in her account. In lines 4-5, she reports that she was told by other people that if she didn't take things easy

she "would come to a standstill." In line 9, she provides an upshot of what happened when she failed to do this - "[s]o I came to a standstill." Thus, Dorothy emphasises the extent to which these people were right, and this constructs the view that she was doing too much as accurate. By prefacing the upshot with "so", Dorothy treats the outcome as a *result* of the way she initially responded to her illness. Thus, her motivation to work and positive attitude are constructed as *contributing* to her decline. In each extract, then, it is made relevant that, in the early stage of their illness, other people's knowledge of their condition proved to be more accurate than the sufferer's. The observations of other people provide a warrant for the apparent impact that ME had on Tracey and Dorothy, and of their motivation to keep working. This can be seen as further evidence of their failure at the time to fully appreciate the seriousness of their illness.

In the following two extracts, participants construct themselves as motivated to work and ME as a serious illness:

Extract 8:4 MEICCP42 Lesley

9 My job was 26 miles away so I practised trips to places first 2 miles
10 away, then 6 miles, then 11 miles, but the 11 mile one caused such a
11 relapse I had to go back to square one.

Extract 8:5 MEICCP39 Lynn

4 I still thought i could work a full day,come home run the
5 house cook meals,iron clean,Paint and decorate,and gardening
6 too. That lasted all of 3 months,before i became so ill,i
7 couldnt get out of bed at all.

In each of extracts 8:4 and 8:5, Lesley and Lynn use detailed narrative and listing to construct themselves as highly motivated to work in the early stages of their illness. Thus, Lesley provides narrative detail when she notes the exact number of miles she drove, and her account lists the attempts she made to improve her performance: "I practised trips to places first 2 miles away, then 6 miles, then 11 miles" (extract 8:4,

lines 9-10). Lynn also gives a detailed account: "I still thought i could work a full day,come home run the house cook meals,iron clean,Paint and decorate,and gardening too" (extract 8:5, lines 4-7). Here, her use of "still" works to suggest that the activities listed were ones in which she engaged before her illness. Thus, she constructs herself as a person who worked hard before being ill, as well as at the start of her illness. Her use of commas gives the impression of a list being made, and the activities she describes suggest a physically demanding schedule. Both accounts are followed by a claim that participants' efforts were counter-productive: "the 11 mile one caused such a relapse I had to go back to square one" (extract 8:4, lines 10-11); "i became so ill,i couldn't get out of bed at all" (extract 8:5, lines 6-7). This works to construct ME as a serious condition.

Thus, we can see that participants' initial response to ME was constructed as one of surprise as to the nature of the illness, in particular its duration and its seriousness. Their initial response also worked to suggest that they were motivated to work. However, the reaction this response produced was constructed as one that actually exacerbated their illness. In the next section, I will examine accounts in which ME sufferers describe how they then learned to manage their condition.

2. Constructions of resting as an appropriate response to ME

In the first three extracts in this section, participants construct resting as an appropriate response to ME by framing it as follows. They first describe aspects of their illness, their previous response to it, and the problems with this response. They then construct their subsequent process of reflection as providing a rationale for resting. This is followed by a claim regarding the impact this had on the management of their condition. The first lines of extract 8:6 were examined as extract 8:5:

Extract 8:6 MEICCP39 Lynn

4 I still thought i could work a full day,come home run the
5 house cook meals,iron clean,Paint and decorate,and gardening
6 too. That lasted all of 3 months,before i became so ill,i
7 couldnt get out of bed at all. Then i took a long hard look,at
8 what i could,and couldnt manage, and decided to stick to a
9 plan,I would do as much as i could and be thankful for it,rest
10 when i had to,and go to bed when i couldnt manage staying
11 up,My physical health was far more important
12 than washed dishes,hoovered floors,and polished sideboards.
13 And a closet full of ironed clothes,i couldnt wear.
14 10 years on,i now wish that i had learnt this all earlier.
15 Ill health is no joke,,no one wants to be disabled by an illness
16 no one wants to have to rely on others to do the things,you once
17 took for granted.

Extract 8:7 MEICCP42 Lesley

46 I couldn't work out what caused relapses - it was quite
47 alarming to wake up with the heavy chested feeling and realise I
48 had overdone it yet again, then try to work out why, when I
49 had felt ok the day before. It was more difficult then as I was
50 more active, and so it was harder to work out which particular
51 activity or combination thereof was the cause. I started to
52 make a note on the big milkmans calender of my main activity
53 for the day - eg if I went to the shops or for a walk.
54
55 It was much later that I realised standing was a common factor
56 causing the worst relapses

Extract 8:8 MEICCP44 Tracey

37 A wonderful Occupational therapist taught me how to deal with this DD
38 [dreaded disease]. How to keep a diary of my activities and the highs
39 and lows of my exhaustion. She taught me to realise that by listening
40 to my mind and body I was not giving in to the illness but learning to
41 manage it - very very difficult I fought every inch of the way. I had to
42 break down my day into small segments of maybe 10 mins activity and
43 then an hours rest - I have gradually built that up to about 1hrs activity
44 and then rest (on a good day)

In the first 3 lines of extract 8:6, Lynn provides a detailed account of the physical activities - working, cooking, ironing, cleaning, painting and decorating and gardening - in which she was engaged prior to and at the start of her illness. Lesley also suggests a high level of activity with her assessment "I had overdone it yet again" (extract 8:7, lines 47-48). In extract 8:8, Tracey allows the reader to infer that she was

active by referring to her "exhaustion" (line 39) and relating the advice given to her by an occupational therapist: "[s]he taught me to realise that by listening to my mind and body I was not giving in to the illness" (lines 39-40). In the subsequent lines of this extract, it becomes apparent that the advice given was to rest, and that therefore Tracy had not been doing this. In extracts 8:6 and 8:7, participants also provide an account of the negative effects of their early levels of activity. Thus, Lynn writes "i became so ill,i couldn't get out of bed at all" (extract 8:6, lines 6-7). Lesley notes that "it was quite alarming to wake up with the heavy chested feeling and realise I had overdone it yet again" (extract 8:7, lines 46-48).

In all three extracts, a description of a previous response to their illness is followed by a construction of the participants' efforts to reflect on their circumstances in order to develop an alternative way to manage their condition. Thus, Lynn describes a process in which she examined the situation and developed a rational way to deal with it. With her claim "i took a long hard look,at what i could,and couldnt manage" (lines 7-8), she suggests a degree of reflexive thinking and self examination. We can infer that this is what led her to decide to "stick to a plan" (lines 8-9). Thus, through reflection and careful thought, she developed a strategy for managing her illness. Lesley describes a similar process of reflexive enquiry in which she tried to work out the possible causes of her incapacity by noting her main activity for the day on her kitchen calendar. In extract 8:8, Tracey describes a detailed management plan: "I had to break down my day into small segments of maybe 10 mins activity and thenan [*sic*] hours rest" (lines 41-43). In each case, management of their illness displays an awareness of the harmful effects of too much physical activity and the benefits of resting.

Participants then describe the different state of knowledge that resulted from a reflexive examination of the possible causes of their symptoms. Thus Lynn writes "10 years on,i now wish that i had learnt this all earlier" (extract 8:6, line 14). In

extract 8:7, Lesley claims "[i]t was much later that I realised standing was a common factor causing the worst relapses" (lines 55-56). Tracey refers to the change in lifestyle that resulted. Referring to the outcome of breaking her day into blocks of activity followed by rest, she writes "I have gradually built that up to about 1hrs activity and then rest (on a good day)" (lines 43-44). Thus, participants' claims all construct their management plans as useful.

In each of the above extracts, then, a previous response to ME is constructed as one that involved a level of activity which caused a worsening of symptoms. The subsequent response of resting is constructed as one that was only tried after the previous response had failed, and only after careful reflection. In Tracey's account it was not she herself, but an occupational therapist, who instigated the process of reflection. Sacks (1979; Sacks *et al.*, 1974) has suggested that categories allow us to infer certain things about the behaviour of the people designated by them. In this case, the category of occupational therapist would reasonably be expected to be knowledgeable about the most appropriate way to deal with a long-standing illness, since that is a large part of the job. We can infer, then, that hers was useful advice. Thus, resting is constructed as an active and strategic response, and not, for example, laziness.

That resting might be a problematic issue for people with ME can be seen in extract 8:8, where Tracey accounts for her schedule of activity and rest by first providing a detailed description of how it came about. Her initial resistance to the Occupational Therapist's suggestions is described using extreme case formulations (Pomerantz, 1986) - "*very very* difficult I fought *every inch* of the way" (line 41) - and this serves to construct herself as someone who would not rest if there were no good reason to do so. Thus, we can see that Tracey attends to the possible negative identity implications of malingering. We can see a similar orientation in Lynn's account: "[i]ll health is no

joke/,,no one wants to be disabled by an illness/ no one wants to have to rely on others to do the things,you once took for granted" (extract 8:6, lines 15-17). Here, she uses a three-part list (Atkinson & Heritage, 1984; Jefferson, 1991) in which the common feature is that illness is not something that people enjoy. The claims made are general - "*no-one* wants to be disabled [...] *no-one* wants to have to rely on others." This works to suggest that not just Lynn, but ME sufferers in general, have no desire to be ill. It also helps to construct Lynn as someone who is not malingering or profiting in any way from her condition.

So far, we have seen how participants describe the process of reflection that they went through before they realised that resting was the best response to ME. Similar constructions can be seen in participants' responses to my question about the advice they would give to new sufferers, and this can be seen in the following two extracts:

Extract 8:9 MEICCP29 Lesley

- 1 Rest, rest and rest again. Do about 70% of what you feel you
- 2 are able to do, so stop **before** you are tired, and **never**
- 3 push yourself if you ever do get to the stage where you are
- 4 tired and feel you want to rest. You have a good chance of
- 5 recovery if you can do this early on.
- 6
- 7 Remember you may not feel the effects of overdoing it till next
- 8 day or even 2 or 3 days later.
- 9
- 10 Think of your energy as if you were living off the interest on
- 11 money in a bank - you need some there to earn interest - if you
- 12 use too much, it takes a long long time to make it up again, and
- 13 if you go into the red you will never catch up..

Extract 8:10 MEICCP37 Lynn

- 1 Rest as much as you need too,listen to your body, only you
- 2 can decide how much rest you need, If that means sleeping 20
- 3 hours a day for a while do it, Then each day try to do a little bit
- 4 more,but still listen to what your body is saying,If you get
- 5 aches and pains,stop,rest,recover and start again,This illness
- 6 will not tolerate stupidity,you soon learn How much you can
- 7 do,and what you cant do,Be prepared to pay the price a few
- 8 days later.

In extracts 8:9 and 8:10, respondents produce advice about how to manage ME, and here they construct the illness as something that sufferers have to manage actively. The advice in each case is followed by a warning which emphasises the need to rest.

There are three ways that Lynn and Lesley construct ME as an illness that needs active management. The first is that they present their advice as a list of rules. Thus, Lesley begins "[r]est, rest and rest again" (extract 8:9, line 1), using repetition within a three-part list for emphasis. Lynn's advice is similar: "[r]est as much as you need too [*sic*], listen to your body, only you can decide how much rest you need" (extract 8:10, lines 1-2). The second is that in each case participants suggest that sufferers should carefully monitor their energy and activity levels. This can be seen in Lynn's advice to "listen to your body" (extract 8:10, line 1). Similarly, Lesley implicitly suggests monitoring when she advises sufferers to "[d]o about 70% of what you feel you are able to do, so stop *before* you are tired" (extract 8:9, lines 1-2). This constructs resting as a planned strategy. The third device that constructs ME as an illness that has to be actively managed is to use the analogy of financial planning. Thus, Lesley writes "[t]hink of your energy as if you were living off the interest on money in the bank" (extract 8:9, lines 10-11). Interest constitutes a fund that is by its nature variable. Therefore, to live off one's interest, and not dip into the capital that produces it, implies active management.

Both Lesley and Lynn produce a warning after their advice. In extract 8:9, Lesley writes "[r]emember you may not feel the effects of overdoing it till next day or even 2 or 3 days later" (lines 7-8). There are two aspects of this warning that are of note. First, it assumes a cause-effect connection between "overdoing it" and what might then occur - presumably relapse. Second, it suggests that the effects will take an indeterminate time - between one and three days - to be felt. If over-activity might leave the ME sufferer waiting for up to three days to know the extent of its effects, we

might infer that it would be wiser to follow Lesley's advice from the start. She produces a second warning after her description of energy as being like interest in the bank: "if you go into the red you will *never* catch up" (line 13; emphasis added). The extreme case formulation (Pomerantz, 1986) adds to the impression that the consequences of overdoing things cannot be remedied and are, therefore, serious. Lynn's warning - "[b]e prepared to pay the price a few days later" (extract 8:10, lines 7-8) similarly draws on the analogy of financial management:

In the last two extracts of this section, I will show how participants provide a case for resting as a response to ME by comparing this with other illnesses:

Extract 8:11 FGME1

783 Claire: it's the only illness that you can't fight you know you
 784 get=
 785 Rosemary: [yes]
 786 Evelyn: [yeah]
 787 Claire: people saying you know "cancer I fought against it"
 788 [you know "I I]
 789 Linda: [mm]
 790 Evelyn: [that's right uhu]
 791 Claire: I did this and I did that"
 792 Linda: mhmm
 793 Claire: you can't fight ME you've got to give i::n

Extract 8:12 FGME1

802 Linda: cos this is why it'll be interesting for you to look at me
 803 because I mean I could fight my brain haemorrhage and
 804 my paralysis and I just used to (.) stri:de out and keep
 805 going=
 806 Claire: yeah=
 807 Linda: and it's no good I mean you know you so I tried to do
 808 the same with the ME and I mean that was fatal it just got
 809 worse and worse and worse

Just prior to the dialogue in extract 8:11, Linda and Claire had suggested that the best advice to give to someone suffering from ME would be to rest. In line 783, Claire characterises ME as "the only illness that you can't fight." She therefore displays sensitivity to the notion that sufferers would normally be expected to combat their

illness. She then uses active voicing (Wooffitt, 1992) to suggest the sort of thing that a cancer sufferer might say about his or her illness - "I fought against it" (line 787); "I did this and I did that" (line 791). The use of past tense suggests that the cancer was, to use the same analogy, defeated. In extract 8:12, we see a similar formulation. Linda describes her own experience: "I could fight my brain haemorrhage and my paralysis and I just used to (.) stri:de out and keep going" (lines 804-805). This suggests that fighting was successful in overcoming the effects of her stroke.

In each extract, participants then give an assessment of fighting ME. Claire claims that "you can't fight ME you've got to give i::n" (extract 8:11, line 793). Linda provides an assessment of the effect that this strategy had: "I tried to do the same with ME and I mean that was fatal it just got worse and worse and worse" (lines 808-809).

Emphasis and repetition work here to stress her point.

Thus, resting is constructed as part of an active management plan. Participants also attended to the negative identity implications of malingering by constructing themselves as actively trying to recover by other means, and this is discussed in the next section.

3. Constructions of sufferers as active in their attempts to get better

In this section, I will examine one extract taken from a focus group discussion in which participants spoke about efforts to get better that did not involve resting.

Extract 8:13 FGME1

2027 Rosemary: em (..) and eh like you I've spent you know spent abs-
2028 thousands of pounds
2029 Claire: mm
2030 Rosemary: running after you know (.) someone who had written up
2031 about this herbal medicine or (.) acupuncture or
2032 Claire: mhmm=
2033 Rosemary: just absolutely everything and I put my heart and soul

2034 into it [and I] was
 2035 Mandy: [yes]
 2036 Rosemary: taking cold baths [laughs] [general laughter] I was taking
 2037 cold baths for three months [general laughter] it
 2038 apparently helped Barry Sheen [laughs]
 2039 Claire: oh well good for him (.) good gracious (.) I thought I
 2040 would have a heart attack if I cold bath=
 2041 Evelyn: mm=
 2042 Claire: so I reckoned I'd put up with the ME rather than [the
 2043 cold bath]
 2044 Rosemary: [well I
 2045 did] so that just shows what what extremes I went to
 [...]
 2055 Rosemary: [laughs] and eventually the money ran out so I had to
 2056 (.) stop trying any [more things]
 2057 Mandy: [but but] eventually it (.) you you
 2058 (.) decide you're not going to put yourself through these
 2059 any more because (.) every time you think (.) "yes I'll
 2060 try that there's that seems to (.) be a good idea the I can
 2061 see the logic in that so I'll try that and I'll give it a good
 2062 try" and of course you are hoping
 2063 Linda: mhmm
 2064 Mandy: that this is going to be the thing that makes all the
 2065 difference and it isn't

In extract 8:13, Rosemary constructs herself as active and committed in her efforts to find something that would help her ME. First, she makes relevant her high level of financial expenditure: "I've spent you know spent abs- thousands of pounds." Second, she uses a three-part list (Atkinson & Heritage, 1984; Jefferson, 1991), the third element being an extreme case formulation (Pomerantz, 1986), to convey the extent of her search for a remedy: "this herbal medicine or (.) acupuncture or [...] just *absolutely everything*" (lines 2031-2033; emphasis added). Third, she makes an explicit claim regarding her level of commitment: "I put my heart and soul into it" (lines 2033-2034). Fourth, she describes a particular remedy that she tried - cold baths. That this is an unusual course of action is signalled by the laughter that follows, and by Claire's claim that follows "good gracious (.) I thought I would have a heart attack if I had a cold bath" (lines 2039-2040). Rosemary provides an upshot in line 2045 that again emphasises her level of commitment: "so that just shows what extremes I went to."

There is a further point that is worth noting here. Rosemary's account is also designed to suggest that trying these methods was a reasonable thing to do. Thus, there was "someone who had written up about this herbal medicine or (.) acupuncture" (lines 2030-2031), which suggests some kind of external warrant. Of the cold baths, Rosemary notes "it apparently helped Barry Sheen⁴" (lines 2037-2038). This works to suggest that there is a rational basis to Rosemary's search for a remedy. Mandy also orients to the need to provide some kind of warrant for trying different treatments. She does this by describing the thought processes of someone who is about to try a new treatment: "that seems to (.) be a good idea the I can see the logic in that so I'll try that" (lines 2060-2061). Thus, these measures are undertaken only after some consideration of the rationale behind them.

Whereas Rosemary claims that she gave up trying any more things because "eventually the money ran out" (line 2055), Mandy's turn overlaps Rosemary's and reframes it as an active choice: "but but eventually it () you you () decide you're not going to put yourself through these any more" (lines 2057-2059). She goes on to construct these alternative treatments as disappointing, by contrasting the sufferer's aspirations with the reality: "and of course you are hoping [...] that this is going to be the thing that makes all the difference/ and it isn't" (lines 2061-2066).

We can see in this extract, then, that when talking about remedies other than resting, participants construct themselves as committed to getting better, as well as active and rational managers of their condition.

⁴Barry Sheen was a world motorcycle champion who suffered from CFS

4. Constructions of others' responses to ME

In this section, I will look at extracts in which respondents spoke and wrote about the responses of other people, such as medical personnel, friends and family, to their illness. This is of interest because of the insights it provides into the context in which participants deal with their condition.

Extract 8:14 MEICCP31 Debbie

- 1 The advise I would give is to make sure your Doctor takes
- 2 notice of you and ensures that you are tested for anything with
- 3 similar symptoms, or refers you to a sympathetic Consultant.

In extract 8:14, Debbie's advice to "*make sure* your Doctor takes notice of you" (lines 1-2; emphasis added) works to suggest that the Doctor's taking notice is something that the ME sufferer cannot take for granted. The reference to a "*sympathetic Consultant*" (line 3; emphasis added) allows us to infer that there are some who would not fall into that category. Both of these points alert the reader to the fact that the relationship between the ME sufferer and his or her doctor or consultant is potentially problematic. We would normally expect a doctor to take notice of his or her patients, and that a Consultant would be sympathetic about the illness for which his or her patients have been referred. Debbie's advice allows us to infer that ME not always considered by health professionals be a condition that warrants their care or attention. In the next extract, Dorothy is more explicit about the problems that can arise for ME sufferers:

Extract 8:15 MEIPCp4 Dorothy

- 5 develop a thick skin cos you're going to need it. Even
- 6 when you have seen dozens of Drs/consultants and have a
- 7 confirmed Dx [diagnosis] of ME and not depression most folks
- 8 you meet will consider that if you have ME you actually have
- 9 depression, but won't admit to it. And they will also often think
- 10 that if you have ME you want to be ill, that you are a quitter, that
- 11 you are just idle, or that you are a pathetic wretch who would get
- 12 better if you tried - a "maladaptive coping strategy" I think is the
- 13 buzz phrase here.

Here, Dorothy works up an account that orients to the fact that other people construct ME sufferers as suffering from depression, and as lazy and unmotivated. She counters these constructions by contrasting them with clinical diagnoses. Thus, she begins by constructing as valid the diagnosis of "ME and not depression" (line 7). This is achieved by referring to the large number of highly-qualified medical people involved - "dozens of Drs/consultants", and to its collaborative nature - "*a confirmed Dx*" (line 7; emphasis added). Doctors and consultants belong to a category of medically qualified and skilled people. We would normally expect such people to have a high level of expertise in the diagnosis of clinical conditions. This provides an inferential context for the other claims that follow. That is, when Dorothy writes that "most folks you meet will consider that if you have ME you actually have depression, but won't admit to it" (lines 8-9), we read these as prejudiced opinions with no basis in fact. The views then attributed to "most folks" construct the ME sufferer as a malingerer. They are presented as a list that gives the impression of a relentlessly negative and unsympathetic perspective: "they will also often think that if you have ME you want to be ill, that you are a quitter, that you are just idle, or that you are a pathetic wretch who would get better if you tried" (lines 9-12). This is glossed using one of the terms of cognitive behavioural therapy⁵: "a "maladaptive coping strategy" I think is the buzz phrase here" (lines 12-13). She therefore suggests that the preceding views are represented by this expression, and presumably by those who might use it. Thus, we can see a quite explicit orientation to potential claims that ME sufferers are lazy and not motivated to get better. Dorothy undermines this argument first by presenting it as the prejudiced views of "most folks" (line 7), and then by describing it as a trendy piece of jargon - a "buzz phrase."

In the next extract, Claire constructs family members as unsympathetic to the problems of ME:

⁵The use of cognitive behavioural therapy to treat ME is discussed in Chapter 1, p36-39

Extract 8:16 FGME1

904 Claire: once you've () fought the battle with yourself and
905 you've decided you've still got other people's (.)
906 attitudes to deal with you know family (.) [as well]
907 Rosemary: [mhmm
908 mhmm]
909 Claire: e:m (..) they want to see you (.) fighting it
910 Linda: yes=
911 Claire: pulling yourself together
912 Rosemary: yes
913 Claire: [not lying around in heaps] doing nothing
914 Mandy: [and back to your old self]
915 Mandy: yes
916 Claire: and (.) you know (.) you're lying there (..) "what's for
917 dinner?"

In extract 8:16, Claire contrasts the perspective of family members with that of the person who has ME. She does this with a direct claim, and by using active voicing (Wooffitt, 1992) to suggest that her account is factual. Thus, she claims of family members: "they want to see you (.) fighting it [...] pulling yourself together [...] not lying around in heaps doing nothing" (lines 909-913). This contrasts the positive action expected by the family with their negative perceptions of the ME sufferer's response to the illness. There is an orientation to the notion that people with ME should be fighting their illness and that they might be lethargic rather than unwell. The family's failure to understand the extent to which the ME sufferer needs to rest is also demonstrated by the contrast in the last two lines, in which Claire appears to quote the words of a member of her family: "you're lying there (..) "what's for dinner?"" This suggests that whoever is speaking does not acknowledge that Claire is lying down because she is unwell and presumably unable to prepare a meal. It also works to construct family members as somewhat selfish, in the sense that they are more concerned with their own needs than those of the sufferer.

5. Summary

In this chapter, I have examined participants' responses to two questions designed to allow an analysis of how they dealt with their illness, and the advice they would give to others. I have shown that they constructed their initial reaction to finding that they had ME as one of surprise. They also constructed themselves as unaware at first of the possible duration and seriousness of their illness. They describe how they continued to work physically hard in the early stages, and that this caused a worsening of their symptoms. Resting was constructed as a strategic way of managing their illness that was only made after this initial, and unsuccessful response, and a period of careful reflection on the things that did and did not help.

When describing their initial response, participants constructed themselves as motivated to work. When warranting their subsequent decision to rest, they constructed themselves as active managers of their condition. Respondents therefore oriented to the possible charge that they might not be motivated to get better, and that they were being lazy. This orientation was made explicit when they described the futility of fighting this illness, and in their accounts of their search for a remedy. It was also a feature of participants' constructions of the responses of other people to the ways in which they managed their illness.

6. Discussion

The literature suggests that, in chronic illness, some coping strategies are more useful than others. In the particular case of Chronic Fatigue Syndrome, the strategy of 'avoidance coping', has been linked to higher reported levels of fatigue. The implication is that fatigue is made worse by sufferers' tendency to avoid activity. This underpins the most common treatments, cognitive behavioural therapy and graded exercise therapy.

We can see in this analysis that participants did orient to the notion that some ways of coping with illness are superior to others, and in particular that resting is an accountable way of dealing with ME. Their accounts were designed to construct *over-activity* as an exacerbating factor in fatigue, and resting as the only successful way of managing their energy levels.

It is also notable that identity issues were addressed when participants constructed the ways in which they cope with this illness. Thus, when talking or writing about their initial response, they constructed themselves as motivated to work, and therefore, we can infer, not malingerers. Similarly, in accounts in which participants constructed rest as an appropriate response to ME, participants attended to the negative identity implications of this approach. That this is necessary is grounded in accounts in which respondents describe the reactions of others to their condition while explicitly orienting to the potential charge that ME sufferers are lazy and not motivated to recover.

We can see, then, how coping with ME is an interactional achievement. That is, participants work at constructing their response to their condition as an active and well-thought strategy. Resting is constructed in opposition to the potential claim that sufferers are being lazy. Thus, identity is implicated in coping. Furthermore, construction of the illness itself is significant. Instead of taking illness schemas as a representation of some kind of internal mental cognitions, constructions of the nature of illness can be seen as performative. When participants gave accounts of their initial surprise as to the likely seriousness and duration of their illness, this enabled them to construct themselves as motivated to work through it, and not as the type of people who would simply give in.

Coping, therefore, can be an accountable issue. In the following chapter, we can see that similar problems arise for people who have suffered stroke.

CHAPTER 9

SUFFERERS' CONSTRUCTIONS OF RESPONSES TO STROKE

At the beginning of the last chapter, I discussed my rationale for constructing questions aimed at finding out how people 'cope' with their condition while at the same time avoiding the use of this term. I therefore asked the following questions, based on those used with ME participants, in an attempt to generate discussion of how it was that people with stroke dealt with their condition:

1. "Can you describe how you dealt with your condition when you first knew about it?"
2. "What advice would you give to someone who has just suffered a stroke at a young age?"

In the first question, the inclusion of "when you first knew about it" was particularly pertinent to my analysis of the ME data, because of the contentious nature of this illness and the difficulties surrounding diagnosis. These factors meant that sufferers' claims regarding the timing of onset were significant in an analysis of how they dealt with their condition over the longer term. The wording was retained in the schedule of questions for stroke sufferers out of a concern to for consistency throughout, given

that one of the aims of this study was to produce some sort of comparison of findings. It became clear from an analysis of responses that sufferers took up this question as a request for information principally about the initial, acute stages of this condition. In the acute stages, the stroke sufferer is usually hospitalised, and often quite unaware of what is going on around them. My interest was in the ways in which people managed their illness once discharged from hospital.

All of the extracts used here were, therefore, in response to the second question. Here, my aim was to stimulate discussion of the ways in which sufferers coped, and might have managed their illness better with hindsight. Thus, it was hoped that responses would not only construct participants' coping strategies but would also incorporate some sort of assessment of the different ways that people might deal with this condition.

Three themes were revealed in a preliminary analysis. First, respondents constructed their response to stroke as active. This is discussed in section one. In section 2, I explore the second theme, which is that carers constructed stroke sufferers as solely responsible for their recovery. The third theme related to the ways in which participants who responded via the internet avoided accountability for their recovery.

1. Constructions of responses to stroke

In the first two extracts of this section, I will show how stroke sufferers constructed themselves as active in their efforts to deal with stroke:

Extract 9:1 FGDS2
254 Eric keep on fighting just .hh from day one start to the fight
255 back you know
256 Jennifer: mhmm

257 Eric: start the fight back and e:m .h I think there's they say
 258 the first six months .h then the second six months so .h
 259 from day one start to do what you can

Extract 9:2 DSIPCp7 Ana

45 Everyone comes to terms with their stroke in their own
 46 way; perhaps you'll never stop feeling angry, but then the
 47 anger may motivate you to continue the struggle to be
 48 independent and live life fully.

In each of the above extracts, participants use the metaphor of combat to refer to the ways in which someone who has just suffered stroke should deal with its effects.

Both Eric and Ana orient to two specific aspects of this combat - its constant nature and the sufferer's active role in getting better. Thus, Eric's advice is "keep on fighting"; "from day one start to do what you can" (extract 9:1, lines 254 and 259).

He makes relevant that this response should be adopted from the start. Ana's advice is to "continue the struggle to be independent" (extract 9:2, lines 47-48). In extract 9:1, line 254, Eric uses a repair in which he inserts the definite article: "start to/ the fight back." He recycles the repaired formulation in line 257: "start the fight back."

Similarly, Ana refers to "the struggle" (extract 9:2, line 47). The use of noun and definite article here is significant. This formulation constructs such a response as generally associated with stroke, and therefore appropriate. Thus, dealing with stroke is constructed in terms of a constant, personal and somewhat inevitable combat. This works indirectly to cast the sufferer in an active role in his or her recovery

In the following two extracts, respondents construct recovery as difficult:

Extract 9:3 FGDS2

205 Euan: yes it goes quite fast to start with and then (.) it slows
 206 down which is a bit (...) e::m (.) demoralising
 207 sometimes in that=
 208 Eric: yeah
 209 Euan: things just don't happen
 210 Jennifer: mmmm
 211 Euan: when you you hope they will

Extract 9:4 FGDS1

- 330 Norman: but em (..) its (.) the advice well as I say I see () it's
 331 really (.) as I say you gotta work out what kind of (.)
 332 person you're talking to you you can see some you can't
 333 advise them that they're gonna be go back to work and
 334 because normal cos that's not gonna happen=
 335 Yvonne: mm=
 336 Norman: but they are gonna get better they are gonna change
 337 Steve: [mm]
 338 Norman: [and] and and within that category they are gonna get to
 339 a a better life than they are at the moment=
 340 Yvonne: but are they?
 341 Norman: yeah they are eh all the people that I've seen
 342 Steve: [mhmm]
 343 Yvonne: [I dinnae] [don't]] think so [I cannae] [can't]
 344 Steve: [aye]
 345 Yvonne: move my [hand]
 346 Steve: [no]
 347 Yvonne: and I've tried for two years and it will not move

In extract 9:3, Euan is talking about the rate at which he improved after his stroke.

Referring to a slowing down in progress, he says "things just don't happen when you hope they will" (lines 208-210). Wooffitt proposed that to formulate something as an 'it' that happened suggests that the occurrence was "not contingent upon human agency or involvement" (Wooffitt, 1992: 103). We can see a similar formulation in extract 9:4, where Norman claims that among the people who have suffered stroke there are "some you can't advise them that they're gonna be go back to work and become normal cos that's not gonna happen" (lines 332-334). In each case, the 'it' that did not or will not happen (expressed here using the similarly indefinite terms "things" and "that") relates to recovery. This formulation therefore emphasises the sufferer's lack of agency where there is an apparent failure to recover.

In both extracts, participants construct their failure to improve and follow this with a claim regarding their motivation to get better. Thus, in extract 9:3, Euan's claim, of his progress, that "it goes quite fast to start with and then (.) it slows down" is followed by an assessment, "which is a bit (...) e::m demoralising sometimes" (lines 205-207). His use of the moderators "a bit" and "sometimes" allow Euan to construct

himself as not completely demoralised and therefore allow us to infer that despite these setbacks he is still motivated to get better. In extract 9:4, Yvonne follows her claim "I cannae move my hand" with "and I've tried for two years and it will not move" (lines 343-347). Thus, she constructs her failure at the same time as her effort to improve. She constructs this effort as real by giving precise information regarding the length of time she has tried to move her hand.

That respondents oriented to accountability issues can also be seen in the following extracts, which were taken from responses to my question about the advice they would give to someone who had just suffered stroke at a young age. Here, participants make relevant the particular kind of support that stroke sufferers receive from healthcare professionals, and the effect that this has on recovery:

Extract 9:5 FGDS2

205 Euan: yes it goes quite fast to start with and then (.) it slows
206 down which is a bit (...) e::m (.) demoralising
207 sometimes in that=
208 Eric: yeah
209 Euan: things just don't happen
210 Jennifer: mhmm
211 Euan: when you you hope they will that's that's what was
212 mentioned earlier you know they co- cope they (.) they
213 concentrate a lot on physical things (.) like (.) with me it
214 was walking (.) and doing arm movements and things
215 like that
216 (6)
217 *Lorna*: maybe that's to do with the centres though they know
218 how to cope with physical things=
219 Euan: mhmm=
220 *Lorna*: but they don't (.) they're not willing to put the resources
221 into the sort of
222 Eric: yes
223 *Lorna*: psychological (.) rehab

Lines 205-211 have been analysed as extract 9:3. They are included here to provide some context, which allows us to infer that talk about the provision of external support is relevant to the issue of failure to make consistently good progress. Here, participants work up an account that constructs rehabilitative support as focused on

physical functioning and neglecting psychological issues. This allows for the inference that psychological support is necessary. Euan's claim that "they concentrate a lot on physical things" (lines 212- 213) allows the hearer to infer that non-physical things are not addressed. Lorna orients to this by offering an account in explanation of this state of affairs. She claims that the centres "know how to cope with physical things" (lines 217-218). She then uses a repair to suggest that their failure to manage the psychological aspects is not because they do not know how to cope, but rather that there is a lack of motivation to do so: "but they don't *they're not willing* to put the resources into the sort of [...] psychological (..) rehab" (lines 220-223; emphasis added).

In the following extract, focus group participants similarly construct medical support as inadequate, and this is used to account for failure to recover:

Extract 9:6 FGDS1

- 631 *Kirsty*: and I feel he was just put out of [hospital 3]
 632 and that was it (.)
 633 *Ian*: and my wife would agree [with that as well]
 634 *Emma*: [do you feel embarrassed]
 635 [unclear]
 636 *Kirsty*: LITERALLY [put out]
 637 *Steve*: [and my wife I know aye]
 638 *Simon*: [I think I think [unclear]]
 639 *Kirsty*: [you take (.) I know I realise that hospitals don't have
 640 the resources]
 641 *Simon*: [I think that's the problem]
 642 *Kirsty*: [but I feel that my brother's not had any support as in]
 643 *Yvonne*: [it's frustrating cos you know you can do it eh]
 644 *Kirsty*: he (.) lives on his own he's (.) he's divorced and what
 645 have you
 646 *Ian*: mm
 647 *Kirsty*: and he's literally just left

In extract 9:6, Kirsty makes a complaint about what happened in the case of her brother: "he was just put out of [hospital 3] and that was it (lines 631-632). We would normally speak in terms of a patient leaving hospital, or being discharged. To use the term 'put out' suggests that Harry's exit from hospital was inappropriately

hasty, and that his role in this was passive. Kirsty warrants this implicit claim in three other ways. First, she uses 'just' in a restrictive form (Lee, 1987) to suggest that something else might have been done, but was not. For example, he might have been offered some ongoing support. She uses "just" in the same way in line 646: "and he's literally just left." Second, Kirsty's use of the formulation "LITERALLY put out" (line 636) represents an explicit claim that this verb reflects what actually happened. Third, in lines 642-644, Kirsty uses a three-part list, with a generalised list completer (Atkinson & Heritage, 1984; Jefferson, 1991), to describe circumstances relating to Harry that would normally warrant help: "my brother's not had any support as in [...] he (.) lives on his own / he's (.) he's divorced / and what have you." A three-part list can be used to orient to a general feature of the items in the list (Jefferson, 1991). In this context, Kirsty is referring to the fact that Harry has no-one at home to care for him. This suggests that he needed a high level of both practical and emotional support, and by implication, that this was not provided. In line 643, we can see that Yvonne treats this lack of support as something that inhibits a level of recovery that would otherwise be certain: "it's frustrating cos you know you can do it eh" (line 643).

We have seen, then, that respondents construct themselves as active in their efforts to get better. However, when recovery is not as well as might be hoped, the construction of an 'it' that did not happen allows them to infer a *lack* of agency. Furthermore, claims about failing to recover are accompanied by claims that construct the sufferer as nevertheless motivated to improve. Respondents construct the provision of healthcare support as inadequate, and as a factor that can be used to account for poor recovery. This also constructs the responsibility for recovery as shared. Thus, we can see that stroke sufferers' accounts are sensitively designed to deal with the possibility of being held to account for getting better. In the next section,

I will explore the issue of accountability in the context of focus group sessions made up of sufferers and carers.

2. Responsibility for recovery

In focus groups, carers constructed sufferers as solely responsible for their level of improvement. This can be seen in the first two extracts of this section:

Extract 9:7 FGDS2

338 *Lorna:* so I think () is there not it's () even in the professionals
339 it's still very much they don't know how much recovery
340 you're gonna make they just sort of say "you just accept
341 what you've got " (.) so it's very much down to the
342 patient to actually say "I can do better than this" and and
343 I I mean we'd say that the people we saw on the wards
344 those that fought the hardest for themselves were the
345 ones that made the best recovery

In Extract 9:7, Lorna explicitly relates improvement after stroke to sufferers' personal, active efforts to recover. Her claim is that "it's very much down to the patient to actually say "I can do better than this"" (lines 341-342). This claim is warranted in three ways. First, Lorna refers to the views of "the professionals" (line 338).

Professionals would normally be considered to have some expertise in their area of work, and by referring to this category, Lorna makes available the inference that such views are credible (Potter, 1996; Sacks, 1974; Sacks, 1979).

The second warranting device used by Lorna is what Wooffitt (1992) has described as 'active voicing'. This helps to establish the objectivity of her claim that the role of healthcare professionals is limited: "they just sort of say "you just accept what you've got" (lines 340-341).

The third way in which Lorna warrants her claim is by producing evidence that makes explicit the association between active effort and recovery: "we'd say that the people we saw on the wards those that fought the hardest for themselves were the ones that made the best recovery" (lines 343-345). This claim is constructed as fact by providing some detail about the people to whom she refers, that is, that they were on the wards. She also uses the first person plural, to suggest that her claim is not just her opinion but is a view taken by at least one other person. It is also notable that Lorna uses the metaphor of combat, which has already been noted as a way of constructing sufferers as active in their efforts to get better. Finally, she emphasises her claim that sufferers are solely responsible for their recovery by referring to "those that fought hardest *for themselves*" (line 344; emphasis added).

In the next extract, focus group participants discuss the sufferer's role in his or her recovery.

Extract 9:8 FGDS1

369 Yvonne: you've actually got to push [yourself]
370 Steve: [aye]
371 Kirsty: nobody can do it for you
372 Norman: you've got to you've got to try
373 Steve: [aye aye]
374 Kirsty: [cos] you can () you're the only you're the only people
375 that can help yourself
376 Steve: that's right aye

In extract 9:8, respondents were discussing the advice they would give to someone who had just suffered a stroke. Yvonne makes a direct claim that constructs the appropriate response to stroke as one involving personal motivation and effort on the part of the sufferer: "you've actually got to push yourself" (line 369). Steve and Norman, both stroke sufferers, and Kirsty, a carer, display their agreement with particular aspects of that claim in the lines that follow. Norman's agreement orients to the personal effort that is involved: "you've got to you've got to try" (line 372). This

helps to construct coping with stroke as hard work. Kirsty's agreement, however, orients to the stroke sufferers' own agency: "nobody can do it for you [...] you're the only people that can help yourself" (lines 371-375). This constructs the sufferer as solely responsible for his or her recovery.

In the next extract, we can see how one of the carers constructs stroke sufferers as lacking in motivation to recover:

Extract 9:9 FGDS1

534 *Emma* if you show sympathy (.) well they tend to sort of well
535 () she'll wallow in it
536 *Kirsty:* aye yeah
537 *Emma::* you know "look at me look what's happened to me"
538 you've got to sometimes you've just got to be a wee bit
539 cruel say "oh come on" and
540 *Kirsty:* aye
541 *Ian:* mm
542 *Emma:* you know and push them

Here, Emma constructs stroke sufferers as lacking in motivation. She makes a claim regarding stroke sufferers, and Yvonne in particular, that "if you show sympathy (.) well they tend to sort of () well she'll wallow in it" (lines 534-535). By describing a hypothetical situation, Emma constructs her claim as a fact. Thus, she constructs the stroke sufferer in a passive role. Emma uses active voicing (Wooffitt, 1992) - "look at me look what's happened to me" (line 537) - to illustrate her claim, and to establish its objectivity. She also constructs carers as responsible for motivating sufferers to take an active part in getting better. With her repetition of the imperative - "you've got to sometimes you've just got to be a wee bit cruel say "oh come on" and you know and push them" (lines 538-542; emphasis added), Emma constructs this as a necessary response. By characterising it as "a wee bit cruel" she orients to the negative identity implications that might arise for the carer. That carers have to motivate sufferers even when they are aware that this might be perceived as cruel further suggests that this course of action is not avoidable.

We have seen that carers construct stroke sufferers as solely responsible, and also lacking in motivation to get better. In the last two extracts of this section, I will show that sufferers orient to being held accountable for any lack of recovery.

Extract 9:10 FGDS2

392 Eric: and they do use this this term t- time time to give it time
393 give it time .hh and nobody knows how long it could be
394 (.) eh I can remember () my doctor saying (.) that if it
395 happens earlier than one year then fine if it's the year
396 then fine and here we are almost at two years (.) and the
397 fight still goes on yeah so it go- can go on for a while
398 but even from the the very first night I've been taken in
399 the in the ambulance .hh they didn't make it clear to me
400 that (.) part of the problem was a starvation of oxygen to
401 the brain you know with a clot (.) and so this .h they (.)
402 gave me this oxygen mask they said () "breathe that" I
403 said "just () take it away I don't want it" you know (.)
404 and nobody said "but you've got to have it because" (.)
405 you know

In extract 9:10 Eric constructs healthcare professionals' role in recovery as limited. He achieves this by referring to the ways in which healthcare professionals have spoken about recovery. These references describe a laissez-faire approach: "they do use this term t- time time to give it time give it time" (lines 392-393); "if it happens earlier than one year then fine if it's the year then fine" (lines 394-396). Here, an 'it' that happens also suggests a lack of agency (Wooffitt, 1992). The repeated phrase "give it time" further implies a passive approach to recovery. This can be contrasted with Eric's claim "and the fight still goes on" (lines 396-397). Here, he uses the metaphor of combat, which has been discussed previously, to suggest that his own response is active.

These contrasting constructions provide an interpretative context for the next part of this extract. Here, Eric talks about the night he had his stroke. In his narrative, he works to counter any potential accusations that he might be in some way responsible for his lack of recovery. His refusal to take oxygen is treated as accountable. He

justifies it by referring to the lack of adequate explanation from ambulance staff: "they didn't make it clear to me"; "nobody said "but you've got to have it because"" (lines 399-404).

In the next extract, an internet correspondent constructs himself as accountable for his lack of recovery:

Extract 9:11 DSIPCp8 Tim
1 I felt
2 very sorry for my self which was the last thing you should do!
3 I suppose the best thing you can do is listen to the doctors , they
4 can give you advice on the the right things to do.but also try to
5 come to terms with whats happend and get on with the physio as
6 soon as you can dont do what I did and believe it would all come
7 back on it,s own with no help thats a big mistake as I have
8 found to my regret get on and work hard at trying to get back
9 the most movement you can early ok.

In extract 9:11, Tim describes his own response to stroke as passive and follows this with an assessment that constructs this in negative terms - for example, "I felt very sorry for my self which was the last thing you should do!" (lines 1-2). Similarly, in lines 6-7, he writes "dont do what I did and believe it would all come back on it,s own with no help thats a big mistake." Here, he constructs himself as personally accountable for his lack of recovery. This can be contrasted with the advice that Tim would give to someone who has just had a stroke at a young age: "get on with the physio as soon as you can"; "get on and work hard at trying to get back the most movement you can early ok" (lines 5-6 and 8-9). He refers to physically active behaviours, and makes relevant the fact that these should be performed from the start. By contrasting these with his own unsuccessful response, Tim constructs an active approach to recovery as preferable.

3. Internet participants' avoidance of accountability

In the last two extracts of this chapter, internet participants construct themselves as active in the process of their recovery:

Extract 9:12 DSIPCp9 Barry

5 When I finally realised what had happened, and the long road to
6 recovery that was ahead, I told myself that I had to recover if I
7 wanted to do all the things I so enjoyed before. I knew that by
8 taking things one day at a time, try as hard as I could during
9 rehab and set myself achievable goals, I would recover - maybe
10 to to the physical standard I was before, but I am mentally and
11 emotionally better off for the experience. That might sound
12 odd, but its true!!

Extract 9:13 DSIPCp6 Colin

3 All I would say is don't
4 listen to people you tell you won't be able to do something as
5 because anyone who speaks to like that probably have only seen
6 stroke in the elderly and if you're young and determined you
7 can achieve what you want. For me a pessimistic surgeon who
8 said I would never walk again drove me on to walking around
9 after 3-4 months. I would certainly use that as an example
10 whilst giving advise. That along with the fact I made it to
11 university 12 months after my stroke

In extract 9:12, Barry uses the vocabulary of volition and effort to construct his recovery from stroke as something within his control: "I *knew* that by taking things one day at a time, *try* as hard as I could during rehab and *set myself* achievable goals, I would recover" (lines 7-9; emphasis added). Thus, he constructs his response as active and his recovery as a result of his own efforts. It also provides an inferential context for what follows, which is an assessment of his progress. Here, he constructs his recovery as not just to his pre-stroke level but as an *improvement* on this: "I am mentally and emotionally better off for the experience" (lines 10-11). We can infer, then, that Barry can take full credit for this state of affairs.

In extract 9:13, we can see a similar formulation. Colin also constructs recovery as something that is influenced by the sufferer's efforts "if you're young and *determined*

you can achieve what you want" (lines 6-7). This provides an inferential context for what follows. Here, he provides an account to establish his successful progress: "[f]or me a pessimistic surgeon who said I would never walk again drove me on to walking around after 3-4 months" (lines 7-10). This constructs his recovery not just as due to his determination, but as beyond what might have been expected. He does this by referring to the views of a skilled clinician, who would normally be warranted with knowledge about the likelihood of recovery. He makes relevant the extent of his recovery again in lines 10-11: "I made it to university 12 months after my stroke." It is notable that in both of these extracts, participants who claim recovery is attributable to their strength of will *also* construct their recovery as extremely successful.

4. Summary

Stroke sufferers in this study used the metaphor of combat to construct themselves as active in their response to stroke. They also oriented to issues of accountability potentially arising from failure to make a consistently good recovery. They did this by constructing their lack of agency when recovery was not good, and by attending to the negative identity implications associated with the possible charge that they are unmotivated. That recovery is an accountable issue can be seen in carers' constructions. In this study, they constructed stroke sufferers not as lacking in agency but rather as solely responsible for recovery from their stroke, and also as unmotivated. Internet participants managed to avoid accountability by constructing themselves as both active and successful in their recovery.

5. Discussion

The traditional view in psychological theory that some coping strategies are better than others has been used to study the ways in which people manage stroke. However,

findings have been inconsistent. Finset & Andersson (2000), for example, report that avoidant coping is associated with depression in stroke sufferers. Kremer & Quednau (2000b), however, suggest that problem-focused coping has negative implications. Such apparent anomalies can be understood if we examine this from a social constructionist perspective, in which talk about recovery is expected to vary with local context and according to the discursive actions being performed at the time. In this study, for example, participants who had suffered stroke constructed their role in recovery as active at times, and as passive at other times. This can work to deal with accountability issues. On the one hand, if stroke sufferers construct themselves as passive, then they can avoid accountability for recovery, but their situation is one in which there is no hope of making a personal impact on their condition. This might make the outlook seem very bleak indeed. On the other hand, when sufferers construct themselves as active in the recovery process, then there is always the potential charge that they are accountable for the extent to which they fail to get better. This has identity implications, which can be seen in stroke sufferers' orientation to construct a self that is active and motivated. Those participants who were able to claim credit for their personal effort in getting better also made the point that their recovery was complete, and so avoid such a charge. It may be relevant that these participants were both internet correspondents, who were not directing their comments to a number of differently-affected stroke sufferers and carers, which was the case for those in the focus groups.

We can see, then, that accountability for coping is related to issues of identity. Similar findings were discussed in the analysis of ME sufferers' accounts of coping. It was also found that coping and identity are influenced by the construction of the illness itself. Thus, ME sufferers oriented to the negative identity implications of malingering. In the case of stroke sufferers, it has been shown that there is little medical treatment available, and the focus is instead on rehabilitation, in which the

sufferer plays a key role. This study has shown that stroke sufferers' participation in recovery is oriented to as an accountable issue.

CHAPTER 10

CONCLUSIONS

This study aimed to explore the experiences of people with two types of chronic illness - ME and stroke at a young age. It focused on three areas: the ways in which sufferers defined their illness, the effects it has on their identity and the ways in which they cope. A discourse analytic approach was adopted, in which it is assumed that illness, identity and coping are an ongoing achievement performed in interaction. Focus group discussions and email correspondence were analysed to see how this is done.

This final chapter begins with a summary of findings. Three themes emerged from the analyses produced in this research. The first is that participants who had ME and those who had suffered stroke oriented to issues of accountability for being unwell and for the ways in which they coped with being unwell. The second relates to the identity work that participants did to maintain a positive self. The third theme concerns the extent to which illness construction, identity and coping are interconnected. I will discuss these themes in turn. This will be followed by a brief comparison of the two methods of data gathering - face-to-face focus groups and internet. The focus of the chapter will then move to an evaluation of findings, and a discussion of potential theoretical and practical applications before a final, brief summary.

1. Summary of findings

1:1 Accountability

A recurring theme in this research is the extent to which participants oriented to issues of accountability for becoming ill, for the extent to which their incapacity was due to illness, and for the success with which they coped. Participants with ME constructed this illness as enigmatic and were thus able to counter the potential charge that they had done something to bring about their symptoms. A similar orientation was seen in stroke participants' constructions of their stroke as unpredictable. That is, if their stroke could not have been foreseen, then there is nothing they could have done to prevent its occurrence, and they could not be held to blame. A feature of focus group sessions with stroke sufferers was that carers were present, and it was possible to carry out further analysis of interactions between carers and sufferers to examine the issue of accountability in context. This was done in chapter 5. It was shown here that participants did orient to such accountability. In their interactions, carers did hold sufferers accountable for their condition, and they constructed stroke sufferers' prior behaviour as a precipitating factor.

Respondents with ME and who had suffered stroke also oriented to the potential charge that their inability to perform activities might be attributable to laziness. Constructions of ME as serious and not psychological worked to suggest that incapacity resulted from the illness itself, and not indolence or psychological weakness on the part of the sufferer. Participants who had suffered stroke oriented to the potential charge of laziness, and carers who were present did at times construct stroke sufferers in this way.

Both groups of participants provided accounts designed to counter claims that they were not motivated to get better. People with ME also had sensitively to negotiate the implications of resting as a response to their illness, in that this might suggest a lack of

effort. Stroke sufferers carefully managed the task of constructing their role in recovery as active at times and passive at others, depending on the level at which improvements had been made. Issues relating to accountability for recovery were particularly salient in focus groups in which carers participated. The importance of carers' response to stroke can be seen in the literature. As already noted, it has been assumed by many that damage to a specific area of the brain can predict impairment. Manzo and colleagues (1995) have, however, suggested that the stroke sufferer's relationship with his or her carer can have a significant effect on the sufferer's capacity to communicate effectively. We can, therefore, see an orientation to participants' accountability for both ME and stroke. A comparison between data collected in different ways suggests that this was particularly evident in face-to-face interactions. Implications are raised for research.

We might infer from these findings that the person with a chronic condition may well, at times, have to account for any incapacity caused by illness, in a context in which his or her complaint is perceived as poorly understood by non-sufferers. There may also be issues of accountability for becoming ill in the first place. Furthermore, people who suffer chronic illness may be held accountable for the ways in which they cope. This study suggests that coping - or being deemed to cope - is an interactional achievement that is skilfully worked up and managed by participants.

1:2 Identity work

Analysis showed that respondents with ME worked to maintain a positive identity when talking or writing about the ways in which they had been affected by their illness. In particular, they worked up a pre-illness identity that was active and sociable. This allowed them to counter the possible charge that they were lazy and unmotivated, an identity that is problematic when the key symptom of this illness is

unexplained and enduring fatigue. By constructing their approach to ME as a process of rational enquiry, and accounting for the methods they had tried, participants also constructed *themselves* as active, motivated and rational managers of their condition. That they did this suggests that there are implications for identity in the ways in which people cope with ME. We saw some evidence for this in their constructions of others' unsympathetic response to sufferers' need to rest. The question of how much illness had changed identity was sensitively managed to attend to identity implications of either being overly negative, or profiting from being ill. A 'balanced' account of the effects of ME was designed to construct the sufferer as a 'better person' despite the negative physical impact of this condition.

Participants who had suffered stroke also carefully managed the way they constructed its effects on identity, particularly in focus group sessions made up of both sufferers and carers. Stroke sufferers in this study constructed others' response to their condition as stigmatising

Both groups of sufferers, then, oriented to the problematic nature of identity that stemmed from their accountability for becoming ill, and for their inactivity. We might, therefore, infer that these issues may be relevant to other people with chronic illness. This study suggests that the issue of change is something that has to be carefully managed so that the effects of illness are acknowledged while at the same time any negative identity implications that may arise from having a chronic condition are avoided.

1:3 The interconnectedness of illness construction, identity and coping

In the course of analysis, it became apparent that illness constructions, sufferers' identity work and accounts of coping were not phenomena that could be easily separated. Thus, with ME, the illness construction of serious and not psychological works to counter possible claims that it is not a physical illness. The ME sufferer's identity is constructed as active and hard-working pre-ME, and this orients to possible doubts about the nature of this condition. Such identity work can also help to defend against accusations of malingering. Resting as an appropriate coping response is carefully worked up to attend to identity issues that are especially relevant when the illness is of uncertain status.

For people with stroke, one of the key issues identified in the literature is that there is no medical treatment. Stroke sufferers in this research designed their accounts of coping to orient to the potential claim (at times made explicit by carers) that they were not motivated or working hard enough to get better.

One interesting difference between the constructions of stroke and ME sufferers is that people who had had a stroke constructed themselves as tired or unmotivated after it, rather than incapable of certain activities. In their case, this worked to help maintain a somewhat positive identity. That is, to claim a lack of energy may, at times, be preferable to claiming a lack of ability. This strategy is a useful one when the sufferer is largely responsible for recovering physical functioning. Participants with ME, however, oriented to the possibility that their illness might be construed as laziness, as a psychological complaint, or in some way associated with depression. They therefore *emphasised* their physical incapacities and in their case this worked to maintain a positive identity. Thus, we can see that illness constructions can influence the kinds of identity work and accountability that arise for sufferers.

2. Comparison - focus group and internet data

A review of the literature relating to computer-mediated communication (CMC) suggests that it may constrain or enable different interactional practices, and that its effects will vary according to the context. Furthermore, although it usually takes the written form, it can nevertheless be said to display oral qualities.

There were two areas in which the mode of communication appeared to be significant in this thesis. The first relates to the social context of internet as opposed to focus group discussions. The second concerns the application of analytic methods in textual and oral communication. I will discuss these in turn.

A potentially significant difference between email and focus group responses is that other people may or may not be present in the interactions. Participants responding in focus groups were able collaboratively to work up accounts, to produce and resist constructions of their illness, its effects on identity and ways in which they coped. They did this in an immediate context that included other people suffering from the same illness. Most of the ME email correspondence was done via a chatline in which responses were available to other members of this particular group. Thus, most of the ME data were provided in a context of some level of social interaction.

The situation was different, however, in the case of people who had suffered stroke. On the one hand, focus group responses were given in the presence not just of other sufferers but also of carers, who also took part in the focus group sessions. On the other hand, stroke sufferers' email correspondence was more likely to be on a one-to-one basis. Thus, we can see potentially more significant context effects in the stroke sufferers' data than in those collected from people with ME.

It is indeed in the analysis of the stroke sufferers' responses that important differences were noted between the two methods of data collection. For example, stroke sufferers who responded via the internet gave more vivid accounts of what it is like to have this condition than those taking part in focus group discussions. Stroke sufferers who participated in focus groups were shown to be held directly accountable, in the course of the sessions, for having had a stroke, for distinguishing the effects of stroke from laziness, and for their role in recovery. While internet correspondents did orient to such issues, they were able to avoid accountability in a way that focus group participants could not. This may be because their claims were not open to direct and immediate challenge by carers. Furthermore, there was no orientation to the sensitive task of responding in a group in which sufferers' disabilities and levels of recovery were mixed. For example, when participants in focus groups were asked about the effects of stroke on identity, the notion of change was sensitively managed to acknowledge the effects of stroke while attending to issues of self-presentation. Internet correspondents constructed change in positive terms, as an active response to stroke. When focus group participants were asked questions related to coping with stroke, they oriented to the problems involved in constructing an association between active effort and recovery. Internet correspondents who claimed unexpectedly high recovery levels were also able to take personal credit for the ways in which they managed their condition.

Although the ME data offered less of a contrast between levels of social presence, there was still an observable difference between data collected via the internet and in the course of focus groups. When describing their condition, for example, internet chatline correspondents - whose responses to me were simultaneously emailed to other members of the group - used both the first person singular and the first person plural. Focus group participants only used the first person plural, and indeed appeared actively to avoid the use of 'I'. It may be that 'you' provided a more general

assessment for which the speaker is less personally accountable, and that this is an issue for people who are in the physical presence of other sufferers. Another observation is similar to that found in the responses of people who had had a stroke. When asked to describe the effects of their illness on them as people, it was only via the internet that ME sufferers spoke in terms of any kind of positive impact.

These findings suggest that the ways in which people talk, or write, about their illness is affected by the social context in which they are approached. Some effects may relate to the physical presence of other people - otherwise, there would have been no demonstrable difference between ME focus group and internet chatline communications. Analysis suggests that the presence of other people may have influenced the extent to which participants oriented to issues of accountability.

The second category of difference between email and focus group correspondence relates to the oral/written distinction. Focus group responses to my questions could be analysed on a turn-by-turn basis, so that analytic findings could be verified by looking at participants' own uptake of what was said, and indeed this was often the initial starting point for analysis. Email correspondence was largely one-to-one; although much of the ME data were collected on a chatline, this was not done 'real time'. While participants knew that their responses would be available to all of the people on the mailing list, the dialogues that ensued tended to be around other subjects (discussed in the 70 or so emails a day that were posted) and were not therefore relevant to this research.

While oral dialogue can be examined for such things as hesitancy, repairs, changes in intonation and overlaps, written communication cannot. For example, when examining stroke sufferers' response to my question about what it is like having had a stroke at a young age, it was clear from pauses and hesitancy in the focus group

transcripts that providing an answer was in some ways problematic. However, the same conclusion was reached in my analysis of internet communication by means of respondents' direct claims about the suitability of their answers.

Some rhetorical devices were equally observable in email correspondence and focus group conversations. These included listing, extreme case formulations (Pomerantz, 1986), narrative accounts, vivid description, use of analogy and metaphor, appearance/reality formulations (Potter & Wetherell, 1989), contrast structures (Widdicombe & Wooffitt, 1995), active voicing (Wooffitt, 1992), reference to 'reliable witness' (Potter, 1996; Sacks, 1974; Sacks, 1979), and 'before and after' formulations.

Finally, some features of written responses were unique to that form of communication. For example, I noted the use of parentheses to introduce and draw attention to a claim (that stroke was not predictable and therefore potentially not preventable by the sufferer). In addition, line breaks were used to emphasise contrast structures and to delineate lists. Thus, we can see that internet communication can be modified to allow forms of expression that might otherwise be communicated, for example, by pauses or changes in intonation.

Data collected via the internet could, then, be analysed for many of the same devices and formulations as those collected in face-to-face discussions. An interesting feature is that emails have a different interactional context from face-to-face communication. The writer may correspond privately, on a one-to-one basis, or in a forum in which other people have access to everything that is written. Nettleton & Burrows (2003) note that social policy in the UK is currently directed towards the provision of internet facilities to a greater number of people, but that we do not yet know the impact this will have on issues such as communication and the dissemination of knowledge.

Other writers have also called for more research into the differences between face-to-face and written, delayed internet communication (Lamerichs & Molder, 2003; Sneijder & te Molder, 2004).

3. Evaluation of findings

This research has taken a social constructionist perspective, and adopted the methodology of discourse analysis to examine illness from the point of view of people with ME and people who have had stroke at a young age. Constructions of illness, its effects on identity and ways of coping have been explored. To date, most of the research into these conditions has been from the medical or the traditional psychological perspective. I have argued that these approaches are limited by their essentialist assumptions about the nature of illness, of identity and of the ways in which people cope. The aim of a discourse analytic approach is to give priority to participants' concerns as far as possible in order to broaden our understanding of how it is that people account for different aspects of their illness in the course of social interaction.

There is very little published research into either stroke or ME which takes a social constructionist perspective. In the general stroke literature, only one paper used a social constructionist (conversation analytic) perspective, exploring stroke sufferers' interactions in the home environment (Manzo, Blonder & Burns, 1995). In ME, only the work of Bland (1995), Horton-Salway (1998; 2001a; 2001b; 2004) and Tucker (2004) take a discourse analytic perspective. Bland's and Horton-Salway's (1998) studies are unpublished theses. Therefore, while they can be consulted in an academic library, they are not publicly available. Bland analyses interviews with 10 ME sufferers for descriptions of their illness. Horton-Salway analyses clinical case definitions of CFS and GPs' accounts of this condition, as well as one illness

narrative constructed by a sufferer and her husband. The same illness narrative is analysed in a later paper (Horton-Salway, 2001b), and in a book chapter, in which she also uses GPs' accounts of ME to illustrate the ways in which meaning is worked up in interaction (Horton-Salway, 2001a). In her most recent paper (Horton-Salway, 2004), she analyses data collected from one ME support group meeting and from an interview with a group member, in order to see how expertise and experience are locally produced in interaction. Tucker (2004) takes four illness narratives and analyses them to see how participants manage blame and accountability.

Thus, this study is unique in providing an insight into sufferers' own accounts of ME and early stroke, the effects it has on their identity and the ways in which they cope. It has taken their accounts as the focus of interest and has given a voice to groups of people who are not well represented in the literature. The use of discourse analytic techniques enabled an exploration of *how* it is that accounts are interactionally managed and the strategies that are used to defend or resist claims about the nature of illness, identity and coping.

Analysis showed that there were three key themes running through both the ME and stroke data. First, people in each group of sufferers oriented to accountability for the onset of their condition, and for its effects. Both ME and stroke participants oriented to the possibility that non-sufferers might not understand their illness. Second, identity in both groups was constructed as problematic, and discourse relating to change was, accordingly, sensitively managed. People with ME and people who had suffered stroke oriented to their accountability for the ways in which they coped with illness. Third, the interconnectedness between illness construction, identity and coping has been demonstrated. These common themes suggest that similar issues might arise for other people with chronic conditions, and that the findings of this study might potentially have a wider relevance.

Some of the analytic findings were specific to ME. It was constructed as a physical, and not a psychological or a psychiatric complaint. Sufferers' identity work and discourses of illness management oriented to this aspect of the illness construction, and therefore emphasised participants' physical incapacities, their pre-illness activity, and their current mental well-being. Discourse analysis allowed an exploration not just of *how* this was done, but also *why* it might be done. That is, the function of constructions was examined in context, and analysis went beyond the linguistic content of what was said or written. This provided the basis for a complex account of illness constructions and their possible relationship to current clinical definitions and treatments. The uncertain status of ME as a physical illness is significant in the ways in which sufferers construct their identity. This finding might be of some relevance to the study of other conditions whose cause is not clear, for example, 'Gulf War syndrome'.

An evaluation of findings must consider not only their place among other work, but also the question of validity. Wetherell, Taylor & Yates (2001) have noted that claims relating to validity should address issues such as logical coherence, the generation of novel perspectives and findings, plausibility and grounding in previous research. I will therefore consider each of these aspects in relation to this study. To begin with, I would argue that the finer detail of analysis is related to the broader analytic conclusions, and that these provide a coherent and logical account of the experience of ME and of stroke. I have noted above that this study adopts a novel perspective and an approach to the study of these conditions, and given this, the findings themselves are of interest. Extracts on which my analysis is based are reproduced in full in the body of the study, and are therefore open to critical examination for the plausibility of its findings. Finally, this study has examined theoretical, methodological and empirical literature in an effort to provide a context in which findings are located and judged.

4. Implications for theory

There are a number of theoretical implications arising from this study, and these are related to two aspects of the ways in which the person with chronic illness is conceptualised. First, we should consider the extent to which the experience of illness can be understood when the individual is viewed as an independent, cognitive entity. Second, we should consider the traditional categorisations of the mind and body. I will discuss these in turn.

4:1 The individual as an independent, cognitive entity

The traditional, cognitive approach to psychology assumes that the individual has, organised within the brain, schemas relating to the nature of illness, specifically its identity, causes, consequences, time-line and potential to be controlled. When a person becomes ill, he or she refers to such schemas, then adopts a coping strategy based upon them. Personality traits have been linked to the propensity to become ill in the first place, and to the type of coping style that is employed. There are obvious moral implications, then, for the person who is chronically ill. This study shows that people with ME and people who have had stroke at an early age do orient in interaction to the kinds of accountability that arise from having these conditions.

Theorists have suggested that the terminology of illness should reflect its effects on the individual, and on his or her relationships with others (Bury, 1988; Bury, 1991; Kleinman, 1988; Radley, 1994). This brings social factors to the fore. However, there is still an assumption that these effects can usefully be separated into the denoted categories. This research suggests that when people construct their illness, they do so in the context of their potential accountability to others. It is not, then, a simple matter to separate the 'individual' effects from the social. Thus, ME and stroke were not defined in accordance with cognitive schemas; rather, their constructions can be seen

as performative and therefore liable to change according to the local context. From the perspective adopted, such variability is a feature of all talk. I have shown, for example, that the clinical definitions of both stroke and ME have changed over time.

ME is particularly interesting because its meaning has been openly contested. This study suggests that participants construct ME, their identity as people with this condition, and the ways in which they cope precisely to counter potential claims that the origin of their fatigue is not physical, and that there may be some association with depression. Such claims can be seen as responses to the ways in which ME has been clinically defined. The traditional approach to sufferers' accounts is simply to take them at face value. Thus, when people with ME have stressed their previously active lifestyle, this has been used to support the theory that a perfectionist personality has brought about, or at the least exacerbated, their condition. Their avoidance of activity has been attributed to a faulty belief system. Thus, not only is the medical account privileged, it may play some role in the ways in which this illness has been constructed by sufferers and non-sufferers alike. This suggests that researchers, academics and clinicians should be aware of the possibility of reification of their theories, and of the likely implications. From the perspective taken in this study, what becomes important is not discovering the 'truth' of the matter, but allowing different accounts to be heard, and offering some interpretation of the processes at work. This should be done in the spirit of an ongoing debate in which people who are most affected are given a voice.

4:2 Categorisations of mind and body

Historically, the mind and body in chronic illness have been studied in the separate disciplines of psychology/psychiatry and medicine, and this had led to theories in which the two are somewhat dissociated. The biopsychosocial model represents an

attempt to adopt a more integrated approach in which the medical perspective is combined with the psychological and the social. I have argued above that categorisations of the individual and social effects of illness on the sufferer are not a simple reflection of the ways in which illness is experienced. Similarly, while the biopsychosocial model does attempt to be inclusive, it still treats the different elements as distinct. Furthermore, the clinical perspective is often privileged (Radley, 1994; Turner, 1992). Salmon & Hall note that "medical debate often disguises as scientific decisions ones that are morally or culturally determined" (Salmon & Hall, 2003: 21). From the perspective of this study, the medical account is, like any other, constructed. We have seen that research and clinical definitions of ME and stroke have both changed over time. Furthermore, the current state of knowledge about each of these conditions has been questioned.

This study suggests that to treat the effects of illness as separately affecting the mind and body can be problematic for people who suffer from each of the conditions discussed. This in turn suggests that the issue might be important for the ways in which we conceptualise chronic illness in general. For those with ME, the construction of their condition in terms of cognitive dysfunction locates responsibility for illness with the sufferer. That this construction might influence the ways in which sufferers experience their illness has been largely ignored. Similarly, the medical emphasis on functional rehabilitation in stroke casts the sufferer in an active role. This study suggests that such a position has to be sensitively managed, that functional incapacity can be accountable, and that sufferers' experience of the effects of stroke are wide-ranging.

5. Implications for practice

There has been some debate about the extent to which the findings of discourse analytic research can be applied in practice. Willig (1999) has noted three ways in which this might be done - as social critique, for empowerment and as a guide to reform. An exposition of the ways in which racism is worked up and managed in everyday talk could, for example, be offered up as a critique of social practices. People in less privileged groups might be empowered by the provision of a counter-discourse, or some knowledge of the kinds of discursive skills they might deploy in resistance. However, both social critique and empowerment strategies can be theoretically problematic from the perspective of this study. That is, there is an underlying assumption in this research that knowledge about the world can only be relative, and it is not therefore possible to suggest that one version of events is more accurate than another. It has been argued, though, that as social actors in the world, researchers can take a moral stand by supporting particular constructions (Shotter, 1992). In this study, I have shown that sufferers' constructions of ME and stroke and their effects have been given little attention in the research and I would argue that they therefore merit closer attention.

This leads us on to the possibility of using discourse analytic techniques to empower certain groups. We must then consider the extent to which the researcher can be seen as separate from the process of social construction. That is, the results of research might offer alternative perspectives, but they might also contribute to the production of a different set of disempowering discourses. Willig (*ibid*) provides as an example the ways in which the promotion of a discourse of pre-menstrual syndrome might be used to provide an account for episodes of violence, but then becomes available to medicalise women's behaviour in general. Thus, while it is important to examine sufferers' constructions of their illness and how it affects them, it is equally important

that analytic conclusions should not be viewed as a once-and-for-all representation of sufferers' experience.

The third way in which discourse analytic research can be applied in practice is as a guide to reform. There are two strategies that are relevant here. The first is that discourse analysis can provide a space for telling versions of events that are not normally heard. The second is that it can be used to encourage people to reflect on the discourses that they and others use.

With the above points in mind, I will now consider the possible practical applications of the findings of this study. Harper (1999) proposes the concept of 'usefulness' as a guide for assessing discourse analytic findings. This is not restricted to the development of novel technologies, but also encompasses the idea that research might lead to a richer understanding and to socially desirable outcomes. I will therefore end this section with a discussion of the ways in which this study might be useful, in these terms, to the following groups - sufferers, healthcare professionals and carers.

People with ME might benefit from having some awareness of the possible impact of their illness constructions on others. If, for example, their intention is to stress the serious, physical nature of their condition, it might be useful to know that accounts in which previous activities and current symptoms are listed can in fact work to suggest that their illness might be self-inflicted and stem from some kind of cognitive dysfunction. This information might be of particular practical value to sufferers who need to provide a valid case for access to Disability Living Allowance. Hammond (2002) demonstrates the particular problems that arise here for people with ME. Bülow & Hydén's (2003) discussion of an ME patient school suggests that a key benefit is that it facilitates participants' 'discursive management' of their condition. By

being exposed to others' views of their illness, patients were in a better position to deal with 'meanings at risk'.

People who have suffered stroke at a young age might be interested to see how the medical account of illness is privileged and that they can deploy this as an effective way of dealing with their accountability. In general, then, if sufferers have some insight into the kinds of processes at work then they can strategically use them to their advantage in problematic interactions.

Healthcare professionals might benefit from an awareness of their part in the construction of illness. For example, some insight into the ways in which sufferers' constructions of ME might have been influenced by medical definitions might encourage practitioners to be more reflective in their interactions with sufferers. Listening not only for the content of what is said, but also its possible function, might lead to a situation in which the patients and clinicians are not diametrically opposed. This could open up the possibility of a more productive level of communication, and more successful management of illness. Similarly, if more account were taken of stroke sufferers' concerns, which go beyond the ability to perform functional tasks, this would result in a better level of care for these people.

Carers might benefit from having some understanding of the importance of non-sufferers' interactions - that is, not just their own - in the ways in which illness is constructed and made accountable. This may help carers to gain some understanding of the experiences of the people they are looking after, and make it easier to empathise. Some insight into the notion of social construction might help carers to see how people are ill in a social context, and that carers themselves manage that situation in a social context. This may help to diffuse notions of accountability and blame.

6. Summary

This study has examined constructions of illness, its effects on identity and ways of coping in people with ME and those who have had stroke at a young age. The findings of this study have important implications for research into these conditions, and in particular point up some of the issues that might stem from the source of data gathered. They also suggest areas of interest for the study of chronic illnesses in general. Furthermore, this research has the potential to be of practical use to sufferers, healthcare professionals, and carers.

It is crucial to pay attention to the accounts of people who suffer chronic illness. In the case of ME, diagnosis is made, and treatment has been developed, on the basis of what the sufferer *says* about his or her illness. In the case of stroke, the importance of exploring illness from the sufferers' perspective has been noted by the World Health Organisation (1995), which also stated that management should in future be focused on priorities of those who have *experienced* stroke. This research has provided a valuable and rare insight into the ways in which people with ME, and people who have suffered stroke, make sense of their illness.

REFERENCES

- Afari, N., Schmaling, K. B., Herrell, R., Hartman, S., Goldberg, J., & Buchwald, D. S. (2000). Coping strategies in twins with chronic fatigue and chronic fatigue syndrome. Journal of Psychosomatic Research, 48(6), 547-554.
- Antaki, C., & Widdicombe, S. (1998a). Identities in talk. London: Sage.
- Antaki, C., & Widdicombe, S. (1998b). Identity as an achievement and as a tool. In C. Antaki & S. Widdicombe (Eds.), Identities in talk (pp. 1-14). London: Sage.
- Armstrong, D. (1983). Political anatomy of the body: Medical knowledge in Britain in the twentieth century. Cambridge: Cambridge University Press.
- Atkinson, J. M., & Heritage, J. (Eds.). (1984). Structures of social action: Studies in conversation analysis. Cambridge: Cambridge University Press.
- Austin, J. (1961). A plea for excuses. In J. D. Urmson & G. Warnock (Eds.), Philosophical papers. Oxford: Clarendon Press.
- Austin, J. L. (1962). How to do things with words. Oxford: Clarendon Press.
- Barthes, R. (1977). Mythologies. London: Paladin.
- Beard, G. M. (1869). Neurasthenia, or nervous exhaustion. Boston Medical & Surgical Journal, 3, 217.
- Becker, G. (1993). Continuity after a stroke: Implications of lifecourse disruption in old age. The Gerontologist, 33, 148-158.
- Bendz, M. (2000). Rules of relevance after a stroke. Social Science & Medicine, 51, 713-723.
- Benner, P., Janson-Bjerklie, S., Ferketich, S., & Becker, G. (1994). Moral dimensions of living with a chronic illness. In P. Benner (Ed.), Interpretative Phenomenology: Embodiment, Caring and Ethics in Health and Illness. London: Sage.
- Bentall, R. P., Powell, P., Nye, F. J., & Edwards, R. H. T. (2002). Predictors of response to treatment for chronic fatigue syndrome. British Journal of Psychiatry, 181, 1248-151.
- Berger, P., & Luckmann, T. (1966). The social construction of reality: A treatise in the sociology of knowledge. New York: Doubleday & Co.
- Bhogal, S. K., Teasell, R., Foley, N., & Speechley, M. (2004). Lesion location and poststroke depression: Systematic review of the methodological limitations in the literature. Stroke, 35(3), 794-802.
- Billig, M. (1987). Arguing and thinking: A rhetorical approach to social psychology. Cambridge: Cambridge University Press.
- Bland, N. (1995). Telling tales of the unaccepted: Conversation analysis of accounts of ME. Unpublished MSc, University of Surrey.
- Bowker, N., & Tuffin, K. (2004). Using the online medium for discursive research about people with disabilities. Social Science Computer Review, 22(2), 228-241.
- Bülow, P. H., & Hydén, L.-C. (2003). Patient school as a way of creating meaning in a contested illness: The case of CFS. Health: An Interdisciplinary Journal for the Social Study of Health, Illness & Medicine, 7(2), 227-249.
- Burkitt, I. (1999). Bodies of thought: Embodiment, identity and modernity. London: Sage.

- Bury, M. (1982). Chronic illness as biographical disruption. Sociology of Health and Illness, 4, 167-182.
- Bury, M. (1988). Meanings at risk: The experience of arthritis. In R. Anderson & M. Bury (Eds.), Living with Chronic Illness: the Experience of Patients and their Families. London: Unwin Hyman.
- Bury, M. (1991). The sociology of chronic illness: A review of research and prospects. Sociology of Health and Illness, 13(4), 451-468.
- Bury, M. (1997). Health and illness in a changing society. London: Routledge.
- Campion, P. (1998). Report on NHS Services for people with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: The National Task Force on CFS/ME.
- Campling, F., & Sharpe, M. (2000). Chronic fatigue syndrome: The facts. Oxford: Oxford University Press.
- Chafe, W., & Danielewicz, J. (1987). Properties of spoken and written language. In R. Horowitz & S. J. Samuels (Eds.), Comprehending oral and written language. San Diego: Academic Press.
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. Sociology of Health and Illness, 5, 168-195.
- Charmaz, K. (1987). Struggling for a self: Identity levels of the chronically ill. In J. A. Roth & P. Conrad (Eds.), Research in the Sociology of Health Care: The Experience and Management of Chronic Illness (Vol. 6,). Greenwich, Connecticut: JAI Press Inc.
- Charmaz, K. (2000). Experiencing chronic illness. In G. L. Albrecht, R. Fitzpatrick, & S. C. Scrimshaw (Eds.), Handbook of social studies in health and medicine (pp. 277-292). London: Sage.
- Clarke, J. N. (2000). The search for legitimacy and the 'expertization' of the lay person: The case of chronic fatigue syndrome. Social Work in Health Care, 30(3), 73-93.
- Clayman, S. E., & Maynard, D. W. (1995). Ethnomethodology and conversation analysis. In P. ten Have & G. Psathas (Eds.), Situated order: Studies in the social organization of talk and embodied activities (pp. 1-30). Washington DC: University Press of America.
- Cohn, S. (1999). Taking time to smell the roses: Accounts of people with chronic fatigue syndrome and their struggle for legitimisation. Anthropology & Medicine, 6(2), 195-215.
- Cooper, L. (1997). Myalgic encephalomyelitis and the medical encounter. Sociology of Health & Illness, 19(2), 186-207.
- Coppola, W. G. T., Whincup, P. H., Papacosta, O., Walker, M., & Ebrahim, S. (1995). Scoring system to identify men at high risk of stroke: A strategy for general practice. British Journal of General Practice, 45, 185-189.
- Corbin, J., & Strauss, A. (1985). Managing chronic illness at home: Three lines of work. Qualitative Sociology, 8(3), 224-247.
- Corbin, J., & Strauss, A. L. (1987). Accompaniments of chronic illness: Changes in body, self, biography and biographical time. In J. A. Roth & P. Conrad (Eds.), Research in the Sociology of Health Care: The Experience and Management of Chronic Illness (Vol. 6,). Greenwich, Connecticut: JAI Press.
- Cowan, S. (1997). Views on community care for people with mental health problems. Unpublished PhD, University of Edinburgh, Edinburgh.
- Cresswell, C., & Chalder, T. (2001). Defensive coping styles in chronic fatigue syndrome. Journal of Psychosomatic Research, 51(4), 607-610.
- Crowley, N., Nelson, M., & Stovin, S. (1955). Epidemiological aspects of an outbreak of encephalomyelitis at the Royal Free Hospital, London, in the summer of 1955. Journal of Hygiene, 55, 102-122.
- David, A. S. (1991). Postviral fatigue syndrome and psychiatry. British Medical Bulletin, 47(4), 966-988.

- Dendy, C., Cooper, M., & Sharpe, M. (2001). Interpretation of symptoms in chronic fatigue syndrome. Behaviour Research & Therapy, 39(11), 1369-1380.
- Derrida, J. (1976). Of grammatology. Baltimore, MD: John Hopkin Press.
- Dingwall, R. (1976). Aspects of illness. London: Martin Robertson.
- Doolittle, N. (1994). A clinical ethnography of stroke recovery. In P. Benner (Ed.), Interpretative Phenomenology: Embodiment, Caring and Ethics in Health and Illness (pp. 211-223). London: Sage.
- Drew, P. (1987). Po-faced receipts of teases. Linguistics, 25, 219-253.
- Drew, P., & Holt, E. (1989). 'Complainable matters: The use of idiomatic expressions in making complaints. Social Problems, 35, 398-417.
- Drew, P., & Holt, E. (1998). Figures of speech: Idiomatic expressions and the management of topic transition in conversation. Language in Society, 27, 495-522.
- Ebrahim, S. (1990). Clinical epidemiology of stroke. New York: Oxford University Press.
- Edwards, D. (1997). Discourse and cognition. London: Sage.
- Edwards, D. (2000). Extreme case formulations: Softeners, investment, and doing nonliteral. Research on Language and Social Interaction, 33(4), 347-373.
- Edwards, D., & Potter, J. (1992). Discursive psychology. London: Sage.
- Eichner, E. (1989). Chronic fatigue syndrome: How vulnerable are athletes? Physician & Sports Medicine, 16, 157-160.
- Ellis-Hill, C. S. (1998). New world, new rules: Life narratives and changes in self concept in the first year after stroke. Unpublished PhD, University of Southampton, Southampton.
- Ellis-Hill, C. S., Payne, S., & Ward, C. (2000). Self-body split: Issues of identity in physical recovery following a stroke. Disability & Rehabilitation, 22(16), 725-733.
- Fernback, J. (2003). Legends on the net: An examination of computer-mediated communication as a locus of oral culture. New Media & Society, 5(1), 29-45.
- Finset, A., & Andersson, S. (2000). Coping strategies in patients with acquired brain injury: Relationships between coping, apathy, depression and lesion location. Brain Injury, 14(10), 887-905.
- Foucault, (1976). The birth of the clinic: An archaeology of medical perception. London: Tavistock.
- Foucault, M. (1972). The archaeology of knowledge. London: Tavistock.
- Frank, A. W. (1991). For a sociology of the body: An analytical review. In M. Featherstone, B. Hepworth, & B. Turner (Eds.), The Body: Social Process and Cultural Theory. London: Sage.
- Frank, A. W. (1998). From disappearance to hyperappearance: Sliding boundaries of illness and bodies. In H. J. Stam (Ed.), The Body and Psychology (pp. 205-232). London: Sage.
- Freidson, E. (1970). Profession of medicine: A study of the sociology of applied knowledge. New York: Harper Row.
- Freudenberger, H. J., & Richelson, G. (1980). Burn-out: The high cost of high achievement. New York: Anchor.
- Fukuda, K., Straus, S. E., Hickie, I., Sharpe, M. C., Dobbins, J. G., Komaroff, A., & Group, International Chronic Fatigue Syndrome Study Group (1994). The chronic fatigue syndrome: A comprehensive approach to its definition and study. Annals of Internal Medicine, 121(12), 953-959.
- Gadow, S. (1982). Body and self: A dialectic. In V. Kestenbaum (Ed.), The Humanity of the Ill. Knoxville: University of Tennessee Press.
- Garfinkel, H. (1967). Studies in ethnomethodology. Englewood Cliffs: Prentice Hall.

- Garfinkel, H., & Sacks, H. (1970). On formal structures of practical action. In J. C. McKinney & E. A. Tiryakian (Eds.), Theoretical sociology: Perspectives and developments (pp. 337-366). New York: Appleton-Century-Crofts
- Gauggel, S., Pelaska, B., & Bode, R. K. (2000). Relationship between cognitive impairments and rated activity restrictions in stroke patients. Journal of Head Trauma Rehabilitation, 15(1), 710-723.
- Gergen, K. J. (1985). The social constructionist movement in modern psychology. American Psychologist, 40, 266-275.
- Gergen, K. J. (1989). Warranting voice and the elaboration of the self. In J. Shotter & K. J. Gergen (Eds.), Texts of identity (pp. 70-81). London: Sage.
- Gibson, J. J. (1979). The ecological approach to perception. London: Houghton Mifflin.
- Giddens, A. (1979). Central problems in social theory. London: Macmillan.
- Gilbert, G. N., & Mulkay, M. (1984). Opening Pandora's box: A sociological analysis of scientists' discourse. Cambridge: Cambridge University Press.
- Gilliam, (1938). Epidemiologic study of an epidemic, diagnosed as poliomyelitis, occurring among the personnel of the Los Angeles County General Hospital during the summer of 1934. Public Health Bulletin, 240, 1-90.
- Glass, T. A., & Maddox, G. L. (1992). The quality and quantity of social support: Stroke recovery as psycho-social transition. Social Science & Medicine, 34, 1249-1261.
- Goffman, E. (1959). The presentation of self in everyday life. New York: Doubleday
- Goffman, E. (1963). Stigma: Notes on the management of spoiled identity. London: Penguin.
- Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. Psychology and Health, 18(2), 141-184.
- Halligan, P. W., & Cockburn, J. (1993). Cognitive sequelae of stroke: Visuo-spatial and memory disorders. Critical Reviews in Physical & Rehabilitation Medicine, 5, 57-81.
- Hammond, C. (2002). A poorly understood condition: Disability living allowance and people with CFS/ME. Social Policy & Administration, 36(3), 254-274.
- Hardey, M. (1999). Doctor in the house: The internet as a source of lay health knowledge and the challenge of expertise. Sociology of Health & Illness, 21(6), 820-835.
- Hardey, M. (2002). 'The story of my illness': Personal accounts of illness on the internet. Health: An Interdisciplinary Journal for the Social Study of Health, Illness & Medicine, 6(1), 31-46.
- Harper, D. (1999). Tablet talk and depot discourse: Discourse analysis and psychiatric medication. In C. Willig (Ed.), Applied discourse analysis: Social and psychological interventions (pp. 125-144). Buckingham: Open University Press.
- Harré, R. (1983). Identity projects. In G. M. Breakwell (Ed.), Threatened identities (pp. 271). Chichester: John Wiley.
- Harré, R. (1985). The language game of self-ascription: A note. In K. J. Gergen & K. E. Davis (Eds.), The social construction of the person (pp. 259-263). New York: Springer-Verlag.
- Heritage, J. (1984a). A change-of-state token and aspect of its sequential placement. In M. Atkinson & J. Heritage (Eds.), Structures of social action: Studies in conversation analysis (pp. 299-345). Cambridge: Cambridge University Press.
- Heritage, J. (1984b). Garfinkel and ethnomethodology. Cambridge: Polity Press.
- Heritage, J., & Atkinson, J. M. (1984). Introduction. In J. Heritage & J. M. Atkinson (Eds.), Structures of social action: Studies in conversation analysis (pp. 1-15). Cambridge: Cambridge University Press.

- Herzlich, C. (1973). Health and illness: A social psychological analysis (Graham, D, Trans.). London: Academic Press.
- Herzlich, C., & Pierret, J. (1987). Illness and self in society. Baltimore: John Hopkins University Press.
- Hollway, W. (1984). Gender difference and the production of subjectivity. In J. Henriques, W. Hollway, C. Urwin, C. Venn, & V. Walkerdine (Eds.), Changing the subject. London: Methuen.
- Holmes, G. P., Kaplan, J. E., Gantz, N. M., Komaroff, A. L., Schonberger, L. B., Straus, S. E., Jones, J. F., Dubois, R. E., Cunningham-Rundlls, C., Pahwa, S., Tosato, G., Zegans, L. S., Purtilo, D. T., Brown, N., Schooley, R. T., & Brus, I. (1988). Chronic fatigue syndrome: A working case definition. Annals of Internal Medicine, 108, 387-389.
- Holmes, T. S., & Rahe, T. H. (1967). The social readjustment rating scale. Journal of Psychosomatic Research, 11, 231-218.
- Horton. (1996). Frustrating survey of chronic fatigue. Lancet, 348(9033), 971.
- Horton-Salway, M. (2004). The local production of knowledge: Disease labels, identities and category entitlements in ME support group talk. Health: An Interdisciplinary Journal for the Social Study of Health, Illness & Medicine, 8(3), 351-371.
- Horton-Salway. (1998). Mind and body in the discursive construction of ME: A struggle for authorship of an illness. Unpublished PhD, Loughborough University.
- Horton-Salway, M. (2001a). The construction of ME: The discursive action model. In M. Wetherell, S. Taylor, & S. J. Yates (Eds.), Discourse as data: A guide for analysis (pp. 147-188). London: Sage.
- Horton-Salway, M. (2001b). Narrative identities and the management of personal accountability in talk about ME: A discursive psychology approach to illness narrative. Journal of Health Psychology, 6(2), 247-259.
- Hutchby, I. (2001a). Conversation and technology: From the telephone to the internet. Cambridge: Polity.
- Hutchby, I. (2001b). Technologies, texts and affordances. Sociology, 35(2), 441-456.
- Hutchby, I., & Wooffitt, R. (1998). Conversation analysis: Principles, practices and applications. Cambridge: Polity.
- Jason, L. A., Eisels, H., & Taylor, R. R. (2001). Assessing attitudes toward new names for chronic fatigue syndrome. Evaluation & the Health Professions, 24(4), 424-435.
- Jason, L. A., Taylor, R. R., Plioplys, S., Stepanek, Z., & Shlaes, J. (2002). Evaluating attributions for an illness based upon the name: Chronic fatigue syndrome, myalgic encephalopathy and Florence Nightingale disease. American Journal of Community Psychology, 30(1), 133-148.
- Jefferson, G. (1989). Preliminary notes on a possible metric which provides for a 'standard maximum' silence of approximately one second in conversation. In D. Roger & P. Bull (Eds.), Conversation: An interdisciplinary perspective. Clevedon: Multilingual Matters.
- Jefferson, G. (1991). List construction as a task and resource. In G. Psathas & R. Frankel (Eds.), Interactional competence (pp. 63-92). Washington DC: International Institute for Ethnomethodology and Conversation Analysis & University Press of America.
- Jewson, N. (1976). The disappearance of the sick man from medical cosmology 1770-1870. Sociology, 10, 225-244.
- Johnston, M., Morrison, V., Macwalter, R., & Partridge, C. (1999). Perceived control, coping and recovery from disability following stroke. Psychology & Health, 14, 181-366.

- Katon, W., & Russo, J. (1992). Chronic fatigue syndrome criteria: A critique of the requirement for multiple physical complaints. Archives of Internal Medicine, 152, 1604-1616.
- Kaufman, S. (1988). Stroke rehabilitation and the negotiation of identity. In S. Reinharz & G. D. Rowles (Eds.), Qualitative Gerontology (pp. 82-103). New York: Springer Publishing Company.
- Kaufman, S. R., & Becker, G. (1986). Stroke: Health care on the periphery. Social Science & Medicine, 22(9), 983-989.
- Keppel, C. C., & Crowe, S. F. (2000). Changes to body image and self-esteem following stroke in young adults. Neuropsychological Rehabilitation, 10(1), 15-31.
- Kirkevold, M. (2002). The unfolding illness trajectory of stroke. Disability & Rehabilitation, 24(17), 887-898.
- Kirmayer, L. J., & Robbins, J. M. (1991). Conclusion: Prospects for research and clinical practice. In L. J. Kirmayer & J. M. Robbins (Eds.), Current concepts of somatization: research and clinical perspectives (pp. 201-225). Washington DC: American Psychiatric Press.
- Kitzinger, J. (1994). The methodology of focus groups: The importance of interaction between research participants. Sociology of Health and Illness, 16(1), 103-121.
- Kitzinger, J. (1995). Qualitative research: Introducing focus groups. British Medical Journal, 311(7000), 299-302.
- Kitzinger, J., & Barbour, R. S. (1999). Introduction: The challenge and promise of focus groups. In R. S. Barbour & J. Kitzinger (Eds.), Developing focus group research: Politics, theory and practice (pp. 1-20). London: Sage.
- Kitzinger, J., & Farquhar, C. (1999). The analytical potential of 'sensitive moments' in focus group discussions. In R. S. Barbour & J. Kitzinger (Eds.), Developing focus group research: Politics, theory and practice (pp. 156-172). London: Sage.
- Kleinman, A. (1988). The illness narratives: Suffering, healing and the human condition. New York: Basic Books.
- Komaroff, A. L., & Buchwald, D. S. (1998). Chronic fatigue syndrome: An update. Annual Review of Medicine, 49, 1-13.
- Kremer, R., & Quednau, K. (2002a). Coping activities of stroke patients: Intensity and effectiveness. Psychotherapie Psychosomatik Medizinische Psychologie, 52(2), 70-76.
- Kremer, R., & Quednau, K. (2002b). Influence of coping activities on 'activities of daily living': A cross-sectional and a longitudinal study on stroke patients. Aktuelle Neurologie, 29(1), 30-35.
- Lamerichs, J., & Molder, H. F. M. (2003). Computer-mediated communication: From a cognitive to a discursive model. New Media & Society, 5(4), 451-473.
- Langhammer, B., & Stanghelle, J. K. (2003). Bobath or motor relearning programme? A follow-up one and four years post stroke. Clinical Rehabilitation, 17(7), 731-734.
- Lau, R. R. (1995). Cognitive representations of health and illness. In D. Gochman (Ed.), Handbook of Health Behavior Research (Vol. 1,). New York: Plenum.
- Lawrie, S. M., & Pelosi, A. J. (1995). Chronic fatigue syndrome in the community: Prevalence and associations. British Journal of Psychiatry, 166, 793-797.
- Leder, D. (1990). The body in medical thought and practice. London: Kluwer Academic Publishers.
- Lee, D. (1987). The semantics of just. Journal of pragmatics, 11, 377-398.
- Leventhal, H., & Benyamini, Y. (1997). Lay beliefs about health and illness. In A. Baum, S. Newman, J. Weinman, R. West, & C. McManus (Eds.), Cambridge

- handbook of psychology, health and medicine (pp. 131-134). Cambridge: Cambridge University Press.
- Leventhal, H., Benyamini, Y., S. B., & al, e. (1997). Illness representations: Theoretical foundations. In K. J. Petrie & J. A. Weinman (Eds.), Perceptions of Health and Illness (pp. 1-18). Amsterdam: Harwood.
- Levine, P., Wessely, S., Hotoph, M., & Sharpe, M. (1999). Chronic fatigue and its syndromes. Psychological Medicine, 29(4), 1006.
- Levine, P. H. (1997). Epidemiologic advances in chronic fatigue syndrome. Journal of Psychiatric Research, 31(1), 7-18.
- Lupton, D. (1994). Medicine as culture: Illness, disease and the body in western societies. London: Sage.
- Manzo, J. F., Blonder, L. X., & Burns, A. F. (1995). The social-interactive organisation of narrative and narrating among stroke patients and their spouses. Sociology of Health & Illness, 17(3), 307-327.
- Mayo, N. E., Wood-Dauphinee, S., Ahmed, S., Gordon, C., Higgins, J., McEwen, S., & Salbach, N. (2004). Disablement following stroke. Disability & Rehabilitation, 21(5), 258-268.
- McEvedy, C. P., & Beard, A. W. (1970). Royal Free epidemic of 1955: A reconsideration. British Medical Journal, 1, 7-11.
- Mechanic, D. (1977). Illness behaviour, social adaptation, and the management of illness. Journal of Nervous and Mental Disease, 165, 79-87.
- Medical Staff of the Royal Free Hospital. (1955). An outbreak of encephalomyelitis in the Royal Free Hospital Group, London, in 1955. British Medical Journal, 19, 895-904.
- Merleau-Ponty, M. (1963). Phenomenology of perception. London: Routledge & Kegan Paul.
- Metzger, F. A., & Denney, D. R. (2002). Perception of cognitive performance in patients with chronic fatigue syndrome. Annals of Behavioural Medicine, 24(2), 106-112.
- Moos, R. H., & Schaefer, J. A. (1984). The crisis of physical illness: An overview and conceptual approach. In R. H. Moos (Ed.), Coping with Physical Illness: New Perspectives (Vol. 2, pp. 3-25). New York: Plenum.
- Murphy, R. F. (1987). The body silent. New York: Henry Holt.
- Nettleton, S., & Burrows, R. (2003). E-scaped medicine? Information, reflexivity and health. Critical Social Policy, 23(2), 165-185.
- Nilsson, I., Jansson, L., & Norberg, A. (1997). To meet with a stroke: Patients' experiences and aspects seen through a screen of crises. Journal of Advanced Nursing, 25, 953-963.
- Nogueira-Antunano, F., Nogueira-Bonanata, G. J., & Pla-Gaspari, G. B. (2003). An exploratory study of the relation between cerebrovascular accidents and personality structures. Revista de Neurologia, 36(9), 821-828.
- Ochs, E. (1979). Transcription as theory. In E. Ochs & B. B. Schieffelin (Eds.), Development pragmatics (pp. 43-72). New York: Academic Press.
- Ogden, J. (2000). Health psychology: A textbook. Buckingham: Open University Press.
- Parker, I. (1989). Discourse and power. In J. Shotter & K. J. Gergen (Eds.), Texts of identity. London: Sage.
- Parker, I. (1992). Discourse dynamics: Critical analysis for social and individual psychology. London: Routledge.
- Parker, I., & Burman, E. (1993). Against discursive imperialism, empiricism and constructionism: Thirty-two problems with discourse analysis. In E. Burman & I. Parker (Eds.), Discourse analytic research: Repertoires and readings of text in action. London: Routledge.
- Parsons, T. (1951). The social system. Glencoe, Illinois: Free Press.

- Partridge, C. J., & Johnston, M. (1989). Perceived control and recovery from physical disability. British Journal of Clinical Psychology, 28, 53-60.
- Pearlin, L. I. (1989). The sociological study of stress. Journal of Health and Social Behavior, 30, 241-256.
- Penley, J. A., Tomaka, J., & Wiebe, J. S. (2002). The association of coping to physical and psychological health outcomes: A meta-analytic review. Journal of Behavioural Medicine, 25(6), 551-603.
- Pimm, T. J. (1997). Stroke. In A. Baum, S. Newman, J. Weinman, R. West, & C. McManus (Eds.), Cambridge Handbook of Psychology, Health & Medicine (pp. 597-600). Cambridge: Cambridge University Press.
- Pizzigallo, E., Racciatti, D., & Vecchiet, J. (1999). Clinical and pathophysiological aspects of chronic fatigue syndrome. Journal of Musculoskeletal Pain, 7(1-2), 217-224.
- Plessner, H. (1970). Laughing and crying: A study of the limits of human behavior. Evanston, Illinois: Northwestern University Press.
- Pollock, K. (1988). On the nature of social stress: Production of a modern mythology. Social Science and Medicine, 26, 381-392.
- Pollock, K. (1993). Attitude of mind as a means of resisting illness. In A. Radley (Ed.), Worlds of Illness: Biographical and Cultural Perspectives on Health and Disease (pp. 49-70). London: Routledge.
- Pomerantz, (1986). Extreme case formulations: A way of legitimizing claims. Human Studies, 9, 219-230.
- Pomerantz, A. (1984). Agreeing and disagreeing with assessments: Some features of preferred/dispreferred turn-shapes. In J. M. Atkinson & J. Heritage (Eds.), Structures of social action: Studies in conversation analysis. Cambridge: Cambridge University Press.
- Potter, J. (1996a). Attitudes, social representations and discursive psychology. In M. Wetherell (Ed.), Identities, groups and social issues (pp. 119-174). London: Sage.
- Potter, J. (1996b). Representing reality: Discourse, rhetoric and social construction. London: Sage.
- Potter, J. (1997). Discursive social psychology: From attitudes to evaluative practices. European Review of Social Psychology, 1-25.
- Potter, J., Gill, R., Edwards, D., & Wetherell, M. (1990). Discourse: Noun, verb or social practice? Philosophical Psychology, 3(2), 205-217.
- Potter, J., & Wetherell, M. (1987). Discourse and social psychology: Beyond attitudes and behaviour. London: Sage.
- Potter, J., & Wetherell, M. (1989). Fragmented ideologies: Accounts of educational failure and positive discrimination. Text, 9(2), 175-190.
- Pound, P., Bury, M., & Ebrahim, S. (1997). From apoplexy to stroke. Age & Ageing, 26, 331-337.
- Pound, P., Gompertz, P., & Ebrahim, S. (1998). A patient-centred study of the consequences of stroke. Clinical Rehabilitation, 12, 338-347.
- Psathas, G., & Anderson, T. (1990). The 'practices' of transcription in conversation analysis. Semiotica, 78, 75-79.
- Radley, A. (1994). Making sense of illness: The social psychology of health and disease. London: Sage.
- Radley, A., & Billig, M. (1996). Accounts of health and illness: Dilemmas and representations. Sociology of Health & Illness, 18(2), 220-240.
- Ranjith, G. (2003). Personal communication.
- Ridsdale, L., Darbishire, L., & Seed, P. T. (2004). Is graded exercise better than cognitive behaviour therapy for fatigue? A UK randomized trial in primary care. Psychological Medicine, 34(1), 37-49.
- Ridsdale, L., Godfrey, E., Chalder, T., Seed, P., King, M., Wallace, P., & Wessely, S. (2001). Chronic fatigue in general practice: Is counselling as good as

cognitive behaviour therapy? A UK randomised trial. British Journal of General Practice, 51(462), 19-24.

Riessman, C. K. (1990). Strategic uses of narrative in the presentation of self and illness: A research note. Social Science & Medicine, 30(11), 1195-1200.

Riley, M., O'Brien, C., McCluskey, D., Bell, N., & Nicholls, D. (1990). Aerobic work capacity in patients with chronic fatigue syndrome. British Medical Journal, 301, 953-956.

Rogers. (1991). Explaining health and illness: An exploration of diversity. London: Harvester Wheatsheaf.

Rosenman, R. H., & Friedman, M. (1974). Neurogenic factors in pathogenesis of coronary heart disease. Medical Clinics of North America, 58, 269-279.

Royal College of Physicians. (1996). 'Chronic Fatigue Syndrome: Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners (CR54). London: Royal College of Physicians.

Rutter, D. R. (1984). Looking and seeing: The role of visual communication in social interaction. London: Wiley.

Sacks, H. (1979). Hotrodder: A revolutionary category. In G. Psathas (Ed.), Everyday Language: studies in ethnomethodology. New York: Irvington Publishers Inc.

Sacks, H. (1984). On doing 'being ordinary'. In M. Atkinson & J. Heritage (Eds.), Structures of social action: Studies in conversation analysis (pp. 413-429). Cambridge: Cambridge University Press.

Sacks, H. (1992). Lecture 1: Rules of conversational sequence. In G. Jefferson (Ed.), H Sacks: Lectures on conversation (Vol. 1,). Oxford: Blackwell.

Sacks, H., Schegloff, E., & Jefferson, G. (1978). A simplest systematics for the organization of turn-taking for conversation. In J. Schenkein (Ed.), Studies in the organization of conversational interaction (pp. 7-55). New York: Academic Press.

Sacks, H., Schegloff, E. A., & Jefferson, G. A. (1974). A simple systematics for the organization of turn-taking in conversation. Language, 50(697-735).

Sacco, R. L. (2004). Risk factors for TIA and TIA as risk factor for stroke. Neurology, 62(8), S7-11.

Salmon, P., & Hall, G. M. (2003). Patient empowerment and control: A psychological discourse in the service of medicine. Social Science & Medicine, 57(10), 1969-1980.

Sapir, E. (1947). Selected writings in language, culture and personality. Los Angeles: University of California Press.

Saussure, F. d. (1974). Course in general linguistics. London: Fontana.

Schegloff, E. A. (1992). In another context. In A. Duranti & C. Goodwin (Eds.), Rethinking context. Cambridge: Cambridge University Press.

Schegloff, E. A. (1996). Confirming allusions. American Journal of Sociology, 104, 161-216.

Schluederberg, A., Straus, S. E., Peterson, P., Blumenthal, S., Komaroff, A. L., Spring, S. B., Landay, A., & Buchwald, D. (1992). Chronic fatigue syndrome research: Definition and medical outcome assessment. Annals of Internal Medicine, 117(4), 325-331.

Scott, P. (1997). The crisis of knowledge and the massification of higher education. In R. Barnett & A. Griffin (Eds.), The end of knowledge in higher education (pp. 1-15). London: Cassell.

Sharpe, M. (1991). Psychiatric management of PVFS. British Medical Bulletin, 47(4), 989-105.

Sharpe, M., Hawton, K., Simkin, S., Surawy, C., Hackmann, A., Klimes, I., Peto, T., Warrell, D., & Seagrott, V. (1996). Cognitive behaviour therapy for the chronic fatigue syndrome: A randomised, controlled trial. British Medical Journal, 312(7022), 22-26.

Sharpe, M. C. (1996). Cognitive-behavioral therapy for patients with chronic fatigue syndrome: How? In M. A. Demitrack & S. E. Abbey (Eds.), Chronic fatigue syndrome: An integrative approach to evaluation and treatment. New York: The Guilford Press.

Sharpe, M. C., Archard, L. C., Banatvala, J. E., Borysiewicz, L. K., Clare, E. W., David, A., Edwards, R. H. T., Hawton, K. E. H., Lambert, H. P., Lane, R. J. M., McDonald, E. M., Mowbray, J. F., Pearson, D. J., Peto, T. E. A., Preedy, V. R., Smith, A. P., Smith, D. G., Taylor, D. J., Tyrell, D. A. J., Wessely, S., White, P., Behan, P. O., Rose, F. C., Peters, T. J., Wallace, P. G., Warrell, D. A., & Wright, D. J. M. (1991). A report - chronic fatigue syndrome: Guidelines for research. Journal of the Royal Society of Medicine, 84, 118-121.

Shilling, C. (1993). The body and social theory. London: Sage.

Short, J., Williams, E., & Christie, B. (1976). The social psychology of telecommunications. London: Wiley.

Shontz, F. C. (1975). The psychological aspects of physical illness and disability. New York: Macmillan Co.

Shotter, J. (1992). Social constructionism and realism: Adequacy or accuracy? Theory and Psychology, 2(2), 175-182.

Shotter, J. (1993). Conversational realities. London: Sage.

Shotter, J. (1981). Telling and reporting: Prospective and retrospective uses of self-ascriptions. In C. Antaki (Ed.), The psychology of ordinary explanations of social behaviour (23 ed.,). London: Academic Press.

Silver, A., Haeney, M., Vijayadurai, P., Wilks, D., Patrick, M., & Main, C. J. (2002). The role of fear of physical movement and activity in chronic fatigue syndrome. Journal of Psychosomatic Research, 52(6), 485-493.

Smith, D. E. (1978). 'K is mentally ill': The anatomy of a factual account (pp. 23-53).

Smout, S., Koudstaal, P. J., Ribbers, G. M., Janssen, W. G. M., & Passchier, J. (2001). Struck by stroke: A pilot study exploring quality of life and coping patterns in younger patients and spouses. International Journal of Rehabilitation Research, 24(4), 261-268.

Sneijder, P., & te Molder, H. F. M. (2004). 'Health should not have to be a problem': Talking health and accountability in an internet forum on veganism. Journal of Health Psychology, 9(4), 599-616.

Spears, R., & Lea, M. (1992). Social influence and the influence of the social in computer-mediated communication. In M. Lea (Ed.), Contexts of computer-mediated communication (pp. 30-65). London: Harvester Wheatsheaf.

Straus, S. E., Dale, J. K., Tobi, M., Lawley, T., Preble, O., Blaese, R. M., Hallahan, C., & Henle, W. (1988). Acyclovir treatment of the chronic fatigue syndrome: Lack of efficacy in a placebo-controlled trial. New England Journal of Medicine, 29(319 (26)), 1692-1698.

Surawy, C., Hackman, A., Hawton, K., & Sharpe, M. (1995). Chronic fatigue syndrome: A cognitive approach. Behaviour Research and Therapy, 33, 535-544.

Taylor, C. (1992). Sources of the self: The making of the modern identity. Cambridge: Cambridge University Press.

Taylor, S. E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. American Psychologist, 38, 1161-1173.

ten Have, P. (1999). Doing conversation analysis: A practical guide. London: Sage.

Townsend, P., & Davidson, N. (1982). Inequalities in health. Harmondsworth: Penguin.

Tucker, I. (2004). 'Stories' of chronic fatigue syndrome: An exploratory discursive psychological analysis. Qualitative Research in Psychology, 1, 153-167.

- Turner, B., & Samson, C. (1995). Medical power and social knowledge. (2nd ed.). London: Sage.
- Turner, B. S. (1992). Regulating bodies: Essays in medical sociology. London: Routledge.
- Turner, J. C. (1982). Towards a cognitive redefinition of the social group. In H. Tajfel (Ed.), Human Groups and Social Categories. Cambridge: Cambridge University Press.
- Van Hudenhove, B., Neerinckx, E., Onghena, P., Lysens, R., & Vertommen, H. (2001). Premorbid "overactive" lifestyle in chronic fatigue syndrome and fibromyalgia: An etiological factor or proof of good citizenship? Journal of Psychosomatic Research, 51(4), 571-576.
- Ware, N. C. (1992). Suffering and the social construction of illness: The delegitimation of illness experience in chronic fatigue syndrome. Medical Anthropology Quarterly, 6(4), 347-361.
- Ware, N. C. (1999). Toward a model of social course in chronic illness: The example of chronic fatigue syndrome. Culture, Medicine & Psychiatry, 23, 303-331.
- Ware, N. C., & Kleinman, A. (1992). Culture and somatic experience: The social course of illness in neurasthenia and chronic fatigue syndrome. Psychosomatic Medicine, 54, 546-560.
- Wenegrat, B. (2001). Theater of disorder: Patients, doctors and the construction of illness. London: Oxford University Press.
- Wessely, S. (1996). Cognitive-behavioral therapy for patients with chronic fatigue syndrome: Why? In M. A. Demitrack & S. E. Abbey (Eds.), Chronic Fatigue Syndrome: An integrative approach to evaluation and treatment. New York: The Guilford Press.
- Wessely, S. (1997). Chronic fatigue syndrome: A 20th century illness? Scandinavian Journal of Work, Environment & Health, 23(suppl 3), 17-34.
- Wessely, S., Butler, S., Chalder, T., & David, A. (1991). The cognitive behavioural management of the post-viral fatigue syndrome. In R. Jenkins & J. Mowbray (Eds.), Postviral Fatigue Syndrome. Chichester: John Wiley.
- Wessely, S., David, A., Butler, S., & Chalder, T. (1989). Management of chronic (post-viral) fatigue syndrome. Journal of the Royal College of General Practitioners, 39, 26-29.
- Wessely, S., & Powell, R. (1989). Fatigue syndromes: A comparison of chronic 'postviral' fatigue with neuromuscular and affective disorders. Journal of Neurological Neurosurgery & Psychiatry, 42, 940-948.
- Wetherell, M. (2001). Debates in discourse research. In M. Wetherell, S. Taylor, & S. J. Yates (Eds.), Discourse theory and practice (pp. 380-399). London: Sage.
- Wetherell, M., & Potter, J. (1992). Mapping the language of racism. London: Harvester Wheatsheaf.
- Wetherell, M., Taylor, S., & Yates, S. J. (Eds.). (2001). Discourse theory and practice: A reader. London: Sage.
- White, C., & Schweitzer, R. (2000). The role of personality in the development and perpetuation of chronic fatigue syndrome. Journal of Psychosomatic Research, 48(6), 515-524.
- White, M. A., & Johnstone, A. S. (2000). Recovery from stroke: Does rehabilitation counselling have a role to play? Disability & Rehabilitation, 22(3), 140-143.
- Whiting, P., Bagnall, A.-M., Sowden, A. J., Cornell, J. E., Mulrow, C. D., & Ramirez, G. (2001). Interventions for the treatment and management of Chronic Fatigue Syndrome. Journal of the American Medical Association, 286(11), 1360-1369.
- Widdicombe, S., & Wooffitt, R. (1995). The language of youth subcultures: Social identity in action. Hemel Hempstead: Harvester Wheatsheaf.

- Wiener, C. L. (1975). The burden of rheumatoid arthritis: Tolerating the uncertainty. Social Science and Medicine, 9, 97-104.
- Williams, G. (1993). Chronic illness and the pursuit of virtue in everyday life. In A. Radley (Ed.), Worlds of Illness: Biographical and Cultural Perspectives on Health and Disease (pp. 92-108). London: Routledge.
- Williams, G. H. (1984). The genesis of chronic illness: Narrative reconstruction. Sociology of Health and Illness, 11, 135-159.
- Willig, C. (Ed.). (1999). Applied discourse analysis: Social and psychological interventions. Buckingham: Open University Press.
- Wilson, A., Hickie, I., Hadzi-Pavlovic, D., Wakefield, D., Parker, G., Straus, S. E., Dale, J., McCluskey, D., Hinds, G., Brickman, A., Goldenberg, D., Demitrack, M., Blakely, T., Wessely, S., Sharpe, M., & Lloyd, A. (2001). What is chronic fatigue syndrome? Heterogeneity within an international multicentre study. Australian and New Zealand Journal of Psychiatry, 35(4), 520-527.
- Wilson, E. (1998, 17 July 1998). ME is a real illness. Daily Mail, pp. 17.
- Wood. (1994,). Da Costa's syndrome (or effort syndrome): Three Goulstonian lectures to the Royal College of Physicians of London, London.
- Wood, P. H. N. (1980). The international classification of impairments, disabilities and handicaps. Geneva: World Health Organisation.
- Wooffitt, R. (1992). Telling tales of the unexpected: The organization of factual discourse. Hemel Hempstead: Harvester Wheatsheaf.
- World Health Organisation. (1995,). Pan European consensus meeting on stroke management, Helsingborg, Sweden.
- Yates, S. J. (2001). Researching internet interaction: Sociolinguistics and corpus analysis. In M. Wetherell, S. Taylor, & S. J. Yates (Eds.), Discourse as data: A guide for analysis (pp. 93-146). London: Sage.
- Zborowski, M. (1952). Cultural components in responses to pain. Journal of Social Issues, 8, 16-30.
- Zola, I. K. (1982). Missing pieces. Philadelphia: Temple University Press.

APPENDIX I

Schedule of questions put to all respondents, with variations according to the illness:

1. How would you describe having ME to someone who doesn't know anything about it?
How would you describe your situation - having had a stroke at a young age - to someone who doesn't know anything about it?
2. In what ways would you say that having ME has affected you as a person?
In what ways would you say that having had a stroke has affected you as a person?
3. What advice would you give to someone who has just developed symptoms of ME?
What advice would you give to someone who has just suffered a stroke at a young age?
4. Can you describe how you dealt with your condition when you first knew about it?
(same question for both ME and stroke)
5. If this applies to you, how did you come to be diagnosed as suffering from ME?
(ME only)

6. What were your reactions when you were diagnosed as suffering from ME?
(ME only)

7. *Before your diagnosis, how did you feel?*
(ME only)

8. How have the people around you reacted to your condition? That is, family, friends, work colleagues.
(same question for both ME and stroke)

9. How do you feel about the way medical people treat you?
(same questions for both ME and stroke)

10. Do you think things would be different if your condition had been caused by something other than ME?
Do you think things would be different if your condition had been caused by something other than a stroke?

11. How do you feel about having had a stroke at such a young age?
(stroke only)

12. Do you have any ideas about how it is that people get ME?
Do you have any ideas about how it is that people get strokes at a young age?

13. What kinds of things help when you are not feeling well?
(same questions for both ME and stroke)

APPENDIX II

Transcription Notation

Extracts are labelled according to their source, as follows:

- FG = Focus Group
- ICC = Internet Chatline Communication (emailed to all members of the web-based support group)
- IPC = Internet Personal Communication (emailed one-to-one)

Internet communications were pasted and copied in the format received, so that spelling and punctuation were preserved as in the original.

Focus group sessions were transcribed using the notation below. Carers' names were in italics, and the researcher's name was underlined.

- [A left hand bracket indicates the point at which overlapping speech begins
-] A right hand bracket indicates the point at which overlapping speech ends
- = An equals sign indicates that one turn follows another with no gap
- () A space surrounded by brackets indicates a short silence
- (.) A dot in brackets indicates a 1-second silence⁶
- (..) Two dots in brackets indicate a 2-second silence

⁶Timing was estimated using an informal beat count as an approximate measure; this is one of the methods recommended by ten Have [ten Have, 1999 #618]

- (...) Three dots in brackets indicate a 3-second silence
- (4) Numbers in brackets indicates seconds of silence equal to the number noted; this is done to draw attention to longer silences, and for ease of reading
- underlining is used to show emphasis
- "speech" Quotation marks are used to denote 'active voicing' (Wooffitt, 1992)
- CAPITALS are used to mark an increase in volume
- We:ll A colon is used to indicate the extension of sound of the vowel directly preceding it; the more colons used, the greater the extension
- ? A question mark denotes rising intonation
- Wha- A hyphen indicates an abrupt stop
- hh The 'h' is used to indicate an outbreath, with each additional 'h' denoting longer length of outbreath
- .hh The 'h' preceded by a full stop indicates an inbreath, with each additional 'h' denoting longer length of inbreath
- [...] This indicates that some text has been omitted
- [comments] Transcriber's comments are in square brackets